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**Teachers' Experiences of Working with  
Children with Life-Limiting Conditions in  
Special Schools**

**Rachel Brunt**

A thesis submitted in partial fulfilment of the requirements for the  
degree of Doctor of Education

School of Education  
Durham University  
2018

# **Teachers' Experiences of Working with Children with Life-Limiting Conditions in Special Schools**

Rachel Brunt

## **Abstract**

This research explores the experiences of teachers who work with children with life-limiting conditions in special schools. The study is located within a qualitative, interpretive paradigm utilising a phenomenographic approach. Semi-structured interviews were used to collect data from eighteen teachers currently teaching children with life-limiting conditions in special schools. Interview data was transcribed and analysed using the Four Stages of Analysis for phenomenographic data (Schröder & Ahlström 2004). Following data analysis, five categories of description were identified; challenges faced when working with children with life-limiting conditions, pedagogical considerations, school health provision, emotional impact and emotional support.

The findings demonstrate that teachers' educational biographies are characterised by a number of significant challenges, particularly around curriculum and assessment, communicating with parents and professionals and attending to medical emergencies. The most significant challenge faced by teachers of children with life-limiting conditions was the death of a child, an event that was regularly experienced by the majority of those interviewed. The challenges of the teaching role were found to have a huge impact on the emotional wellbeing of teachers which in turn was found to impact on their personal and professional lives.

Emotional support was sought through formal and informal channels, including through professional counselling or via friends and family. However, barriers to this support were found to include a lack of understanding, awareness and an underestimation of the time the support was needed for. This research provides a clear and original understanding of the experiences and support needs of teachers who work with children with life-limiting conditions in special schools. It has important implications for those responsible for teacher training and professional development programmes, particularly in the areas of grief and bereavement, as well as for senior leadership teams responsible for ensuring the emotional wellbeing of their teachers.

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## List of Abbreviations

<b>ASD:</b>	Autism Spectrum Disorder
<b>CLDD:</b>	Complex Learning Difficulties and Disabilities
<b>EHCP:</b>	Education and Health Care Plan
<b>KEFs:</b>	Key Educational Factors
<b>NHS:</b>	National Health Service
<b>NQT:</b>	Newly Qualified Teacher
<b>PGCE:</b>	Post-Graduate Certificate in Education
<b>PMLD:</b>	Profound and Multiple Learning Difficulties
<b>PTSD:</b>	Post-Traumatic Stress Disorder
<b>SEND:</b>	Special Educational Needs and Disabilities
<b>SENDCO:</b>	Special Educational Needs and Disabilities Coordinator
<b>SLD:</b>	Severe Learning Difficulties
<b>SLT:</b>	Senior Leadership Teams
<b>SSAT:</b>	Specialist Schools and Academies Trust
<b>UK:</b>	United Kingdom
<b>USA:</b>	United States of America

## **Declaration**

I declare that this research and the findings within are a result of my own work and have not been submitted wholly or in any other form for another degree at Durham University or elsewhere.

## **Statement of Copyright**

The copyright of this thesis rests with the author. No quotations from it should be published without the author's prior written consent and information derived from it should be acknowledged.

## Acknowledgements

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To the very special children and their families who fuelled this research and were discussed within it. You bring such joy to our world and such devastating sadness when you are no longer with us. It is a privilege to work so closely with you all.

Finally, to my family. Drs. Hall, you have all provided much inspiration, support and advice over the years and have shown me the value of further study and research. I could not have achieved this without you all. Jenny, the baton is now yours. To my husband Tom, for your love, support, endless reminders to back up my work and for pretending to know what I was talking about over the past six years, a heartfelt thank you. Last but not least, to Phoebe. Your arrival this year gave me a new impetus to complete this research. You have been with me throughout much of the writing process and it would have been a very different experience without you. I hope to be as much of an inspiration to you, as my Mum is to me.

# Dedication

*For Jess, Zareen, James and Darrel*

## **The Elephant in the Room**

By Terry Kettering

There's an elephant in the room.  
It is large and squatting, so it is hard to get around it.  
Yet we squeeze by with "How are you?" and "I'm fine..."  
And a thousand other forms of trivial chatter.  
We talk about the weather.  
We talk about work.  
We talk about everything else...  
Except the elephant in the room.

We all know it is there.  
We are thinking about the elephant as we talk together.  
It is constantly on our minds.  
For, you see, it is a very big elephant.  
It has hurt us all.

But we do not talk about the elephant in the room.  
Oh, please, say her name.  
Oh, please, say her name again.  
Oh, please, let's talk about the elephant in the room.

For if we talk about her death,  
Perhaps we can talk about her life.  
Can I say her name to you and not have you look away?  
For if I cannot,  
Then you are leaving me alone...  
In a room...  
With an elephant.

# Chapter One: Introduction

## 1.1 Personal Motivation

This research stemmed heavily from my own personal experience as a teacher in a special school. Having taught children within the same special school for over nine years I personally witnessed the changing nature of special educational needs and disabilities (SEND) of children now entering my classroom. Within my first class as a Newly Qualified Teacher (NQT), students had a range of SEND including Downs' Syndrome and moderate Autism Spectrum Disorder (ASD), however, just two years later students were entering school with complex medical conditions such as intractable epilepsy and diabetes. Within the subsequent years, as a primary-trained teacher, I was tube feeding students both through a gastrostomy and via a Nasal-Gastro tube daily. I had learned how to administer rescue medication for complex epilepsy, inject students with insulin, administer oxygen and was responsible not just for the daily education of these students, but for potentially life-saving medical care. This changing nature of SEND is a phenomenon not just specific to my school or locality but is being replicated nationwide (Blakemore, 2012; Carpenter, 2010a). The reasons for this change will be discussed in more detail in Chapter Two.

Due to this 'new breed' of students now entering my classroom (Carpenter, 2010a), my role and perspective as a 'teacher' has changed dramatically. I no longer have a traditional teacher-student pedagogic relationship that my mainstream teaching peers employ. Instead, my relationships with students have become a complex process, intricately intertwining deeply personal relational activities with intensely caring actions to meet their ever-changing and demanding needs. These students not only require highly personalised and individual teaching, but demand a duty of medical care over and above spiritual and 'loco parentis' dimensions of care. I became terrifyingly aware, throughout those first encounters of students with life-limiting conditions, that these students could potentially die within my classroom and under my care. This very real, daunting and tangible responsibility is something that I grapple with every day. It is something that I struggle to separate and confine to my 'day job', it moves with me, invades my personal life and has come to define who I am as a teacher and as a person.



At the outset of this research project I felt myself fortunate that I had not experienced the death of a student. I often wondered how we would deal with this tragic event as a school community and as teachers. Sadly, towards the end of this research, my fears became reality as, within the space of six months, two children unexpectedly died whilst in hospital. Although I was not and had never been their class teacher, I experienced first-hand the dramatic effect these deaths had on our school community, staff members and other students. The emotional turmoil experienced during this time is rarely mentioned within the literature. Instead, researchers have focused on outlining the duties expected of teachers following a student death (Bryant, 1978). It has been this realisation, these experiences and these emotions experienced within myself, that have created curiosity, provided a starting point and, ultimately, fuelled this research (Ross & Morrison, 1992). There is very little existing research that explores the emotions, fears and feelings that teachers who teach and care for children with life-limiting conditions experience daily within special schools. This is something I aim to address.

## **1.2 Purpose and Significance of the Study**

There is a distinct lack of literature that explores the pedagogical and emotional response to teaching children with life-limiting conditions (Hart & Garza, 2013; Leaman, 2000). Most studies focus on the academic concerns and perceptions of parents and young people within mainstream (Meuleners, Binns, Lee & Lower, 2002; Notaras et al., 2002). Some, historical research outlined the duties of a teacher during the death of a student, paying little attention to the emotional turmoil that may also be experienced (Bryant, 1978). Most studies conclude that teachers lack knowledge in certain conditions and in their medical responses (Fleitas, 2003; Roberts & Whiting, 2011), and almost all suggest that medical professionals need to provide greater assistance and understanding of the complexities involved (Lightfoot, Wright & Sloper, 1999; Mukherjee, Lightfoot & Sloper, 2002). Yet, few explore the views of teachers, parents and young people within special education. Even fewer studies explore the emotions, fears and feelings of teachers who work with children with life-limiting conditions on a daily basis.

### **1.2.1 The Purpose of the Study**

Considering my own personal teaching experiences and the lack of recent literature in this area, the aim of this research is to better understand the views, experiences and emotions of teachers who have children with life-limiting conditions in their special education classrooms. I want to know how they deal with the very real possibility of a child dying whilst in their class and in their care. I also want to better understand the support systems in place for teachers as well as their training needs to enable them to care for this 'new generation' of learners (Blakemore, 2012). Carpenter (2010a) states that the number of children with learning and health needs is rising, and as society and medicine continue to change and advance, these numbers will increase further. It is therefore imperative that a greater understanding of the experiences of teachers in these situations is gained in order to facilitate better training and support for those on the frontline.

### **1.2.2 The Significance of the Study**

The education of children with SEND has changed dramatically since the end of the Second World War (see section 2.2). Due to this introduction of a more inclusive education system, children who would otherwise have been institutionalised are now entitled to an education. Indeed, mainstream schools are now required to include and educate a greater number of children with SEND. As a result, within special schools, teachers are having to meet the needs of children with the most complex medical and educational difficulties. Existing research has primarily focused on the needs of children with life-limiting conditions within mainstream schools (St Leger & Campbell, 2008; Upton & Eisner, 2006), ignoring the needs of teachers who are required to educate them. Indeed, Robinson and Summers (2012), throughout their international literature review, found that research examining the experiences of teachers working with children with life-limiting conditions did not exist. To address this gap in the literature, the Teaching for Life project was conducted to explore the experiences of teachers who educate children with life-limiting conditions (Durrant, Robinson, Ekins, Summers & Jones, 2014). However, this research focused primarily on teachers within mainstream schools, some of whom did not have direct experience of working with children with life-limiting conditions. It can be argued that the experiences of the mainstream teachers in Durrant et al's (2014) study are qualitatively different to those who teach within special schools, due to the differences in severity of need.

The experiences of teachers within special schools remain largely ignored. This research is therefore hugely significant and will provide an original contribution to knowledge.

### **1.3 Research Aims and Objectives**

The aim of this research is to gain an understanding of how teachers handle the responsibility of having children with life-limiting conditions in special education classrooms and stems from my own teaching experiences. It is from these encounters of children with life-limiting conditions that the following research question was formulated:

*How do teachers encounter, conceptualise and understand their experiences of working with children with life-limiting conditions in special schools?*

In thinking about the research question, two main objectives became apparent:

- To develop a detailed understanding of the experiences of teachers who work with children with life-limiting conditions in special schools,
- To investigate the pedagogical constructions that teachers within this context hold about the capabilities and needs of their students.

Within these objectives and to enable the collection of rich data to fully explore the research question, the following supplementary research questions emerged:

1. What are the educational biographies of teachers who work with children with life-limiting conditions in special schools?
2. What are the pedagogical and day-to-day working experiences of this group of teachers?
3. What beliefs and values do these teachers hold about the students with whom they work?
4. How do these impact upon their actions and emotions in relation to the life-limitation that their students experience?

Due to the sensitive and highly individualised nature of the topic it became clear from the outset that this research required an approach that would enable me to explore the experiences of individuals from their unique point of view (Bogdan &

Taylor, 1975). Therefore, to obtain rich and detailed data (Silverman, 2013) about the lived experiences of teachers who teach children with life-limiting conditions in special schools, an interpretive and thus qualitative framework was employed. Furthermore, attempting to examine “the qualitatively different ways in which people experience, conceptualise, perceive and understand” the phenomenon in question (Richardson, 1999, p. 53), firmly roots this research within the phenomenographic perspective. As such, and in line with phenomenography, a semi-structured interview method that utilised open-ended questions was used to gather rich and detailed data to understand the individual’s perspectives, views and experiences of the phenomenon (Dahlgren & Fallsberg, 1991; Denscombe, 2007). These questions and the development of this research project are described in more detail in Chapter Three.

## **1.4 Structure of Thesis**

### **1.4.1 Chapter Two - Literature Review**

Chapter Two begins with an historical overview of the national and international policies that have facilitated educational change for children with SEND. The subsequent review of the literature is separated into three distinct sections. The first aims to explore the changing nature of SEND amongst children both nationally and internationally including the increased prevalence of children with life-limiting conditions. It provides a discussion as to the reasons behind this change and the issues and challenges this change poses to educators and healthcare professionals, for example, pedagogical considerations and the need to establish multi-agency working.

The second section of the literature review examines existing research into the experiences and emotions of teachers who are teaching children with life-limiting conditions in both mainstream and special schools. It discusses the teachers’ perceived abilities to meet the complex needs of children with life-limiting conditions and explores the emotional aspects of caring for these children, including teachers’ fears, anxieties and joy.

The final section discusses the phenomenon of death and dying in schools. It examines research into the impact of student death on schools, its pupils and

teachers. The range of emotions experienced by teachers following the death of a student is explored, in addition to possible ways of making this experience easier through training or robust support systems.

#### **1.4.2 Chapter Three - Methodology**

Chapter Three outlines the methodological decisions made throughout this research. The first section outlines the qualitative research paradigm this study resides within, in addition to my epistemological and ontological position. A discussion of phenomenography as a research approach is also conducted to firmly root this study in a theoretical background. Secondly, the research design is discussed in terms of decisions made throughout the participant recruitment and interview design phase. Finally, the stages of the research process are outlined in relation to the current study. The interview process is described, and decisions made throughout data collection and analysis are discussed. Ethical considerations that are pertinent to this study are discussed, in addition to how quality can be ensured and enhanced throughout this research.

#### **1.4.3 Chapter Four – The Outcome Space**

This chapter will give an illustration and analysis of the outcome space to show how each category of description links together. This outcome space will provide an overall picture of the experiences of teachers interviewed in this study, who educate children with life-limiting conditions in special schools. It was felt important to provide this illustration at the outset of the findings chapters to show the data analysis journey as a whole. In addition, my positionality as a research will be outlined. As an introduction to the research findings, Chapter Four concludes with a description of how the research findings will be presented, including the format of direct quotations to illustrate the results.

#### **1.4.4 Chapter Five – Category of Description One – Challenges Faced when Teaching Children with Life Limiting Conditions.**

The first chapter of the research findings outlines the challenges faced by teachers who work with children who have life-limiting conditions. Each challenge expressed by teachers interviewed is discussed in turn. These challenges include; curriculum and assessment pressures, time pressures, communicating with parents and professionals, medical emergencies and experiencing student death.

#### **1.4.5 Chapter Six – Category of Description Two – Emotional Impact**

The second category of description chapter discusses the emotional impact of the teaching role. Teachers expressed a range of positive and negative emotions which were categorised using the Junto Emotions Wheel (Chandra, 2016). Each emotion is discussed in turn in relation to the situations and events that trigger them. The impact these emotions have on teachers' personal and professional lives is also discussed.

#### **1.4.6 Chapter Seven – Category of Description Three – Emotional Support**

Due to the huge range of positive and negative emotions experienced by teachers, this chapter discusses the emotional support available to them. Teachers seek support through a range of sources including professional counselling, friends, family and colleagues. This chapter also discusses the barriers to emotional support teachers experience, often due to a lack of understanding of the unique nature of this teaching role.

#### **1.4.7 Chapter Eight – Category of Description Four – School Health Provision**

This chapter discusses the important role of school nurses within special schools. It outlines teachers' experiences of school nurses in relation to their presence across the sample. The resulting impact of this availability is discussed from both a positive and negative perspective.

#### **1.4.8 Chapter Nine – Category of Description Five – Pedagogical Considerations**

The final chapter of the findings outlines the pedagogical considerations teachers employ in attempting to overcome some of the curriculum and time pressures outlined in Chapter Five. Various teaching priorities were expressed by teachers, including whether they should focus on academic attainment or enrichment activities that improve the quality of life of their students. Some teachers attempted to find a balance between the two extremes which is discussed using supporting quotations.

#### **1.4.9 Chapter Ten – Discussion**

This chapter will summarise the key findings of this study in relation to existing research within the fields of health and education. The limitations of this research

will be outlined in addition to recommendations for future research and implications for stakeholders within special education.

## **1.5 Definitions of Key Terms**

Within the literature there is a vast array of terminology used to refer to children with SEND and life-limiting conditions, with many such definitions changing over time, amongst professionals and across localities (MacKay, 2009). To ensure consistency and transparency throughout, I will use the terms SEND and life-limiting conditions throughout this research as defined below.

### **1.5.1 Special Educational Needs and Disabilities (SEND)**

Children with SEND can be defined as “a child or young person [who has] a learning difficulty or disability which calls for special educational provision to be made for him or her...[and who]...has a significantly greater difficulty in learning” (Department for Education [DfE], 2015a, p. 285). In addition, the DfE (2014) also identify that children with SEND may also have health conditions that require additional educational provision to be provided for them.

### **1.5.2 Life-Limiting Conditions**

Throughout the literature numerous terms are used to describe the severity of medical conditions amongst children, for example; chronic illness (Nabors & Lehmkuhl, 2004), life-threatening and life-limiting conditions (Fraser, Miller, Aldridge, McKinney & Parslow, 2011), and ‘medically fragile’ or ‘technology-dependent’ (Heaton, Noyes, Sloper & Shah, 2005; Rehm, 2002b). In line with current research and policy within the UK, the term ‘life-limiting conditions’ will be used throughout. Life-limiting conditions can be defined as “conditions for which there is no reasonable hope of cure and from which children will die” (Fraser et al., 2012, p. 924). Also included within this definition are life-threatening conditions “for which curative treatment may be feasible but can fail, such as cancer” (Fraser et al., 2012, p. 924).

Furthermore, I intend to include children who are technology-dependent under the life-limiting umbrella used within this research. This is because the medical device or technology that the child is dependent on is “to compensate for the loss of a vital bodily function...to avert death or further disability” (Wagner, Power & Fox, 1988,

p.3). In contrast to the international literature search into life-limiting illnesses conducted by Robinson and Summers (2012), I also consider epilepsy to be a life-limiting condition. This is a conscious decision made from personal experience and elsewhere in the literature, due to the heightened risk of death that a tonic clonic seizure may bring to any individual with epilepsy and an overall risk of premature mortality for those with an epilepsy diagnosis (Hain, Devins, Hastings & Noyes, 2013; Shafer, 2013).

### **1.5.3 Complex Learning Difficulties and Disabilities (CLDD)**

Due to the wide range of children who could be described as having life-limiting conditions, it is worth further clarifying the exact nature of students referred to throughout this study. Within this study, I am solely interested in the experiences of teachers of children educated in special schools. Whereas children with cancer or asthma do have life-limiting conditions, in absence of other cognitive conditions or brain injury, the majority will almost certainly be educated in mainstream schools. Therefore, children discussed in this study are more likely to come under the definition of having CLDD.

As Carpenter, Cockbill, Egerton and English (2010) discuss, children with CLDD are:

Those with co-existing conditions (e.g. Autism and ADHD), or profound and multiple learning difficulties...those with difficulties arising from premature birth; those who have survived infancy due to medical advances; those with disabilities arising from parental substance and alcohol abuse; and those with rare chromosomal disorders. Many may also be affected by compounding factors such as multisensory impairment or mental ill-health, or require invasive procedures, such as supported nutrition, assisted ventilation and rescue medication.

(Carpenter et al., 2010, p. 3)

According to this definition, the children discussed in this research are highly complex with a range of differing needs. The majority of children identified as having life-limiting conditions could also be defined as having profound and multiple learning difficulties (PMLD), meaning they may have physical needs requiring the need for a wheelchair, be non-verbal, doubly incontinent, medically vulnerable and working at the earliest stages of development.



# **Chapter Two: Children with Life-Limiting Conditions in Schools**

## **2.1 Introduction**

Throughout the past nine years, as a teacher in a secondary special school, I have witnessed first-hand the changing nature of SEND now entering my classroom. During this time, I have seen a significant increase in the numbers of children with complex medical needs that can limit their life expectancy. Teachers and teaching assistants are now required to conduct daily, often medically invasive procedures, without any in-depth medical training beyond that which is provided by the school nursing team. It is apparent throughout this review of the literature that my experience is not an isolated situation, but one that is repeated nationally and internationally. It is a phenomenon that is projected to increase further both in quantity and complexity (Carpenter, 2010a).

Following a historical overview of the policies that introduced the inclusive education system we see today; this chapter is divided into three main sections. The first aims to explore the observed increase in children with life-limiting conditions now reaching school-age. It aims to discuss the causes and determine the issues that may arise for educators and healthcare professionals, for example, when developing effective pedagogies or when communicating with parents and professionals. Secondly, this chapter aims to explore what life is like teaching children with life-limiting conditions. It examines existing research that aimed to obtain the views and experiences of teachers who teach children with life-limiting conditions and discusses emotions and concerns in relation to meeting the needs of these children. Finally, this chapter concludes with an exploration of the concept of death and dying in schools and its impact as a whole.

## **2.2 Historical Overview**

UK Governmental and Educational policy alongside continuous political changes have impacted dramatically on the education of our most vulnerable learners. Following the Second World War children with SEND were categorised differently with those displaying the most complex of need referred to as 'educationally subnormal' or, 'ineducable' (HMSO, 1944). For these children, education was not

seen as a 'right' or a 'need'. Instead they were institutionalised, often in hospital settings under the duty and care of the health service (Runswick-Cole & Hodge, 2009). The health service continued to hold responsibility for these children until the Education (Handicapped Children) Act in 1970 when the care of the 'educationally subnormal' and 'ineducable' was transferred to Local Authority control (HMSO, 1970). Despite this transfer in care, many children still remained in long-term hospital placements or at home full-time with little or no educational input (Male, 2015).

The introduction of the Warnock Report in 1978 (Warnock, 1978) eradicated the previous categories of need as described in the 1944 Education Act (HMSO, 1944), instead introducing the term 'special educational needs' for all children with 'individual educational needs' (Runswick-Cole & Hodge, 2009, p. 200). These children were now entitled to an education alongside their mainstream peers (Warnock, 1978). It was not until 1994, however, that the Government began to commit to inclusion as first introduced in Warnock's (1978) report. The Salamanca Statement (United Nations Educational, Scientific and Cultural Organisation [UNESCO], 1994) stated that "those with special educational needs must have access to regular schools" (p. viii) and that Governments should "adopt as a matter of law or policy the principle of inclusive education" (p. ix). Further Governmental policies have built upon this idea of inclusive education, reinforcing the Salamanca Statement's key principles (Department of Education and Employment [DfEE], 1996; Department for Education and Skills [DfES], 2001; DfES, 2004; House of Commons Education and Skills Committee, 2006). This has resulted in increasing numbers of children with SEND being successfully included within mainstream schools (Male, 2015).

The resulting impact of the Government's inclusion agenda, alongside recent advances in medical technology and neonatal care (Heller & Tumlin, 2004; Wolke, 2011), has been a changing level of need seen amongst children with SEND in special schools. Whereas previously special schools may have catered for children with mild to moderate learning difficulties, these children are now able to access mainstream education with minimal adaptations (Frederickson & Cline, 2007). What results is an increase in children who have Severe Learning Difficulties, PMLD and/or complex health needs in special schools (Frederickson & Cline, 2007; Male & Rayner, 2007).

More recent policies including the Children and Families Act (HMSO, 2014), the updated SEND Code of Practice (DfE, 2015a) and statutory guidance for supporting pupils at schools with medical conditions (DfE, 2014; 2015b) reflect this changing nature of SEND and further emphasise the legal role and duty of schools in meeting those health needs. What is not reflected in the more recent Governmental policies however, is the impact on staff who are required to teach these children. Research has found that this changing nature of need poses a new challenge to teachers in special education who require specific and specialist training to teach and care for our most complex and vulnerable children (see section 2.3.3) (Blakemore, 2012; Durrant et al., 2014; Robinson & Summers, 2012).

## **2.3 The Changing Nature of Children with Special Educational Needs and Disabilities**

### **2.3.1 Incidence and Prevalence of Life-Limiting Conditions in Children**

Prevalence data about the type and severity of SEND is difficult to reliably obtain due to the differences in rates of diagnoses, hospital admissions and deaths. For example, “not all children and young people who are known to have a life-limiting condition will receive an official diagnosis, either because their condition is so rare, or because the complexity of their symptoms make it difficult to do so” (J N Research, 2013, p. 12). Relying on death certificate data has also become problematic in recent years due to a decreasing death rate with greater numbers of children now surviving longer than ever before (Carpenter & Rawson, 2015; Fraser et al., 2015). A definitive number of children who have life-limiting conditions in the UK and elsewhere is also difficult to establish due to the lack of empirical data and the variance in assessment criteria used. It is widely considered that the prevalence of children with SEND and life-limiting conditions varies considerably amongst localities and population groups (Male, 2015).

Despite these issues, prevalence rates have been estimated with approximately 10-12% of children in the UK and 10-20% of children in the USA having a long-term, potentially life-limiting medical condition (Department of Health [DoH], 2012; Jaress & Winicki, 2013). Within England specifically, it is estimated that 49,000 children, aged between 0 and 19 years, have a life-limiting condition (Fraser et al., 2011), a number more than double that which was estimated previously (Cochrane,

Liyanage & Nantambi, 2007), and a number that has increased within England steadily over the past two decades (DoH, 2004; Fraser et al., 2012). Increases in the prevalence of children with life-limiting conditions were also seen in Scotland, Wales and Northern Ireland (Fraser et al., 2015; Ling, O'Reilly, Balfe, Quinn & Devins, 2015). Within the most severe categories, approximately 16 children per 10,000 aged between 0-19 currently require palliative care services (ACT, 2009; Hunt et al., 2015). The highest incidences of UK children with life-limiting conditions were found to be in those under 1 year with males outweighing females in all year groups (Fraser et al., 2011). Ethnicity and socio-economic status were also related to higher rates of prevalence (Fraser, et al., 2011).

Even though obtaining reliable prevalence data is problematic (Fraser et al., 2012), there is general consensus both anecdotally and empirically, to suggest that there have been significant increases in the numbers of learners identified as having life-limiting conditions (Male, 1996b; Male, 2015; Parrott, Tilley & Wolstenholme, 2008). Empirical data collected by the Department for Children, Schools and Families (2009) found that the number of pupils with PMLD in England rose by approximately 29.7% between 2004 and 2009 and continued to rise by almost 1,500 children between 2010 and 2016 (DfE, 2010; 2016). This rise has also been found amongst children identified as having CLDD in the UK (Blackburn, Spencer and Read, 2010) and those living with complex health needs (DoH, 2004).

Given that children under 1 year have the highest incidence rate of life-limiting conditions (Fraser et al., 2011), and the recent increase in survival rates observed (Carpenter & Rawson, 2015) it is clear that the prevalence of children with life-limiting conditions will increase further, with some estimating an increase of around 14% over the next twenty years (Emerson & Hatton, 2008).

### **2.3.2 Possible Causes of Increased Prevalence of Life-Limiting Conditions in Children**

A number of different factors are attributable to the cause of increased prevalence rates of children living with life-limiting conditions. Most notable are the improved survival rates for premature babies (Marlow, Wolke, Bracewell & Samara, 2005), increased birth rates (Emerson, 2009), and the developments in medical technology leading to the use of portable technical devices which can now be used by non-

medically trained personnel at home and in the community (Glendinning, Kirk, Guiffrida & Lawton, 2001).

One of the most important factors in the development of a life-limiting condition is prematurity at birth. Premature births have been increasing throughout developed countries over the past two decades and are now 5-7% of all live births (Hornby & Woodward, 2009). Premature births have been reported to be even higher, at 12% of all live births, in the USA (Martin, Kochanek, Strobino, Guyer & MacDorman, 2005). Due to medical advances, including developments in perinatal and neonatal intensive care, resuscitation methods and the use of steroids to increase heart and lung maturity (Hornby & Woodward, 2009; Taylor, Klein & Hack, 2000), children who are born preterm now have an improved rate of survival (McClusky & McNamara, 2005). The EPICure UK study reported that 80% of children born before 26 weeks gestation now survive (Marlow et al., 2005). Similarly, in New Zealand a study found that 90% of babies born weighing less than 1,500 grams survived (Woodward, Mogridge, Wells & Inder, 2004).

However, with increased survival rates comes a high possibility of developing a life-limiting condition. In the New Zealand study, 63% of babies surviving at less than 1,500 grams, had a disability (Woodward et al., 2004). These results have been replicated worldwide with population studies suggesting that up to 50% of children born extremely premature or with extremely low birth weights now have neurodevelopmental disabilities (Farooqi, Hagglof, Sedin, Gothefors & Serenius, 2006; Johnson, Wolke, Hennessy & Marlow, 2011). These disabilities appear to be related to a reduction in or injury to the white matter within the brain (Carpenter & Egerton, 2013), with commonly seen difficulties related to motor difficulties, developmental delay and intellectual disabilities (Johnson et al., 2009).

Despite these high numbers of children developing disabilities, there appears to be some disagreement as to the prevalence of major impairments, with studies in the UK and Norway suggesting that of preterm survivors, only 10-15% were classed as having a major disability such as cerebral palsy (Cooke, 2005; Moster, Lie & Markestad, 2008). Studies in Germany have also found that 18% of surviving preterm children had a major impairment (Neubauer, Voss & Kattner, 2008). Regardless, these international findings demonstrate the heightened and continued risks associated with premature births (Anderson & Doyle, 2008). Evidence is also

provided to explain the increase in school-aged children with life-limiting conditions. For example, studies have shown that among school-aged children born with extremely low birth weights, 64% had disabilities or chronic conditions compared with just 20% of children who had normal birth weights (Hack et al., 2005).

The increase in survival rates of premature babies, the associated impact on their health and the fact that these children are now able to survive long enough to attend school (Mukherjee et al., 2002; Sloper & Lightfoot, 2004), have important implications for educators and healthcare professionals in all areas and age-groups. This will be especially true over the coming years as increasing numbers of adults with PMLD are now requiring health and social care services (Emerson, 2009). This is supported by national prevalence data for England where interestingly, the greatest increase in prevalence seen over the past decade has been within young people aged between 16 and 19 years, adding weight to the idea of increasing survival times (Fraser et al., 2012; Simmonds, 2013) and increased pressure on staff and resources (Henderson, Beer, Wolke & Johnson, 2012).

A further cause of increased survival rates is the development of mobile technology in addition to directed funding to support healthcare needs at home and at school (Davies & Carter, 2013; Ekins, Robinson, Durrant & Summers, 2017). Students with life-limiting conditions requiring the use of technologies such as catheterisation, ventilation and gastrostomies can now be cared for at home or in the community rather than in hospital settings (Glendinning et al., 2001; Shiu, 2001). In addition, these life-saving technologies can be used by parents, carers or teachers with adequate training (Glendinning et al., 2001), resulting in the ability of these children to attend school.

As with prevalence data, a precise number of technology-dependent children within the UK is difficult to obtain. Cautious estimations cite the number of children dependent on medical technologies at around 6,000 in the UK (Glendinning et al., 2001), however this number has increased in line with medical advances throughout the last decade, particularly in the numbers of children relying on ventilation and gastrostomies (Amin et al., 2014; Ludvisgen & Morrison, 2003; Townsley & Robinson, 2000). Indeed, increases in the numbers of technology-dependent children in special and mainstream schools have also been seen

internationally. In Japan, despite a decreasing youth population, the number of children with disabilities is increasing (Japanese Ministry of Health, Labour and Welfare, 2008, as cited in Shimizu & Katsuda, 2015). In Japanese special schools approximately 6.4% of children are technology-dependent with increases in the numbers of children reliant on medical technology also seen within mainstream schools (MEXT, 2013, as cited in Shimizu & Katsuda, 2015). These international figures are also supported by research from the USA. Although recent prevalence data is unavailable (Spratling, 2015; Toly, Musil & Carl, 2012), researchers believe the number of children dependent on medical technology is much higher than the 1987 estimate of 11,000 to 68,000 children (Carnevale, Rehm, Kirk & McKeever, 2008; Office of Technology Assessment, 1987).

With the discussed advances in medical technology and increased survival rates, what results is a population of ‘first-generation survivors’ (Aruda & Newinsky, 2011, p. 210); children that, just a generation earlier, would not have survived the severity of their medical condition. Due to the uniqueness of this population, little is known about their life-expectancy or associated quality of life (Aruda & Newinsky, 2011). As such, these children are paving the way and now surviving long enough to attend school. It is therefore important to identify and discuss the issues and challenges educators and healthcare professionals face when caring for children with life-limiting conditions.

### **2.3.3 Issues for Educators and Healthcare Professionals**

Given the increase in numbers of school-aged children with life-limiting conditions (see section 2.3.1), it follows that this will pose a number of challenges for professionals when attempting to meet their complex health, social and educational needs (Rehm, 2002a). Some of the issues faced by professionals include developing interventions and pedagogies to meet educational needs (Blackburn & Carpenter, 2012), training teachers and support staff adequately to deal with medical interventions (Asprey & Nash, 2006; Ekins et al., 2017) and in communicating effectively with other healthcare professionals and parents (Mukherjee et al., 2002).

### **2.3.3.1 Developing Effective Pedagogies**

Research into the learning patterns of children with CLDD and life-limiting conditions has described these children as a ‘new breed’ of learners who are ‘wired differently’ and therefore require individualised and specific interventions to meet their needs (Carpenter & Egerton, 2005; 2013). Indeed, learning patterns currently seen in children with CLDD are different to those of children with SEND we have seen previously. As such, educators must “transform their response to the learner from the largely standardised to the profoundly personalised” (Hargreaves, 2006, as cited in Carpenter, 2010b, p. 5), by providing a deepened level of individual support. This apparent difference in learning pattern and style requires a ‘pedagogical re-engineering’ to ensure these children are best equipped to survive in a 21<sup>st</sup> century society (Carpenter, 2010b). Teachers can no longer rely on differentiation to meet the varied and complex needs of these learners. Instead they must offer more by involving the child in the learning process and mapping new ways to engage them in teaching activities (Cartwright, 2010; Porter & Ashdown, 2002).

Moreover, work commissioned by the Specialist Schools and Academies Trust (SSAT) developed a range of engagement materials to assist teachers in determining the individual ways children with life-limiting conditions engage with their learning and the world around them (Carpenter et al., 2015). According to the SSAT (2012), without engagement, effective and sustainable learning cannot occur. The engagement materials produced therefore enable teachers to reflect on the learner within seven key areas of awareness, curiosity, investigation, discovery, anticipation, persistence and initiation (SSAT, 2012). Adapting learning activities based on an individual’s score on the Engagement Profile within the seven key areas ensures that deeper and more active learning takes place enabling meaningful progress to be made (Hargreaves, 2006).

It is essential therefore that teachers are given knowledge about the complexities of need found in some children born prematurely and are trained adequately on how to engage them (Hornby & Woodward, 2009). Previous research has shown however, that this information is not communicated effectively with educators and therefore identification of children born prematurely is not widely occurring in



schools (Moriarty, Beer & Johnson, 2011), leading to teachers who do not have the knowledge to meet their educational needs effectively (Johnson et al., 2014).

This need to focus on individual learning pathways (Carpenter et al., 2010) may pose further challenges for educators who feel constrained by the National Curriculum. Since the implementation of the National Curriculum in 1988 (HMSO, 1988), there has been a requirement that all children learn all subjects regardless of levels of SEND. However, as children with more complex SEND are entering education, some individual schools feel it more appropriate to develop their own curricula to meet the current complexity of need (Rayner, 2011). This is partly due to the belief that the National Curriculum is no longer relevant for children with life-limiting conditions (Grove & Peacey, 1999) and to the lack of time to deliver all subjects alongside other therapies such as physiotherapy (Male, 2006), something which the teachers in Durrant et al's (2014) study were worried about. It is important to note however that this apparent shift in the development of curricula more suited to the needs of children with PMLD and life-limiting conditions is limited to a small but growing number of special schools and is not yet a reflection of wider practices nationally. The National Curriculum is still taught in the majority of special schools nationwide, however, there is some evidence to suggest that this is beginning to change (Lawson, Byers, Rayner, Aird & Pease, 2015).

The recommendations put forward by the recent Rochford Review (Rochford, 2016) may facilitate more widespread change in the way children with PMLD and life-limiting conditions are taught and assessed. The Rochford Review aimed to...

...consider the best way to ensure that pupils who have not completed the relevant key stage programmes of study and are therefore working below the standard of statutory testing arrangements, have the opportunity to demonstrate attainment and progress at primary school under the government's new assessment arrangements.

(Rochford, 2016, p. 8).

The publication of the Rochford Review marks the first time it has been acknowledged that following chronologically age-appropriate schemes of work (DfE, 2013a) and undertaking statutory testing (DfE, 2013b) are wholly inappropriate for children with SEND working at the earliest stages of

development. Whereas previously, children with SEND working below National Curriculum levels would have been assessed against the P-Scales, Rochford and colleagues acknowledged that this linear progression, may not be appropriate for our most complex learners (Rochford, 2016). This is supported by a Rochford Review survey which found that “the majority (78%) of respondents felt that P-Scales are not fit for purpose in their current form” (Rochford, 2016, p. 14). The Rochford Review has therefore recommended that the statutory use of P-Scales be removed and that new standards be introduced for children participating in subject-specific learning (Rochford, 2016). In addition, Rochford also made recommendations on the assessment of children not engaged in subject-specific learning, utilising the engagement research of Carpenter and colleagues (Carpenter et al., 2015; SSAT, 2012) described above.

It is unclear how the recommendations of the Rochford Review (2016) will translate into everyday practice, particularly as the recommendations are entering a pilot phase of development and are only stipulated for primary-aged children. However, for the first time in years, work is being done on a national scale to improve the assessment requirements for children with SEND. These changes to assessment processes may facilitate further change within the curriculum to ensure it is more appropriate and meaningful for the needs of individual children.

This move towards an assessment system and curriculum better suited to children with life-limiting conditions may also be in response to the fluctuating levels of need children experience throughout their illnesses (Aruda & Newinsky, 2011). Children who have frequent tonic clonic seizures for example, can have long periods of recovery following a seizure whereby they may need to sleep or have continued periods of seizure activity ‘in status’ (Barton & Webster, 2006). This results in children who, although are attending school, may not be able to participate in everyday activities (Zijlstra & Vlaskamp, 2005), and thus may require different teaching approaches. This poses a significant challenge for teachers particularly of children who are towards the end of life (Davis, 1989; Ekins et al., 2017).

Teachers need to respond sensitively, knowing when to adapt the curriculum to meet the decreasing abilities of students reaching the end of life. Research suggests that during these times, children should be engaged in something more meaningful

(Zijlstra & Vlaskamp, 2005). However, a specific challenge for educators is when to reduce academic expectations for children with life-limiting conditions. Expectations that are too high or prematurely low may prove dangerous in ensuring learners are fully engaged in their environment, peers, caregivers and learning (Davis, 1989; Fleitas, 2003). Prematurely low expectations, or those that over-compensate for medical conditions such as epilepsy could lead to under-stimulation, impacting on the child's quality of education (Zijlstra & Vlaskamp, 2005). Teachers in Durrant et al's (2014) survey, particularly those without experience of teaching children with life-limiting conditions, stated they would want to make lessons fun for children due to their limited life-span. During interviews and focus groups within A'Bear's (2014) study, teachers reported concerns and lack of knowledge regarding the capabilities of children with medical needs. As such, teachers feared expecting too much from them. Increasing knowledge and awareness of teachers to the danger of inappropriate expectations, as well as providing teachers with pedagogical strategies to meet the needs of a wide range of SEND (UNESCO, 2009), may be an effective way of ensuring that all students are able to access an appropriate education that is sensitive to their individual needs.

### **2.3.3.2 Teacher Awareness, Knowledge and Training**

A further issue in meeting the needs of children with life-limiting conditions in schools is in ensuring that school staff are fully prepared to meet those needs. Increasing numbers of children are being discharged from hospital reliant on a range of medical technologies including ventilators, tracheostomies and gastrostomies (Ekins et al., 2017; Palfrey et al., 1992; Watson, Townsley & Abbott, 2002), with the expectation that they will participate in the normalcies of life, including school. Yet despite this increase, schools often find themselves ill-equipped to meet these needs in terms of staff knowledge and training (Barton & Webster, 2006; Ekins et al., 2017), administering medications and responding in emergency situations (Alikor & Essien, 2005; Getch & Neuharth-Pritchett, 2009).

Teachers and healthcare professionals within Yates et al's (2010) longitudinal study identified a lack of knowledge in meeting the general educational and social needs of children with medical conditions, with many fearing extreme social isolation for the young people involved. Specifically, with individual medical conditions, Wait

et al. (2013) conducted a review of current guidance on the management of tonic clonic seizures and rescue medication across 6 countries. They found that in an Epilepsy Action survey of 185 schools in England, the majority of schools did not have an epilepsy policy and a considerable proportion of teachers had not received any epilepsy training in the previous three years (Wait et al., 2013). This is supported by Stanviloff (2000, as cited in Barrett, 2001), who found that teachers have little understanding of common life-limiting conditions such as asthma and epilepsy which is not addressed throughout their teacher education. Norris and Closs (1997, as cited in Bolton, Closs & Norris, 2000), also found that Scottish teachers interviewed felt ill-prepared to deal with medical care. These findings are not just limited to teachers within the UK. In Ohio, large numbers of teachers surveyed reported low-levels of confidence in meeting the academic and social needs of children with epilepsy (approximately 70%), as well as low-levels of knowledge about the condition (Nabors, Little, Akin-Little & Iobst, 2008). Brook & Galili (2001) surveyed 58 teachers in Holon, Israel and found they lacked knowledge around a range of chronic medical conditions, and that, similarly, teachers had not received any medical training.

In support, Asprey and Nash (2006) in their interviews with parents, school staff and young people, also found that the majority of parents (57%) were concerned with the school's lack of knowledge about their child's medical condition. This was particularly felt in secondary schools and colleges due to the large number of staff that came into contact with their child. This finding is replicated numerous times in the literature (Notaras et al., 2002; Roberts & Whiting, 2011; Nurmi & Stieber-Roger, 2012). Indeed, parents were primarily concerned with whether teachers were adequately informed about their child's condition, with the preparedness of school staff being one of the biggest risks to attendance for children who are dependent on medical technology (Rehm, 2002a). This situation is a 'crisis of confidence' with parents and teachers increasingly concerned about whether untrained personnel can meet the medical needs of children in schools (Lepkowska, 2012, p. 426).

It is clear that teachers need highly-specialised knowledge as well as practical information to enable them to care for children with life-limiting conditions (Fontaine, Zijlstra & Vlaskamp, 2008). Yet there are many examples in the literature of training programmes not being provided by schools for their staff. Clay,

Cortina, Harper & Cocco (2004) surveyed 480 staff members in one state in the USA and found despite almost all participants (98.7%) stating they knew a student in school with a chronic illness, 64% reported no continued professional development or training for dealing with medical issues. Additionally, 85% of the 131 teachers surveyed in Lucas, Anderson and Hill's (2012) study were found to have received no training in the management of asthma. Similarly, in a larger study across the USA, Bishop and Boag (2006) found only a minority (14%) of teachers surveyed had received training in epilepsy within their teacher education programmes. Tellingly, over 90% of teachers requested further information on epilepsy and dealing with seizures (Bishop & Boag, 2006), suggesting there are huge discrepancies in the training provided and teachers' perceived training needs. Support from discussions around nursing provision in UK schools, states that "the lack of training and support for school staff who have to deal with a growing number of children with increasingly complex health needs is a tragedy waiting to happen" (Prentis 2012, as cited in Henshaw, 2012). This highlights the risk to children and school staff of the expectations to perform medical interventions without appropriate training and support and is something that needs careful consideration given the projected increase in numbers of children requiring such care.

For many teachers, a lack of knowledge results in heightened anxiety and fear regarding the child, the condition and the possibility of a medical emergency (Boden et al., 2012). One way of combatting this could be to increase the knowledge of teachers about various medical conditions and emergency situations. Numerous international studies have examined the impact of teacher education programmes on teachers' knowledge and confidence in meeting medical needs within their classrooms (Duggan, Medway & Bunke, 2004; Smith, Chen, Plake & Nash, 2012). For example, Sapien, Fullerton-Gleason and Allen (2004) found that a one-hour educational video presented to school teachers in the USA increased knowledge of asthma management. The significant impact of this brief training video may be explained by the teachers in McCarthy, Williams and Eidahl's (1996) study who expressed their limited time for gaining information about medical conditions. It may be that practical resources in video format are easier to access and more helpful than written information given the time constraints of teachers. Similarly, teachers surveyed in Turkey were found to have improved knowledge,

attitudes and abilities to manage epileptic seizures following a teacher education programme, with a 57% increase in those reporting knowing what to do in an emergency (Bekiroglu, Özkan, Gürses, Arpacı & Dervent, 2004). Barrett (2001) found that by improving the medical knowledge of teachers, positive effects were seen on anxiety reduction, confidence and attitudes towards children with medical needs. Verifying this trend, Duggan et al. (2004) found that the confidence levels and knowledge of Canadian teachers were improved by a short two-session training programme and was especially effective for teachers with no previous experience. This again demonstrates the value of providing in-service training to educators. However, due to the lack of control groups and small sample sizes in the above studies (Hinton & Kirk, 2015) as well as the stark difference between health and education within the UK and abroad, these results should be treated with caution.

Contrastingly, Nabors et al. (2008), surveyed 247 elementary school teachers in the USA and found that although special education teachers reported a greater knowledge of medical conditions when compared with mainstream teachers, this superior knowledge did not translate into greater confidence when meeting the needs of children with life-limiting conditions. Yet it is important to note that the teachers in Nabors et al's (2008) study were not asked about their experiences of teaching children with life-limiting conditions. Despite a greater knowledge of medical conditions, a lack of experience in their classrooms may impact on confidence levels. Therefore, causal relationships are difficult to determine.

However, whereas widespread, general teacher training on life-limiting conditions is scarce, reassuringly, child-specific training appears to be provided for teachers who are performing medical interventions regularly. For example, teachers across the USA reported that in over 70% of cases, child-specific training was provided to those involved in daily medical interventions such as tube feeding and colostomy care (Heller, Best, Dykes & Cohen, 2000). Yet child-specific training is not the complete solution to the wider problem. Indeed, in Heller et al's (2000) study, despite the high numbers of teachers reporting to have received child-specific training, only half of them reported feeling very knowledgeable about the condition with over 80% of respondents requesting further training (Heller et al., 2000). Furthermore, in Durrant et al's (2014) survey, teachers expressed anxieties, particularly around the safe and correct administration of medication, even though formal training had been given.

What is required therefore is formalised, child-specific training to ensure that teachers are confident in delivering medical care to children with life-limiting conditions (Ekins et al., 2017; Hinton & Kirk, 2015). In addition, regular updates and access to training courses need to be prioritised to ensure that teacher knowledge and confidence remains high. Without such training, many children are being put at unnecessary risk of harm (BBC, 2010; Heller, Coleman, Best & Emerson, 2013).

### **2.3.3.3 Communicating with Parents**

In their quest to obtain further knowledge, many teachers turn to parents for medical advice and guidance. For example, in a large, quantitative survey of teachers in India, it was found that 37.5% of teachers gained information about a child with epilepsy from parents (Thacker, Verma, Ji, Thacker & Mishra, 2008). Similarly, Bishop & Boag (2006), found that teachers gleaned most of their information about a child's medical condition from parents. In fact, McCarthy et al's (1996) study found that parents were cited as the most valuable and helpful source of information available to teachers.

Yet, communicating with parents can be fraught with issues. International research has shown that relying on medical information from parents can be problematic, especially due to medically inaccurate misconceptions parents may have. Eyong, Anah, Asindi & Ubi, (2012), in their quantitative study of 105 teachers of epileptic students in Nigeria, found that as the majority of teachers gained medical information from families, over half of teachers also gained possible harmful misconceptions, for example that children with epilepsy are less intelligent. It is important to note however that cultural and contextual differences may impact on the results of this study. Access to medical information may be more difficult in countries such as Nigeria when compared with the UK and there are distinct differences in terms of their health and education systems. Therefore, the generalisation of these results must be treated with caution. Nonetheless, Mukherjee, Lightfoot and Sloper (2000) found that teachers in their UK focus groups were also concerned with medical inaccuracies of parents. Indeed, parents themselves expressed difficulties in recalling and understanding accurate medical information following consultations.

Surveys of parents of children with life-limiting conditions have found that parents perceive communication with teachers to be lacking (Asprey & Nash, 2006), due in part to the absence of a specific, named teacher to liaise with (Robinson & Summers, 2012). Poor communication between teachers and parents has also been reported elsewhere in the UK (Rozsahegyi, 2008), and internationally such as in the qualitative study of 15 mothers of children with cerebral palsy in Taiwan (Huang, Sugden & Beveridge, 2009). Mukherjee et al. (2000) found some parents expressed concerns that teachers did not always listen, or take medical information seriously, adding weight to the argument that medical information is needed from medical professionals as well as from parents. Difficulties in communication between teachers and parents have also been reported to heighten upon the child reaching sixteen, whereby confidentiality issues arise (Asprey & Nash, 2006). This is supported by teachers in Durrant et al's (2014) study who struggled with the notion of sharing and discussing information amongst parents, students and other professionals.

The views of teachers also demonstrate that communication with parents is not always straightforward. In their qualitative study of primary school staff, Boden et al. (2012) found that teachers reported a lack of support and investment from parents which impacted on their ability to support a child with diabetes.

Contrasting findings in the same study reported that parents could also be too 'overprotective' (Boden et al., 2012, p. E10), which also impacted on the quality of care teachers could offer. This adds more recent support to the findings of McCarthy et al. (1996), who also found that teachers identified overprotective parents, those with unrealistic expectations or those who did not provide effective care for their child, as barriers to providing high-quality medical care to their students.

Teachers have reported concerns in communicating with parents, specifically when discussing their uneasiness and apprehensions about meeting a child's needs (Mukherjee et al., 2000; Robinson & Summers, 2012), resulting in many teachers feeling uncomfortable communicating openly with parents. The emotional needs of parents can also be a potential barrier to effective communication (Mukherjee et al., 2000). Teachers surveyed by Durrant et al. (2014) reported that, although parents were a valuable resource when gathering information and knowledge, the emotional trauma experienced by parents made this communication difficult. Price,



Jordan and Prior's (2013) qualitative, UK-based study examining the perspectives of thirty-five health and social care professionals, including teachers who care for children at the end of life, found that parents' own emotional trauma impacted negatively on lines of communication. The professionals who took part in Price et al's (2013) focus groups found themselves a target for angry and upset parents, which had a negative impact on effective communication and professionals' own emotional wellbeing.

It is clear that, although improving communication between teachers and parents will be of benefit to all, it is not the most reliable method of ensuring teachers are fully able to meet the needs of their students (Robinson & Summers, 2012). Further communication and close liaison with and between parents, teachers and medical professionals is needed to provide the best possible care for these children.

#### **2.3.3.4 Collaborative, Multi-Agency Working**

To ensure that teachers are able to deliver an individualised curriculum, have access to a greater range of training opportunities and thus meet the complex levels of need they encounter, collaborative relationships with a range of stakeholders including family, healthcare professionals and social care services are required (Carpenter et al., 2010; Capurso & Dennis, 2017). Teachers gather a great deal of medical information about students with life-limiting conditions from parents (Bishop & Boag, 2006; Thacker et al., 2008). Although teachers highly value this information, they also require professional information to ensure they are fully aware of the implications of the child's condition (Mukherjee et al., 2000; Shiu, 2004). Collaborative, multi-agency working with teachers, professionals and families can ensure all possible information about a child's condition is gathered effectively. However, these collaborative relationships can pose a significant challenge to those involved.

Previous research has found that despite the increased demand for specialist services such as physiotherapy, occupational therapy and speech and language therapy, actual provision was lacking and, in some cases, 'in crisis' (Audit Commission, 2002, p. 32). Recent research has also found differences in quality of provision across localities with some services found to be inadequate (DfE, 2011; Office for Standards in Education [Ofsted], 2010), ultimately demonstrating that

despite some improvements, there is still an increasing demand for specialist services which is not being met (Rayner & Male, 2013). This access to high-quality health and social care provision within schools is incredibly important in ensuring that children with life-limiting conditions continue to access inclusive education and maintain high-levels of attendance, without the interruptions of health and therapy appointments outside of school (Seymour, 2004).

A further issue is the apparent lack of control from an educator's perspective on the quality and quantity of services offered to schools. Eight of the 167 headteachers surveyed in Rayner and Male's (2013) study struggled with the inability to line manage health professionals working in schools due to being commissioned by the National Health Service (NHS) and not education (Rayner & Male, 2013). These headteachers identified their need to buy in specialist services or to use school funds to supplement the services provided by the local health authority. Headteachers also identified that further funding should be provided to schools to ensure they were able to adequately access the health services they needed in a timely manner, something they did not feel was possible within the current funding structure.

In addition, almost one-third of headteachers surveyed felt the time health services had working in schools was 'totally inadequate' with many reporting needing significantly more time to meet the medical needs of their students (Rayner & Male, 2013, p. 17). Specifically, headteachers identified an urgent need for school nurses and highlighted the unavailability of services such as psychology and social care. This has huge implications for the adequate care of children with life-limiting conditions. For example, some children are having to wait for health services and school nurses to be in place before they are able to attend school due to the school's inability to meet their medical needs (Rayner & Male, 2013). Furthermore, despite an increase in the school population as well as the numbers of children living with life-limiting conditions, the provision of health services for schools including the numbers of school nurses, is decreasing significantly as a result of living wage increases and approximately £200m in health budget cuts in England (Ekins et al., 2017; Fagan, Williams, Fennell & Russell, 2017; Press Association, 2015).

Educators are endeavouring to overcome these shortcomings through multi-agency working to better coordinate care (Hewitt-Taylor, 2010; O'Connor, Howell-Meurs, Kvalsig & Goldfeld, 2014). Children with life-limiting conditions require access to a

number of integrated services and professionals to ensure they are properly cared for (Watson et al., 2002). Without this collaborative approach, there is a danger of separation and fragmentation of a child's health and educational needs which can impact on how a child is perceived both medically and educationally (DoH, 2004; Thies, 1999). For example, if the medical and educational needs of a child are seen as separate, the impact of the child's medical condition on their learning may be overlooked (Thies, 1999). Similarly, health professionals may miss out on valuable information from teachers on how their medication is affecting the child or how their symptoms may have changed. Multi-agency working can thus ensure the child is seen holistically regardless of whether they are at school, home or hospital.

In an attempt to prevent this separation and promote collaborative working, Education and Health Care Plans (EHCP) have been developed for children with SEND in the UK. These EHCPs replace the old Statements of Learning Difficulty and aim to identify the educational, social and health needs of a child, as well as to outline how all services can work together to achieve a set of agreed outcomes (DfE, 2015a). As the implementation of EHCPs has only just begun, research into their effectiveness is limited. However, it has been found that overall, parents feel satisfied that their child is at the centre of the approach and also appreciate the range of professionals working together to ensure their child's needs are met (Skipp & Hopwood, 2016). Whilst this process is clearly seen as more positive than previous procedures, Skipp and Hopwood (2016) demonstrated that the challenge of collaborative and multi-agency working still exists amongst some professionals and that there are still areas for improvement as the EHCP process becomes established. As an outcome of their research project, Skipp and Hopwood (2016) developed a support website providing training tools, templates and feedback to ensure the EHCP process is consistent across agencies and localities.

Despite these efforts, collaborative working can be problematic and can be a barrier to providing support for children, teachers and their families (Bruzzese et al., 2010; Tolbert, 2009). One of the main barriers to multi-agency working involves communication between stakeholders. Some teachers report not knowing which services were available to offer support, in addition to discrepancies in the levels of communication held with paediatricians (Ekins et al., 2017). For example, Dyson, Lin & Millward (1998) found that some teachers and paediatricians communicated well with each other, whereas other teachers reported little or no communication

with paediatricians, possibly on the grounds of confidentiality. Delays in teachers receiving information from healthcare professionals has also been seen to be a barrier to effective communication (Ekins et al., 2017). Teachers reported that they were not seen as partners amongst healthcare professionals which impacted on the quality of communication they received (Dyson et al., 1998). However, interestingly, these results were also found amongst healthcare professionals who identified similar barriers to effective communication with teachers, such as time constraints, the inability to identify a lead professional within schools and concerns about confidentiality (Bradley-Klug, Sundman, Nadeau, Cunningham & Ogg, 2010; Mukherjee et al., 2002). It is therefore apparent that special attention needs to be given to the development of effective communication systems if collaborative, multi-agency working is going to best meet the needs of children with life-limiting conditions (DfE, 2015b; Ekins et al., 2017; Watson et al., 2002).

A key factor in the success of collaborative working is the role of the school nurse. Nurses have a significant role to play in the care of children with life-limiting conditions in schools (Spargo & Northway, 2011), yet the numbers of school nurses are decreasing in line with budget cuts throughout the NHS and education (Ekins et al., 2017; Fagan et al., 2017; Press Association, 2015), a phenomenon that is also replicated across the USA (Biag, Srivastava, Landau & Rodriguez, 2014). In fact, in 2009 there were approximately 1,500 school nurses in the UK working with eight-million school children (Spargo & Northway, 2011), resulting in a single nurse being responsible for the care of more than 2,500 children (Royal College of Nursing, 2009). However worryingly, in 2015, the number of qualified school nurses had fallen to just under 1,200 (Henshaw, 2015). The majority of school nurses within the literature are commissioned on a part-time basis by the NHS, with a small minority employed by education (Merrell, Carnwell, Williams, Allen & Griffiths, 2007). This is of growing concern given the increase in numbers of children with life-limiting conditions. It is clear that teachers cannot solely rely on the presence of a school nurse during a medical emergency in the classroom (Barrett, 2001; Council on School Health, 2008).

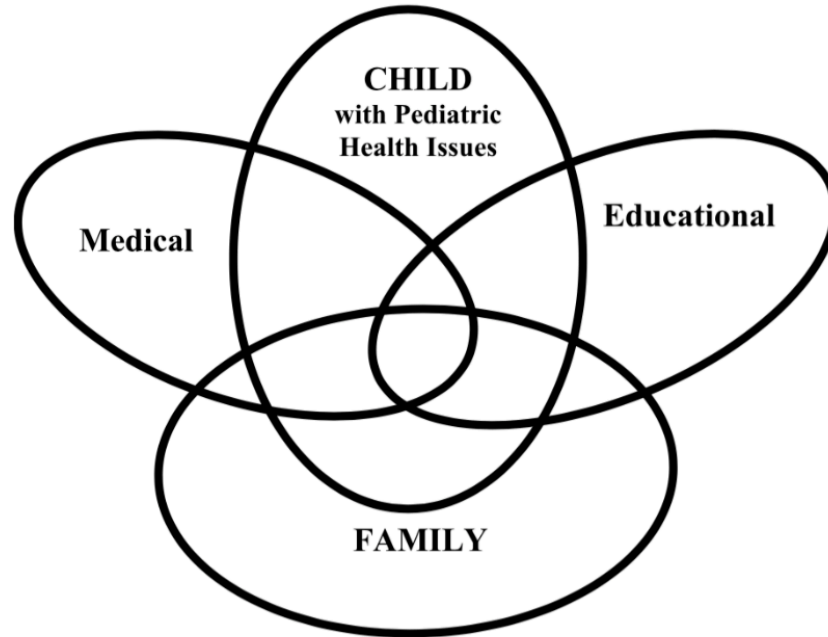
School nurses are considered to be 'expert resources in the ongoing training, care and support for teachers, parents and children with life-limiting conditions (Biag et al., 2014; Spargo & Northway, 2011) and as such, increasing school nurses could have a corresponding impact on the ability of professionals to work together (Biag

et al., 2014). School nurses have been found to be the crucial player working between education, health and social care (Leier, Cureton & Canham, 2003; Spargo & Northway, 2011) with their input described as a ‘critical step’ for improving health services within schools (Brenner, Wheeler, Wolfe, Vernon-Smiley & Caldart-Olsen, 2006), yet still school nursing services within the UK have been found to be variable or indeed, lacking (Ekins et al., 2017; Fagan et al., 2017).

Some schools are attempting to overcome this budget deficit through the employment of healthcare assistants “who can provide ‘hands-on’ care to the child with complex needs in home, school and respite settings” (McConkey, Barr & Baxter, 2007, p. 31). More and more schools are combining this healthcare role with the teaching assistant post, something McConkey et al. (2007) call the ‘hybrid worker’ (p. 31), to meet the increased complexity of medical need in schools (Abbott, McConkey & Dobbins, 2011). Some schools are already managing this ‘hybrid’ role effectively, however what still remains, is definitive guidelines for the accountability, training and funding of these posts, an area that continues to be a source of conflict between education and healthcare services (Abbott et al., 2011; McConkey et al., 2007).

Despite these issues, there is evidence of good practice existing across a range of local authorities internationally (Karpook & Werner, 2016; Nageswaran, Ip, Golden, O’Shea & Easterling, 2012). Furthermore, there is an increasing legal requirement of a multi-agency, collaborative approach to meeting individual needs, such as in the introduction of EHCPs discussed above (DfE, 2015a; DfE, 2015b; Mukherjee et al., 2000; Watson et al., 2002).

The Biopsychosocial Model reviewed by Grier & Bradley-Klug (2011) and illustrated in Figure 2.1, is one method used to facilitate multi-agency working. This model aims to “promote communication and collaboration among family members, educators and medical professionals” in order to fully support the child (p. 88).



**Figure 2.1:** Biopsychoeducational Model – Ecological Framework. (Grier & Bradley-Klug, 2011, p. 93).

This model sees the relationships between all stakeholders as vitally important and stresses the need for individuals to appreciate other relationships, for example between home and school when discussing medical issues, to establish effective interventions for the child. Primarily this model was developed for school psychologists to use with children with medical conditions (Grier & Bradley-Klug, 2011), however it could also hold importance for educators and medical professionals when establishing collaborative working relationships in the UK. For example, if parents are reluctant to share information with school about their child’s medical condition, using this model it is easy to see where and how interventions can break down. Acknowledgement of this model by all individuals ensures that an efficient network is created, enabling problem-solving and the development of effective interventions, ultimately ensuring the child’s success across a range of settings (Grier & Bradley-Klug, 2011).

The application of the Biopsychoeducational Model was empirically tested with a case study of a child with cancer. Using this model, Grier and Bradley-Klug (2011) found that a great deal of information was obtained and shared between a range of agencies including health and education. In addition, problem-solving using the Biopsychoeducational Model enabled the trialling of various interventions at home

and school to best support the child's needs. What resulted was observed progress throughout behavioural, academic and social measures of performance (Grier & Bradley-Klug, 2011). Despite this success, schools may have difficulties in implementing such an approach given the shortage of school psychologists or school nurses who could take the lead (Ekins et al., 2017; Power, Shapiro & DuPaul., 2003). Another significant barrier to the success of this model is the lack of communication between parents and school personnel regarding their child's medical needs (see section 2.3.3.3), as well as the lack of communication between medical professionals and schools (Grier & Bradley-Klug, 2011).

In support and further development of this model, Capurso and Dennis (2017) highlighted the importance of using a systemic approach to ensure the student and their medical condition are seen holistically in a range of different contexts. Capurso and Dennis (2017) further built on the ideas within the Biopschoeducational Model (Grier & Bradley-Klug, 2011) to develop their six key educational factors (KEFs) for the education of students with a medical condition. These KEFs emerged as part of the LeHo project that aimed to improve communication and access to education for children with medical conditions (Capurso & Dennis, 2017). The six KEFs of relationships, making sense and constructing knowledge, assuming roles in front of others, metacognition, individualities and inter-institutional communication (Capurso & Dennis, 2017), encompass a range of contexts including the hospital, home and school, with the primary aim of guiding schools through the complexities of educating children with medical conditions. These KEFs can be used as a tool to assess children and institutions as well as measure developmental progress within each area (Capurso, 2015).

High-quality, multi-agency working can reduce teacher anxiety when dealing with medical emergencies, improve knowledge and develop skills (Barrett, 2001). Yet, despite these examples, what is clear from the literature, is that high-quality, multi-agency working to meet the needs of children with life-limiting conditions is an ideal seldom found in reality (Grier & Bradley-Klug, 2011; Skipp & Hopwood, 2016). Current experiences are improving but still fall short of that ideal (Spargo & Northway, 2011). Children with life-limiting conditions have a significant range of complex medical needs which educators are increasingly having to manage. However, disjointed agency working, lack of funding, awareness and training are

impacting on teachers' abilities to meet those needs. Practical considerations to overcome some of these issues have been briefly discussed, yet what remains is the effect of these issues on teachers who are trying to meet the medical, educational and social needs of these children in their classrooms.

## **2.4 Teaching Children with Life-Limiting Conditions**

*“Where there is school there is life and hope”*

(Baum, 1998, as cited in Asprey & Nash, 2006, p.10).

School can be a place of normality for children with life-limiting conditions, away from the stresses of hospitals, treatment and medical professionals (Asprey & Nash, 2006). It is an important part of childhood and one that is promoted throughout Governmental policy (DfE, 2015b). As previously explored, the numbers of children with life-limiting conditions are increasing (Blackburn et al., 2010; DoH, 2004; Fraser et al., 2011). However, there is a scarcity of research into how teachers feel when meeting the needs of these children. Are teachers confident in meeting the medical needs these children attend with? Do they have access to training and adequate support systems to help them deal with the emotional toll of caring for children who are life-limited? The limited amount of research in this area is presented below in addition to a discussion around the role of emotions in teaching. It is of note that the majority of studies examining feelings of teachers educating children with life-limiting conditions have been conducted within mainstream schools and utilise a quantitative research design, thus limiting the amount of in-depth responses that illustrate exactly how teachers feel.



### 2.4.1 The Emotional Practice of Teaching

*What people don't understand about teaching is that it sticks with you, all the time. There is no getting up from your desk at the end of the day and walking away. I think about my students as I fall asleep at night and first thing in the morning. I realise that a lot of jobs are 24/7 these days, but there's a unique emotional labour to teaching that often goes unnoticed.*

(Hudson, 2016).

To explore the emotions and feelings that teachers may experience within the classroom when meeting the needs of children with life-limiting conditions, it is necessary to first examine the concept of the emotional practice of teaching (Hargreaves, 1998). As the quotation above illustrates, teaching is not a process that is performed or conducted in an emotional vacuum. It is a dynamic, creative and passionate pursuit that involves the use and interpretation of emotions (Hargreaves, 1998). Emotions have been defined as “mental states accompanied by intense feeling and (which involve) bodily changes of a widespread character” (Koestler, 1967, p. 226). Hargreaves (1998) argues that teaching is entwined with positive emotion used to enable the formation of relationships conducive to learning and the sharing of creativity and passion. Teachers are emotional beings with their job often requiring emotional acts such as caring, intuition and consideration (Elbaz, 1991; Hargreaves, 1998). It is this concept of caring teaching, as opposed to the process of ‘providing care’, which is of importance when examining how teachers experience the act of teaching children with life-limiting conditions.

One concept of caring teaching that is pertinent to teachers of children with life-limiting conditions, is that of adjusting or hiding individual emotions in order to interact with a student (Isenbarger & Zembylas, 2006). In the context of children with life-limiting conditions this may involve the hiding of negative emotions such as sadness regarding the child’s condition, in order to display positive emotions needed to interact successfully with the child. Zembylas (2002; 2003) recognises that when emotions are changed or hidden in this way, teachers are performing ‘emotional labour’ (Hargreaves, 1998; 1999). Furthermore, researchers have also identified the concept of ‘emotional understanding’ (Denzin, 1984), or ‘emotional work’ to describe the “efforts made to understand others, to have empathy with their situation, to feel their feelings as part of one’s own” (England & Farkas, 1986,

p. 91, as cited in Isenbarger & Zembylas, 2006, p. 123). Again, in the context of teaching children with life-limiting conditions this may not only be empathising with the feelings of the medically-complex child, the forming of affectionate relationships, but also listening and providing advice to parents who are coming to terms with their child's condition and care needs (Isenbarger & Zembylas, 2006).

It is clear that the process of caring teaching involves considerable emotional investment on the part of the teacher. Negative implications have been found to include teacher burnout, stress and isolation (Fineman, 1993; Pogrebin & Poole, 1991). This is supported by Isenbarger and Zembylas' (2006) case study which found that the emotional labour of the participant was concerned with the management of negative emotions such as sadness, guilt and frustration towards a challenging pupil, leading to isolation from her colleagues who did not share the same views. Yet findings have also suggested that caring teaching is not always a negative experience. Within the same case study, Isenbarger and Zembylas (2006) found that the emotional aspects of caring teaching had a positive effect on self-esteem as the process of caring teaching proves rewarding and fulfilling. It is unclear however, if the positive effects experienced within this case study are due to individual characteristics and personalities. The participant within this case study appeared to have excellent emotional understanding and cared deeply for her students. As a result, she did not distinguish between emotional labour and caring. Consequently, it may be that for teachers with unique, individual characteristics, the positive or negative outcomes of emotional labour may differ significantly.

Interviews with thirty-two teachers in Canada demonstrated that teachers described their caring relationships in terms of love, a positive emotion that resulted from the emotional labour employed (Hargreaves, 1998). This fulfilment, job satisfaction and love may explain how teachers are able to cope with the emotional demands of caring teaching despite the negative impact of such emotional work. Indeed, "teachers make heavy emotional investments in these relationships. Their sense of success and satisfaction depends on them" (Hargreaves, 1998, p. 838). Hargreaves' statement suggests that teachers work to fulfil a moral purpose and as such their emotions within teaching depend on their success (Comer, Haynes, Joyner & Ben-Avie, 1996). For example, a sense of achievement can bring about positive emotions such as happiness (Oatley, 1991), whereas if a moral purpose is not fulfilled, negative emotions such as anxiety, anger and frustration may result

(Hargreaves, 1998). This is important for schools to ensure that teachers are given every opportunity to achieve their goals, particularly in relation to caring teaching. Barriers to caring teaching can include paperwork, meetings, unrealistic expectations and inappropriate pedagogy (Hargreaves, 1998), providing a challenge for senior leadership teams (SLT) and teachers alike.

#### **2.4.2 Teacher Perceptions and Emotions**

Given the emotional nature of the teaching role (Hargreaves, 1998) and the degree of emotional labour that it requires (Isenbarger & Zembylas, 2006), it is important to examine the thoughts and feelings of teachers when faced with children with life-limiting conditions. Research has shown that the responsibility of dealing with such children on a day-to-day basis can instil a variety of negative emotions within teachers, including that of grief, fear and anxiety which ultimately heighten the emotional labour of their work. These negative emotions are explored in more detail below.

##### **2.4.2.1 Grief**

Grief has been expressed in the literature when discussing the deterioration of a student's condition or upon a student's return to school after an acute medical episode (Kliebenstein & Broome, 2000). Teachers also expressed feelings of helplessness during these periods, especially towards end of life and worried that they were not providing high enough expectations during these times, thus adding to the emotional drain teachers reported (Kliebenstein & Broome, 2000). Sadness was also identified within focus groups of teachers and healthcare professionals when dealing with children requiring palliative care (Price et al., 2013). This sadness was reported to stem from feelings of inadequacy and frustration that arose when caring for a dying child (see section 2.5 for a discussion about grief following a bereavement).

##### **2.4.2.2 Fear**

Fear is an emotion that is often raised in the literature when analysing the views of teachers who teach children with life-limiting conditions (Bolton et al., 2000). The main source of fear in McCarthy et al's (1996) qualitative study of teachers in the USA was in relation to knowing how to respond in an emergency situation. Boden et al. (2012) in their qualitative study of twenty-two primary mainstream teachers

found that, when told of a child with diabetes joining their class, teachers expressed feelings of panic, nerves and fear with some reporting to feel 'terrified' and 'scared' (Boden et al., 2012, p. E8). Boden et al. (2012) attributed some of this anxiety and fear to the invasive nature of injecting insulin and testing blood. Thacker et al. (2008) in their survey of seven-hundred teachers in India also found that a third of teachers were afraid of having a child with epilepsy in their classroom. It is important to question the representativeness of the sample in Thacker et al's (2008) study however. As the teachers surveyed were from a developing country, where public education regarding medical conditions such as epilepsy is limited, their views are strongly influenced by cultural values and beliefs. For example, some of the teachers surveyed were unsure whether epilepsy was caused by insanity and a minority believed that it was caused by a 'supernatural phenomenon' (Thacker et al., 2008, p. 688). It is these cultural beliefs therefore, that may have had an impact on the results of this study (Hinton & Kirk, 2015).

#### **2.4.2.3 Anxiety**

Anxiety is also a common emotion discussed by teachers when describing their experiences of teaching children with medical conditions (Abdel Gawwad, 2008; Durrant et al., 2014; Olsen, Seidler, Goodman, Gaelic & Nordgren, 2004). Stanviloff (2000, as cited in Barrett, 2001) found that during medical emergencies, teachers experienced feelings of anxiety and helplessness. Interestingly, these feelings were found to be heightened when working with children with SEND (Stainback & Stainback, 1996).

Further anxiety was found in Barrett's (2001) study of teachers' knowledge and feelings when managing medical emergencies. However, as Barrett (2001) acknowledges, due to the geographical constraints of the study, the levels of anxiety experienced by teachers could be attributed to the rural location of schools and therefore the increased response times of emergency medical care. The anxiety expressed by teachers interviewed in Boden et al's (2012) study was not just related to times of medical emergencies however. Teachers described feeling anxious and performing 'constant surveillance' when a child with diabetes was in their care, regardless of whether they were in class, the playground or the community (Boden et al., 2012, p. E9). This constant awareness was also found in Jones' (2005) qualitative study of PMLD teachers when discussing children with medical needs.

A number of other international surveys have also found that teachers worry about their abilities to deal with medical emergencies including situations involving a decision of when to call for emergency medical care (Anderson et al., 2005; Bishop & Boag, 2006; Lee, Lee, Chung, Yun & Choi-Kwon, 2010; Mecarelli et al., 2011). Additional, qualitative findings have been reported by Esperat, Moss, Roberts, Kerr & Green (1999) who, in their open-ended questionnaires to school teachers in Texas, found that delays in communicating with, and access to health professionals such as the school nurse during medical emergencies heightened feelings of anxiety; “I had a child with a grand mal seizure, and I really didn’t know what to do. It took several minutes to get the nurse into the classroom. We were all nervous wrecks afterwards” (Esperat et al., 1999, p. 175). This is also supported by Anderson et al. (2005), who found that teachers were especially concerned with the lack of healthcare provision and support on-site in schools.

A common theme throughout Esperat et al’s (1999) and Kliebenstein and Broome’s (2000) study was the reinforcement by teachers that they were ‘regular-education teachers’ and not medically-trained professionals (Esperat et al., 1999, p. 177), with a primary aim of educating their students (Kliebenstein & Broome, 2000). This frustration experienced by teachers not only represents the anxiety and ill-preparedness felt when teaching these children, but also the pressures on teachers to ensure that educational needs of all students are met alongside their medical needs. Time to meet the medical needs of children with life-limiting conditions was also found to be a source of anxiety for teachers surveyed in Durrant et al’s (2014) study. Although this anxiety was mainly expressed by teachers without teaching experience of children with life-limiting conditions, teachers with experience did state that often the education of these children becomes “secondary to a child’s medical needs” (Durrant et al., 2014, p. 19).

#### **2.4.2.4 Fear of Liability and Responsibility**

Feelings of anxiety and fear are often compounded further by a fear of liability and responsibility in medically-complex situations, a phenomenon that is widely found amongst teachers engaged in health practices within the literature (Barrett, 2001; Ekins et al., 2017; Henshaw, 2012; Hewitt-Taylor, 2010). Indeed, as highlighted in Hill & Hollis’ (2012) survey, “teachers are asked to perform tasks that only a

registered nurse is allowed to do in the real world. Practicing medical assistance is not the role of the teacher” (p. 185).

Fear of litigation has also been found amongst community nurses who have highlighted issues with the training of ‘non-parent carers’ (DoH, 1997, as cited in Watson et al., 2002), resulting in educators being unable to access vital training to enable them to appropriately meet the medical needs of these children. Part of this fear of litigation may stem from further afield than teachers’ own perceptions. For example, Wait et al. (2013) found that teaching unions within the UK had raised concerns over the administration of rectal diazepam as a rescue medication for epilepsy due to the invasive and intimate nature of the procedure. Wait et al. (2013) also found that across the six countries included in their guidance review, most warned teachers against volunteering to administer rescue medication to their epileptic pupils. Similarly, some of the teachers interviewed in Mukherjee et al’s (2000) study were discouraged from performing medical interventions by the local education authority, adding weight to Boden et al’s (2012) argument that teachers often find themselves with the unenviable dilemma of providing care for their students or legally protecting themselves.

This fear of liability has resulted in teachers limiting their knowledge, for example, by refusing training in resuscitation techniques or other care skills out of fear for liability proceedings should something go wrong (Boden et al., 2012; Rehm, 2002a). It is important to note however, that in Rehm’s (2002a) study, the concerns over legal challenges and liability were hypothetical concerns and not based on real events experienced by those questioned. However, the fact that teachers have been shown to fear litigation over delivering medical care to children, based on real events or not, suggests that it is an issue worthy of further exploration. Hewitt-Taylor (2010) recognises this, suggesting that some of these legal fears could be overcome through high-quality, pre-planned, multi-agency working to ensure that educators feel confident in meeting the needs of children with life-limiting conditions.

#### **2.4.2.5 Emotional Exhaustion**

One of the major impacts of experiencing negative emotions and the emotional labour of teaching is that of emotional exhaustion and burnout (Fineman, 1993;

Pogrebin & Poole, 1991). Male & May (1997) surveyed a range of teachers teaching different levels of SEND and found that emotional exhaustion was highly experienced according to the Maslach Burnout Inventory (Male & May, 1997). Although not specific to teaching children with life-limiting conditions, the findings of Male and May's (1997) study are noteworthy and add weight to the negative implications of emotional labour discussed earlier (Hargreaves, 1998; Isenbarger & Zembylas, 2006). Indeed, other studies have also found that many SEND teachers find the job incredibly stressful due to curriculum and workload pressures (Male, 1996a).

When looking specifically at teaching children with life-limiting conditions, it may be that the nature of the relationship between teacher and child contributes to the intensity of the resulting emotional impact. Unlike other healthcare professional relationships whereby professionals may only encounter their patients for brief periods of time, the relationship between teacher and child can be a longitudinal one. It is this longitudinal, caring relationship, particularly if it stems over a number of years, that can increase the emotional impact of the caring teaching role. Similar findings have been reported within the healthcare literature, particularly within children's nursing (Clarke & Quinn, 2007; Costello & Tinder-Brook, 2000). For example, teachers and palliative healthcare professionals in Price et al's (2013) qualitative study found that the emotional impact of their job was more intense given the conflict between the 'personal' and 'professional' relationships experienced (p. 77). Professionals in this study were aware of the risk of becoming emotionally attached to the children in their care and were often seen by the parents as 'friends' (Price et al., 2013, p. 77). This in turn, led to the increased emotional impact of their professional role when the child died.

#### **2.4.2.6 Positive Emotions**

Despite these negative emotions, the picture is not always so dark. Like the research into emotional labour by Hargreaves (1998), Closs and Norris (1997, as cited in Bolton, et al., 2000) also found within their open-ended interviews, that alongside negative emotions of fear and anxiety, also lay positive emotions such as happiness and satisfaction at the achievements of their students and in the relationships formed with parents. Teachers who had actually worked with children with life-limiting conditions found their experiences interesting and easier than they

had imagined. Mackenzie (2012) in their qualitative study of Special Educational Needs and Disabilities Coordinators (SENDCOs) found that teachers who had successfully developed resilience and avoided emotional burnout, expressed their love and enjoyment of the job and acknowledged the rewards of working with children with SEND. Howard and Johnson (2004) used semi-structured interviews to examine how Australian teachers remained resilient within a stressful teaching environment. They found that developing a sense of agency, having access to strong support networks including from SLT, as well as taking pride in achievements, were major factors for remaining resilient and enjoying the teaching role (Howard & Johnson, 2004).

Teachers and other healthcare professionals involved in palliative care also found their work personally fulfilling, despite the negative emotions experienced (Price et al., 2013). This identification of positive emotions from teachers who have actual experience of teaching children with life-limiting conditions suggests that some of the anxiety and fear described in the literature could result from the unknown and a consideration of the 'worst case scenario'. As identified by Howard and Johnson (2004), the development of resilience within teaching was dependent, in part, on access to strong support networks. The quantity and quality of emotional support available to teachers could therefore impact upon the levels of positive and negative emotions experienced and may influence the teachers' abilities to effectively deal with them. This emotional support offered to teachers will be explored in more detail below.

### **2.4.3 Sources of Emotional Support for Teachers**

It is clear that the emotions experienced by teachers when faced with children with life-limiting conditions are vast and wide-ranging, with many teachers crying out for support in dealing with the emotional strains of the role (Durrant et al., 2014; Price et al., 2013). How well teachers are able to deal with the emotional intensity of their roles when teaching these children depends on the availability and quality of emotional support. Ensuring that teachers are well supported and able to deal adequately with the emotions they experience, will ultimately lead to an improved educational experience for children with the most complex medical needs.



Appropriate support and training can help to alleviate some of the concerns and fears expressed by teachers. For example, in a survey of mainstream and special education teachers in the USA, the increased presence of school nurses was found to increase the confidence of teachers as well as increase communication between health and education (Hill & Hollis, 2012). This could be due to feelings of reassurance that there is a medical professional on-site to make decisions where needed. Similarly, some of the fear identified in McCarthy et al's (1996) study was perceived to be alleviated given the availability of school nurses or the presence of emergency care plans. This is in contrast to the teachers in Barrett's (2001) and Esperat's (1999) studies, where the lack of access to medical professionals heightened feelings of anxiety and fear. It is important to note however that simply the presence of a school nurse on-site may not fully reduce negative emotions. As Hill & Hollis (2012) and McCarthy et al. (1996) emphasise, teachers need to know where the nurse is when needed, and access to medical advice needs to be timely. If teachers are unaware of whether the nurse is on-site or of their exact location in the event of a medical emergency, the role of the school nurse as a source of support is diminished. Likewise, as previously noted, the availability of school nurses is variable, particularly in the current financial climate (Fagan et al., 2017) and therefore the presence of school nurses to alleviate fear and anxiety in teachers cannot be guaranteed.

Informal support from other colleagues within special schools has been found to be of particular use to teachers of SEND. Billingsley, Carlson & Klein (2004) found that for NQTs in special schools, the informal support of their teacher colleagues was reportedly more useful than formal support methods such as induction mentoring. This was attributed to the individual, emotional and contextual support that other colleagues could give to teachers through informal channels (Billingsley et al., 2004). However, due to the low response rate (32%), it may be that the teachers who did not respond to the survey were less well supported than those who did. Kinman, Wray and Strange (2011), in their survey of 628 teachers in the UK, found that perceived higher levels of social support, for example in having an approachable manager to speak to or in having colleagues to turn to in difficult situations, resulted in lower levels of emotional exhaustion and higher levels of job satisfaction. Furthermore, a greater level of social support within schools was found to protect teachers from the negative effects of emotional labour as discussed

previously (Kinman et al., 2011). It is clear therefore, that school leaders and teacher colleagues need to be aware of the emotional impact of the teacher role and be available to offer informal support where needed to protect their employees from damaging emotional exhaustion and burnout (Kinman et al., 2011).

Despite this range of informal support, some teachers identified a lack of formal support systems when teaching children with life-limiting conditions. Price et al. (2013) found within their focus groups of teachers and healthcare professionals involved in palliative care, that there was a perceived lack of support in how to deal with the emotional intensity of their caring role. Specifically, teachers and care professionals requested more guidance in how to maintain a 'professional distance', given the longitudinal relationships formed with children and their families throughout end of life care (Price et al., 2013, p. 77). Interestingly, Sonnentag, Kuttler and Fritz (2009), found that employees who were able to effectively separate their work and home lives and develop 'emotional boundaries' were less susceptible to the negative emotional impact of their roles. This empirical evidence provides weight to the argument that teachers need further, more formal training in how to deal with the emotional aspects of their roles.

Formal support systems which aim to combat the emotional impact and potential burnout of the teacher role should be built into wider school policy and ethos, alongside an informal supportive culture, as described above. It is acknowledged that teachers educating the most vulnerable children are at higher risk of psychological conditions such as Post-Traumatic Stress Disorder (PTSD), anxiety and depression (Ekins et al., 2017). For this reason, having someone available for teachers to talk to is vital. Indeed, many of the teachers interviewed in Durrant et al's (2014) study expressed a desire to talk to someone who had experience of a similar situation but who was far enough removed to not be burdened by their worries or concerns. There is a growing awareness of the needs of professionals who are working with children with life-limiting conditions in schools and therefore a range of charities that aim to provide more formal support are beginning to emerge. The Education Support Partnership provides full-time telephone support and counselling to all teachers regardless of their concerns or worries, and the charity Together for Short Lives also has a helpline for teachers who work with children requiring palliative care or nearing end of life. Details of these charities

and helplines, along with others who can offer support following bereavement can be found in Appendix One.

In conclusion, teaching has been found to be an intensely emotional practice, requiring a high-level of emotional labour (Kinman et al., 2011). However, once children with life-limiting conditions are introduced into classrooms, it is clear that the risk of emotional exhaustion, burnout and negative emotions such as fear and anxiety is heightened. Informal and formal support systems such as being available to listen to the concerns of teachers, as well as providing further helpline counselling and support can help to alleviate some of the negative impact of this emotional, caring role. Nonetheless, teachers of children with life-limiting conditions are at a specific risk of mental health issues such as depression and PTSD and are in desperate need of further training and support to develop emotional resilience and protect them from further problems in the future.

## **2.5 Death and Dying in Schools**

*“The tragedy of the loss of a child’s life is great. Doctors are prepared in their training for the loss of a patient; clergy are instructed in how to deal with death. But at no time in a teacher’s training is a student’s death considered.”*

(Scott, 1981, p. 22).

As the numbers of children living with life-limiting conditions increase and as developments in medical technologies continue to improve the life-expectancies of these children, it thus follows that the experience of death and dying in schools is becoming increasingly frequent and perhaps even inevitable. As Scott (1981) identifies, teachers are ill-prepared to deal with this eventuality and may have never contemplated that a child from their class could die. It is therefore imperative that this phenomenon is explored in greater detail to determine how such situations can be dealt with sensitively for all concerned.

The apparent scarcity of research into the phenomenon of an expected student death in school seems to reflect the somewhat British societal belief that discussions around death is a topic to be avoided (Horridge, 2011; Lovelace & Thompson,

2000; Ward, 1988). Death education is not statutory within the English National Curriculum and therefore is not something frequently explored within a classroom, between teacher and student (Bennett, & Dyehouse, 2005; Lowton & Higginson, 2003). Dealing with the death of a student is also omitted from the curriculum of initial teacher training (Stepanek & Newcomb, 1996), meaning that for many, the concept of a student dying will be something never considered. Yet, at some time in a teacher's career, the death of a student is likely to be experienced (Munson & Hunt, 2005). For some, this event may be a 'once-in-a-career tragedy' (Hinds, 2007). However, for those who work with the most poorly and most complex of children, it may be an event that is unfortunately, regularly experienced (Hinds, 2007). Indeed, studies have shown that for special educators the death of at least one student was experienced by the majority of teachers, with some teachers experiencing the deaths of as many as twenty children throughout their careers (Bohling & Keiser, 1997, as cited in Munson & Hunt, 2005; Smith, Alberto, Briggs & Heller, 1991). Significantly, it can be argued that this figure could now be even higher given the increases in the number of children with life-limiting conditions being included in education, in addition to advances in medical technologies increasing the life expectancies of such children (see section 2.3) (Heller et al., 2013).

### **2.5.1 Teachers' Responses to the Death of a Student**

There is limited research within the existing literature on the effects of student deaths on teachers. Much of the research conducted outlines the roles of teachers following a student death, rather than their reactions to it. Teachers are often referred to as facilitators following a student death. Their role is discussed in terms of what they need to do for the family, for other students and for the school as a whole (Bryant, 1978; Munson & Hunt, 2005). Teachers dealing with the death of a student as thinking, feeling human beings are rarely discussed (Lazenby, 2006; Munson & Hunt, 2005), their thoughts, feelings and coping strategies are too often neglected. Teachers are seemingly expected to deal with the death of a student purely as professionals, being available to counsel students and family members without a second thought for their own personal thoughts or feelings. (Munson & Hunt, 2005). This 'disenfranchised grief' can have detrimental effects on the wellbeing of staff both professionally and personally and results out of a possible failure to acknowledge the emotional aspects of their caring role (Rowling, 1995).

Teachers therefore often find themselves in the unenviable position of having to deal with their own grief in addition to supporting and counselling many others including colleagues, students and parents (Munson & Hunt, 2005; Smith et al., 1991). Many teachers have found that dealing with the two is immensely difficult and therefore often put their own feelings aside in order to meet the needs of those around them (Rowling, 1995). For example, in Lazenby's (2006) qualitative study of thirteen bereaved teachers in Alabama, it was found that teachers experienced high-levels of grief, but the lack of formal support further reinforced the expectations that teachers needed to put their feelings aside to support their students. In fact, a teacher in Lazenby's (2006) study described a situation of approaching a counsellor for support only to be told "you're going to have to be there to help the children" (p. 53).

A minority of studies have aimed to explore the response of teachers to the death of a student and have outlined the impassioned responses felt by teachers experiencing such a phenomenon (Anderson, 2013). Although Lazenby (2006) found that teachers needed to put their feelings aside to support others, it did not stop them from experiencing grief. Indeed, Lazenby (2006) found that all teachers interviewed described their love and compassion for their students and that by its very nature, this love turned to grief when a student died. Interestingly, Lazenby (2006) found that for the special education teachers interviewed, a deeper bond existed with students due to the longitudinal nature of their relationship and the teaching of life skills alongside academic skills. This led to a heightened sense of grief when a student died. Similarly, Durrant et al. (2014) found that mainstream teachers experience increasingly intense feelings of anxiety and fear as a student deteriorates and eventually dies. Eddison (2013) discusses the fact that he became "a blubbering wreck" (p. 49), following the death of a student which was unexpected for both himself and his headteacher. Ward (1988) also found, within her ethnographic research, that special education, pre-kindergarten teachers experienced intense feelings of grief and were deeply saddened by the death of a child.

Some authors acknowledge that the death of a child is experienced in a qualitatively different way to the death of an adult. As Van Eys (1977) acknowledges, "we have feelings about the death of a child that are far stronger than our reactions to the dying adult" (p. 222), in part due to feelings of unfulfilled hopes and dreams, a life lost rather than a life well-lived. Furthermore, feelings

associated with the death of a child have been described as “the most painful and enduring” (Goldman, 1998, p. 52). At Treloar School and College in the UK, where student deaths are experienced frequently due to the rare and complex needs of its students, the staff are “affected profoundly...they cry, they’re gutted, they flounder, they’re at a loss. It doesn’t get any easier” (Hinds, 2007, p. B21). These experiences show that, despite almost regular student deaths, teachers are still deeply affected and experience intense feelings of grief.

In support, medical research too is beginning to recognise that healthcare professionals including nurses often experience grief when a patient dies (Adwan, 2014; Barton, 1977; Mandell, McClain & Reece, 1987). Plante and Cyr (2011) examined the level of grief experienced by 101 Canadian healthcare professionals following the death of a child and found that intense levels of grief were experienced by every participant questioned. Interestingly, younger healthcare professionals (under twenty-five years of age), reported higher levels of grief than older professionals (over fifty years of age). Despite this, and in contrast to the findings of Lazenby (2006), the length of time the healthcare professional had been providing care for the dying child had no significant impact on the intensity of grief experienced (Plante & Cyr, 2011). Redinbaugh et al. (2003) also found that doctors in the USA were emotionally affected by the death of a patient but found that emotional responses were heightened in female doctors and those who had cared for patients for a longer period of time. In support, Hollingsworth, Wesley, Huckridge, Finn and Griksaitis (2018) found within their quantitative survey of trainee paediatricians, that some of the participants were “deeply affected, and may be psychologically harmed” by the death of a child in their care (Ward Platt, 2018, p. 3). These findings are concerning given perhaps the lengthier and more longitudinal nature of a teacher-pupil relationship. If trainee paediatricians and medical professionals who may have known a child for a matter of days, weeks or months can be so ‘deeply affected’ by the death of a child, how are teachers expected to deal with their feelings surrounding the death of a child they may have known and had a relationship with, on a daily basis and for years?

Teachers, although professionals within the classroom, are not immune to these feelings when experiencing the traumatic event of the death of a child. As well as experiencing intense emotions such as confusion, grief, anger, fear, guilt and vulnerability (Anonymous School Leader, 2013; Munson & Hunt, 2005; Ward,

1988), teachers are also required to provide support to colleagues, families and other students (Durrant et al., 2014). What is clear from this limited research, but also from personal experience is that teachers are deeply affected by the death of a student, however, how well teachers are supported to manage and cope with these feelings, seems less clear.

### **2.5.2 Education and Training in Death and Dying**

As previously discussed, teachers are deeply affected by the death of a student. However, research has shown that teachers lack the education and formal training needed to help them deal with the death of a student in school (Hart & Garza, 2013; Pratt, Hare & Wright, 1987; Reid & Dixon, 1999), despite playing such a crucial role in the provision of information and support for families and other students (Heller, et al., 2013). It is apparent that teachers simply do not have access to the training programs that adequately prepare them for a student death nor enable them to manage their grief effectively (Holland & McLennan, 2015; Lazenby, 2006; Secret Teacher, 2017).

Brownell & Emberland (2000, as cited in Munson & Hunt, 2005) found that 62% of teachers had received just one lecture on grief in relation to the death of a child throughout their training. Similarly, Holland and McLennan (2015), in their survey of schools in North Yorkshire, found that two-thirds of schools had not received any training on pupil bereavement and thus were ill-prepared to deal with a bereavement eventuality. Furthermore, all of the teachers interviewed in Lazenby's (2006) study reported having never attended a training session on the topic of death in schools, despite most of the interviewees expressing that it would have been helpful. A third of teachers in Heller et al's (2013) study also reported having not received any training to prepare them for the death of a student. However, it is important to note that two-thirds of teachers questioned in Heller et al's (2013) study had received training, with approximately half of these teachers receiving training during college or university courses. This is promising given that in 1991, 75% of teachers reported having no training on student death, compared with just 33.2% in 2012 (Heller et al., 2013). This increase in teacher training may be reflective of the rise in student deaths as a result of the greater numbers of children with life-limiting conditions now surviving until school age (see section 2.3). However, given this increase, it can be argued that the number of teachers now

receiving training in student bereavement is not high enough. More can be done in universities to prepare teachers or at least ensure they have considered the possibility of a student death before commencing their first teaching post.

The continuation of training for teachers on the possibility of a student death is imperative to ensure they are able to fulfil their role in supporting others at the same time as working through their own grief (Price et al., 2013). 47.3% of teachers in Heller et al's (2013) study requested further in-service training to help prepare them for a student death. This is also supported by Lazenby (2006) and Holland and McLennan (2015) who found that approximately half of teachers in the former, and half of schools in the latter, would have found extra training helpful.

Increasing access to high-quality training programmes around bereavement is something that should be considered by all school leaders in order to adequately support those who may experience the death of a student. Indeed, in studies where bereavement training programmes have been utilised, staff were found to have increased confidence when dealing with bereavement in schools (Paul & Quinn, 2015). The expertise and specialisms of a variety of professions should be sought when implementing a collaborative approach to bereavement training, including from hospices, mental health services, school nurses and specialist bereavement counsellors through consultancy and direct work in addition to within initial teacher training routes (Heller et al., 2013; Papadatou, Metallinou, Hatzichristou & Pavlidi, 2002; Paul & Quinn, 2015), to ensure that teachers feel more prepared to deal with a student death eventuality throughout their careers.

### **2.5.3 Support Systems for Teachers Dealing with a Student Death**

In addition to lack of education, teachers are also believed to lack access to adequate support systems that might enable them to grieve appropriately and therapeutically (Hart & Garza, 2013; Lazenby, 2006). Research has shown that the number of schools who are adequately prepared in terms of protocols and procedures for the death of a student are firmly in the minority (Mahon, Goldberg & Washington, 1999; Rowling & Holland, 2000), with studies showing as many as 83% of teachers reporting the absence of support systems to help them deal with a student death (Munson & Hunt, 2005; Smith et al., 1991). Within Lazenby's (2006)



qualitative study of thirteen teachers in the USA, all participants expressed the lack of support available to them following the death of a student.

Ward Platt (2018) acknowledges the link between the severity of emotional response following the death of a child and the later development of mental health problems such as PTSD. If this is true, it thus follows that a lack of support systems for teachers, and therefore the inability to deal with their emotions following a student death, can have detrimental effects on their health and wellbeing later in life. Consequently, and somewhat unsurprisingly, the lack of support from schools has been found to be attributed to teacher burnout following a student death (Munson & Hunt, 2005). Given these difficulties and dangers with not providing support following the death of a student, what can be done to make this time easier and more manageable for all involved? How can we best support our teachers to deal with and make sense of these tragedies? Within the literature a number of formal and informal sources of support have been highlighted that aim to support teachers and healthcare professionals through a very traumatic time. These are discussed in more detail below.

#### **2.5.3.1 Formal Support Systems**

To protect teachers from the detrimental effects of the failure to acknowledge their own grief, support plans, systems and protocols can be put in place. Well-planned support systems can help not only those teachers experiencing the death of a student first-hand but can also help to decrease anxiety and assist those responsible for providing support (Grant & Schakner, 1993; Hart & Garza, 2013). For example, teachers and SLT can prepare for a child's death before the event by developing a grief plan, outlining how to support teachers, families and students in addition to the identification of supporting resources (Munson & Hunt, 2005). Some studies have suggested the implementation of a 'crisis team' (Callahan & Fox, 2008; Jellinek & Okoli, 2012; Vann, 1992), to manoeuvre the school through the emotionally charged, initial shock of a student death. Crisis teams should be solely responsible for the communication of the student death to all involved with the child and should be there to coordinate the school's response as well as to support staff and students (Bennett & Dyehouse, 2005; Jellinek & Okoli, 2012). They should consist of the headteacher, an assistant head, counsellor, psychologist or social worker, trained teacher (Jellinek & Okoli, 2012), and as could be argued in

the present climate of special schools, a school nurse. The development of the crisis team and the outlining of their role and duties in a student death situation is something that has been requested by teachers in a number of studies (Papadatou, Metallinou, et al., 2002). Developing crisis teams in this way could allow SLT the opportunity to think through their response before the immediacy of a student death, allowing them to carefully consider the affect the death will have on staff and the school as a whole, thus going some way to combat the emotional detachment of SLT experienced within the literature.

The implementation of crisis teams could also help to prevent inadequate sources of support as found in existing research. For example, teachers questioned within Heller et al's (2013) study found that support from leadership or supervisory teams was lacking. Instead, teachers stated that they would have preferred a greater amount of individual support. A lack of formal support from employers has also been found in other studies (Lazenby, 2006), with supervisors expecting teachers to "go on with everyday business" (p. 55) and with headteachers not expecting their teachers to be badly affected by the death of a student (Eddison, 2013). This emotional detachment on the part of SLT is something that should be carefully considered. Indeed, in the account of the frequency of student deaths experienced at Treloar School and College in the UK, SLT have commented on their community approach to grief and the involvement of all staff in celebrating the life of their students (Hinds, 2007). Yet despite this community approach, the Director of the school identifies the need "to be aware of what members of staff might be going through, especially if they have lost several pupils, and what their personal histories of bereavement might be" (Hinds, 2007). These experiences demonstrate the need to formally create a supportive community environment and the role that SLT can have in creating such an ethos.

It may be that schools and SLT can learn something from medical practice to formally help their teachers deal with their grief appropriately and effectively. Common practice within the medical literature, appears to show that the presence of a debrief during and after patient death can be helpful for healthcare professionals when dealing with their grief (Rogers, Babgi & Gomez, 2008). Indeed, 67% of healthcare professionals surveyed in Plante and Cyr's (2011) study wanted to have multidisciplinary meetings to debrief after every child death. In support, Leemon, Fitzsimons & Dalzell (2016) found that of the 54% of paediatric

trainees who had been involved in a debrief following the resuscitation or death of a child, all respondents (100%) felt that the debrief was a positive experience. Ward Platt (2018) discusses the importance of multidisciplinary meetings and, where effectively planned and delivered, these meetings can allow the discussion of and reflection on emotions experienced. Ward Platt (2018) argues that these meetings could potentially be an effective way of dealing with strong emotional responses. However, as found by Hollingsworth et al. (2018), in their survey of 303 trainee paediatricians in the UK, attending a formal debrief following the death of a child was positively associated with symptoms of acute stress reactions and PTSD. In support, the NICE guidelines and the Department of Health both advise not to hold one-off debrief sessions following the death of a child in hospitals because of the risk of adverse outcomes for those involved (Hollingsworth et al., 2018; Roberts, Kitchiner, Kenardy & Bisson, 2009; Rose, Bisson, Churchill, Wessely, 2002).

Bateman, Dixon and Trozzi (2012) outline a structured group debrief called the 'wrap up' which is held within 48 hours of the death of a child and is led by someone trained in group debriefs. In their survey of twenty-seven paediatric residents, Bateman et al. (2012) found that the 'wrap up' debrief was appreciated in terms of its timeliness, multidisciplinary nature and the fact that it was led by a trained professional. Paediatric residents felt these group debriefs were effective in helping them to deal with the death of a child. The use of debriefs within education following the death of a student should therefore be considered carefully by SLT. It may be that with a sufficiently trained professional, perhaps a named person within the crisis team, these meetings could be useful in helping teachers deal with their emotional responses following a student death. A well-planned and delivered debrief is certainly something that some of the teachers in Lazenby's (2006) study thought would be useful. Elsewhere, nurses have reported that having a palliative care and bereavement team available to talk to was crucial in the aftermath of the death of a child, though its availability could not always be guaranteed (Lindsay, Cross & Ives-Baine, 2012).

Formal counselling and psychological support are other ways that school leaders can provide formal support for their teachers following the death of a student. Within the medical literature counselling has been identified as a useful resource for healthcare professionals experiencing the death of a child, however participants expressed the need for this to be more widely available (Plante & Cyr, 2011). In

contrast, within the educational literature, counselling has not been made available for teachers, instead focusing solely on the other students at the school, ignoring the teachers' need for support in dealing with their emotions (Lazenby, 2006). Details of charities that provide helpline support for teachers experiencing a student death can be found in Appendix One and could be used as part of a formal crisis team response within schools.

### **2.5.3.2 Informal Support Systems**

Research has found that the ability of staff members to cope with their grief following the death of a student is dependent on the presence of informal support systems such as relationships with family and colleagues, time and space to come to terms with what has happened and their access to death rituals such as attending funerals (Baverstock & Finlay, 2006; Hinds, 2007; Moores, Castle, Shaw, Stockton & Bennett, 2007). 85% of healthcare professionals surveyed in Plante and Cyr's (2011) study identified that talking with others such as their colleagues (70%) and friends and family (48%) was useful in coming to terms with and emotionally accepting the death of a child. These findings are supported elsewhere with teachers in Lazenby's (2006) study identifying other teachers, family and surviving students as their main source of support. However, the nurses in Lindsay et al's (2012) study expressed having to deal silently with their feelings of grief as they could not share their experiences of infant deaths with friends and family for fear of upsetting them, in addition to issues of patient confidentiality (Rashotte, 2005). Four of the teachers in Lazenby's (2006) study also expressed issues with talking with family members about their grief due to their family's lack of awareness that teachers in fact experience grief.

Another important consideration is allowing staff time and space to grieve for themselves. Within healthcare, 53% of participants expressed the need for a short break following the death of a child, with some wanting to spend more time with the bereaved family or at home (Plante & Cyr, 2011). Teachers have "the hardest task of all – being with the children, constantly, all day – no break...just to be there for the children" (Bennett & Dyehouse, 2005, p. 24). Acknowledging this and giving teachers time to talk with a professional is essential to support them through a difficult time (Hinds, 2007). Lazenby (2006) also found that a participant's faith was identified as a source of support for many of the teachers interviewed. Time

and space to grieve alone could therefore be used as an opportunity to seek and immerse oneself in this faith when dealing with emotional responses to the death of a student. Providing this time should be within the remit of the crisis team to recognise and make allowances for the individual grieving process that school staff are experiencing (Jellinek, Bostic & Schlozman, 2007).

Allowing staff time to attend the funeral if desired is also an important consideration in the aftermath of a student death (Bennett & Dyehouse, 2005). Teachers have stated the importance of attending the funeral of a student who had died and emphasised its therapeutic benefit (Ward, 1988). Schools can support this through the use of supply teachers on funeral days to cover for staff wanting to attend the funeral (Bennett & Dyehouse, 2005), or by closing the school to ensure as many staff and students can attend if they so wish (Anonymous School Leader, 2013). However, SLT should also consider the stressful nature of attending the funeral for staff. Teachers have expressed the need to be strong for the bereaved family whilst attending the funeral, in addition to putting their own grief on hold in order to speak at funerals of their students (Lazenby, 2006). Providing time to talk and reflect on these experiences after the funerals can be one way of SLT continuing to provide support for their staff (Rowling & Holland, 2000).

In a similar way to the improvements in training, the presence of support systems has also shown a vast improvement throughout the last two decades (Heller et al., 2013). Yet, there is still work to be done to ensure that all teachers have support if and when needed. One of the main improvements in the levels of support following a student death has been the role of the school nurse. More recently, school nurses have become an important source of information and support, with the majority of teachers wanting to receive support from the school nurse in the form of answering questions, clarifying information and talking through feelings (Heller et al., 2013; Lazenby, 2006). This increase in school nursing support can be attributed to the rise in students with life-limiting conditions in schools but should be treated with caution considering the cuts to school nursing budgets we are currently experiencing (Fagan et al., 2017; Lepkowska, 2012). The formation of a 'crisis team' containing a number of key individuals from SLT, healthcare and social services could ensure this reduction in school nursing service does not impact on the emotional support available for teachers experiencing a student death. It is clear that SLT need to consider carefully their response to a student death and ensure

that teachers and other school staff have access to appropriate support either formally or informally to protect them from psychological harm and the later development of mental health problems.

Whatever the school response to the death of a student, whether expected after a period of deterioration and palliative care, or unexpected after a tragic accident or acute medical episode, acknowledging grief and the different reactions to it is something that school leaders need to do to reduce the risk of disenfranchised grief (Rowling, 1995) and teacher burnout following a student death (Munson & Hunt, 2005). It is important to note that there is not one universal strategy for dealing with this phenomenon, there is not a set of guidelines that can be followed by every school, and there is no guarantee of success (Bennett & Dyehouse, 2005). Schools must learn from each child, every experience and adapt their practices accordingly so that a strong, collaborative approach can be implemented to practically and emotionally support all involved.

## **Chapter Three: Methodology**

### **3.1 Introduction**

This chapter aims to provide a rationale of the methodological decisions I have made throughout this research journey. It will explore the research paradigms available within educational research and determine my epistemological stance and ontological position. The chapter will further discuss the research methods employed and associated rationale. Alternative research methods will be considered and discussed in terms of their relevance to the research question. The procedure employed will be outlined, as well as associated ethical and quality considerations when conducting this qualitative research.

### **3.2 Research Methodology**

#### **3.2.1 Research Paradigm**

Within the existing literature (see Chapter 2), a number of theoretical perspectives and research paradigms were utilised to explore the experiences of teachers who educate children with life-limiting conditions. A paradigm is “a cluster of beliefs and dictates...for scientists in a particular discipline...what should be studied, how research should be done, [and] how results should be interpreted” (Bryman, 1988, p. 4). Different paradigms consist of varying and specific ontology, epistemology, methodology and methods (Scotland, 2012) and as such, theorists believe that they are incommensurable because they are based on such diverse beliefs (Bryman, 2012; Coe, 2012). The two main research paradigms of positivism and interpretivism will be discussed, in addition to a consideration of a mixed methods approach that aims to integrate different standpoints and views.

##### **3.2.1.1 Positivism**

Positivism is a way of seeing the world as straightforward and objective (Willig, 2008). It is seen to be “concerned with objectivity, prediction, replicability and the discovery of scientific generalisation or laws” (Ernest, 1994, p. 22). Ontologically, positivist researchers believe that there is one truth and therefore, one reality which independently exists (Cohen, Manion & Morrison, 2007; Pring, 2000). As such it is believed to be possible within a positivist paradigm to scientifically examine a

phenomenon 'from the outside' without the perceptions, interests and views of the researcher impacting on or biasing the results (Willig, 2008). The aim of research within a positivist paradigm is thus to impartially and objectively, unveil the truth (Bryman, 2012; Crotty, 1998). Researchers exploring the experiences of teachers from a positivist standpoint therefore, believe that the hypotheses they hold about such experiences can be scientifically tested and the gathering of facts, for example, within a questionnaire or experiment can lead to the formation of laws (Bryman, 2012).

Some studies within the existing literature, have investigated the views of teachers from a positivist standpoint, administering questionnaires to collect reliable, representative and scientific data (Cohen et al., 2007). For example, Clay et al. (2004) used a quantitative questionnaire to gather the responses of 1,184 school staff members in relation to their views and experiences of chronic illnesses. Although this method enabled the researchers to gather a large amount of data which could be easily analysed in order to produce statistics, a low response rate of just 40% meant that actually only 480 staff members took part. This could have led to a degree of bias from non-respondents, in that Clay et al. (2004) were unable to say whether those that chose not to participate had differing experiences from those that did (Denscombe, 2007). In addition, gathering just quantitative data using a questionnaire approach limits the type of data analysis that can be used and thus restricts the depth of understanding that can be gained from the data (Clay et al., 2004).

On the other hand, conducting research within the positivist paradigm can be of benefit to researchers and the general field of education. For example, utilising a positivist approach is widely considered to be scientifically rigorous enabling researchers to be confident in the reliability and objectivity of their findings (Benton & Craib, 2001; Hasan, 2016). This could be important for educational research as findings that are reliable and generalisable to the wider population are favoured by policy-makers, thus influencing future educational laws, policies and processes (Benton & Craib, 2001). The favouring of positivist approaches within the production of policies and laws is due to the replicable and observable findings upon which the positivist truth is based (Clark, 1998; Hasan, 2016). The absence of researcher and interpretation bias is thus one of the main perceived advantages of positivism as a research paradigm.



However, as Crotty (2009) highlights, “the scientific world is not, of course, the everyday world that people experience” (p. 28). Critics of the positivist paradigm point towards the fact that striving for an objective truth largely ignores the diversity of individuals within the social world, and thus a very narrow view of social reality is obtained. Generalising from empirical research, according to critics, is problematic as it ignores individual intentions and actions. For example, two individuals observed to be doing the same thing could actually be doing something completely different. Scotland (2012) illustrates this point by considering two students writing the correct answer to a multiplication calculation. Although both students arrived at the correct answer, one student could be answering the calculation via memory, whereas the other student could be using a mathematical technique such as repeated addition in order to arrive at the correct answer. Similarly, the teachers in the present study could be experiencing the phenomenon of medical emergencies in the same way, through fear for instance, but their reasons for and actions that lead to the experience of fear could be completely different, perhaps because of prior experiences or lack of support. Positivism ignores the differing reasons for this behaviour and thus fails to understand the phenomenon from the participants’ point of view (Scotland, 2012). For the purpose of this study, it needs to be determined from the outset whether a cause and effect relationship can be established within a diverse group of teachers experiencing the same complex phenomenon, or whether differing backgrounds and views of the world can influence personal experience. It is by determining my own viewpoint on this matter that will impact on the research paradigm and methodological choices made throughout this study.

### **3.2.1.2 Interpretivism**

In contrast to the positivist approach, interpretivists believe that the social world is fundamentally different to the natural world and cannot be researched in the same way (Crotty, 1998). Instead of looking for causality and explanation within the social world, interpretivists suggest our emphasis should be on understanding (Crotty, 1998). Ontologically, interpretivism is therefore based on relativism, in that reality is subjective and dependent on the person experiencing it (Guba & Lincoln, 1994). Interpretivists therefore aim to understand the social world from the point of view of the people experiencing it, with each person experiencing a different reality (Frowe, 2001; Marton & Booth, 1997). Without this understanding from a

participant's perspective, interpretivists believe that knowledge cannot be gained and therefore the social world cannot be understood (Cohen et al., 2007). It thus follows that in order to research participants' experiences of the social world, different research methods to those utilised in positivist approaches are needed.

Some studies within the existing literature (see Chapter 2), have used a qualitative framework, employing research methods such as open-ended questionnaires or interviews to gain detailed insights (Denscombe, 2007). Lazenby (2006) utilised an interpretivist, qualitative approach when interviewing thirteen teachers in the USA about the death of a student. These one-to-one interviews allowed Lazenby to gather a large amount of rich data to explore the experiences of teachers, especially around a very sensitive topic. Similarly, Boden et al. (2012) acknowledged within their study that, unlike previous research, the qualitative research design utilised, enabled a "deeper understanding of the views and concerns of both teachers and healthcare professionals" (p. E12). Indeed, this research approach enabled the researchers to probe and further discuss issues, leading to an increased understanding of the needs and experiences of school staff.

Despite these benefits, it is important to note that using a qualitative research approach does have limitations. For example, in Boden et al's. (2012) study, the experiences of teachers discussed in the research findings may be specific to the local area in which the research was conducted. This is especially poignant given the difference in quality and provision of medical services across the UK (Care Quality Commission, 2017; Together for Short Lives, 2016). Due to the small sample size involved in qualitative studies, it is also possible that a degree of self-selection bias (Denscombe, 2007) is present. For example, it may be that the teachers who agreed to take part in Boden et al's. (2012) study were more likely to have negative views of teaching children with diabetes or have greater concerns. However, it is important also to consider the opposite. It may be that teachers who found themselves floundering with the demands of teaching children with life-limiting conditions, did not have the physical or mental capacity to take part in a time-consuming research study.

In a similar way to positivism, interpretivism has not escaped criticism. Interpretivist research is often criticised for its lack of scientific rigour (Scotland, 2012). Indeed, if the basis of interpretivist research depends on the interpretations of

both research participant and researcher, it follows that the findings of such research is subjective and believed by some, to be lacking in validity (Angen, 2000; Rolfe, 2006). In this way, generalisations to a wider population are often impossible, something that may be of particular importance in education due to the need to create national policies. This is because findings from interpretivist research are often based within a particular cultural and individual context, with many variables. As such, findings are not representative of national views (Bassey, 2001; Scotland, 2012). It is often the case therefore, that educational research, which has the potential to inform national policies, is based on research grounded within the positivist paradigm (Bassey, 2001; Berliner, 2002). In response to this criticism, Bassey (2001) developed the idea of ‘fuzzy generalisation’, that within educational research, tentative generalisations can in fact be made through the notion of predictions. For example, by saying that “if  $x$  happens in  $y$  circumstances,  $z$  may occur (Bassey, 2001, p. 10). Within the context of the present study, a fuzzy generalisation could be that in the event of a student death, teachers *may* experience the emotions of  $x$ ,  $y$  and  $z$ . These ideas are discussed in more detail in section 3.6.2.

To combine the benefits of both interpretivism and positivism, and in an attempt to limit the disadvantages of a single paradigm, some studies have utilised a mixed methods approach. This approach aims to combine qualitative and quantitative research within a single study (Bryman, 2012; Creswell, 2012). For example, Durrant et al. (2014) used an online questionnaire to gather the views of ninety mainstream teachers in relation to teaching children with life-limiting conditions but also chose to interview thirty-eight teachers enrolled on the SENDCO training programme. Although the online questionnaire enabled a large amount of views to be gathered relatively easily, it did not provide the depth of answers required to fully understand the views of this group of participants. Despite the authors combining a mixed methods approach, the disparity between the online questionnaire group and the interview group meant that the views of both groups were not comparable due to their differing roles. As the researchers themselves acknowledge, the teachers interviewed were undertaking their SENDCO training and may therefore have had more experience of working with children with life-limiting conditions than more general mainstream teachers who completed the questionnaire (Robinson, Ekins, Durrant & Summers, 2018). A more effective approach may have been to use a questionnaire to begin with, and then choose a

smaller sample from the same cohort to gather more in-depth views throughout the interview phase. Kokotsaki (2011) utilised this approach in their phenomenographic study of student teachers' views of creativity in the classroom. The results of Kokotsaki's (2011) open-ended questionnaires were then followed up within semi-structured interviews allowing interesting themes to be explored in greater depth, thus maximising the opportunity for reflection.

Despite the combination, and therefore the benefits, of both paradigms, mixed methods approaches have been criticised. Some authors believe that research methods are inextricably linked to an epistemological viewpoint. It thus follows that where such different views of the world exist, they cannot be combined (Bryman, 2012; Coe, 2012; Scotland, 2012). A refinement of my epistemological viewpoint is therefore needed before resting on a research paradigm.

### **3.2.2 Epistemological and Ontological Position**

At the outset of the research process, it is important to ascertain my own theoretical standpoint in relation to the research question. Ontology is concerned with "what constitutes reality, in other words *what is*" (Scotland, 2012, p. 9) whereas epistemology and its associated assumptions are "concerned with how knowledge can be created, acquired and communicated, in other words *what it means to know*" (Scotland, 2012, p. 9). Unlike positivists, I am open to the view that there are many different forms of truth and knowledge (Crotty, 2009). I feel this stems from being a teacher of children with SEND, many of whom have life-limiting conditions. As such, I am more concerned with the individual perspectives of the students I teach rather than comparing them to national trends and statistics. On a daily basis I work with individuals who require me to meet their unique needs at their own specific developmental level. With this level of diversity, it seems impossible that there can be one true, objective knowledge (Denzin & Lincoln, 2011). Thus, I feel knowledge and truth must be created, formed or constructed by the individual. Ontologically, I struggle with the view that reality stems from the imagination (Morgan and Smircich, 1980), settling more towards the view that reality is continuously constructed by individuals (Robson, 2002), especially in the face of the day-to-day reinventions of experience and values that I often feel characterises my teaching life. However, I understand and can relate to the view that for some experiences, particularly those that are traumatic or emotional, we may not

consciously construct meaning. Instead, we may experience things that “assert a reality in consciousness, the manifestation of a phenomenal world, but not necessarily accessible to understanding in the course of everyday affairs” (Morgan & Smircich, 1980, p. 494). Therefore, with this view of the world, the aim of the research process is to sensitively allow the participants to consciously access these manifestations in order to express their understanding (Morgan & Smircich, 1980).

As the quantitative studies outlined above and in Chapter Two have found, employing a positivist approach to research within the area of teachers’ experiences can provide generalisable and comparable results, however a deep understanding of how these experiences frame their emotional wellbeing and attitudes towards education is lacking. As discussed, it is my belief that teachers have a variety of different viewpoints, attitudes and personal backgrounds which they bring to the classroom, ultimately shaping their actions within and experiences of the world. For me, it does not follow therefore, that all teachers objectively experience the same phenomena in the same way. Consequently, and in relation to my research question (see section 1.3), an interpretivist approach based within social constructionism was used within this study to fully understand and explore how teachers experience the phenomenon of teaching children with life-limiting conditions in special schools from their own, unique perspectives. This research not only seeks to understand these experiences from their own points of view (Snape & Spencer, 2013), but also to determine what effect these experiences have on the attitudes of teachers, as well as the associated impact on the personal and professional lives of those involved.

### **3.2.3 Rationale for the Methodology Used**

My epistemological and ontological position firmly route my theoretical perspective within the interpretivist paradigm (see section 3.2.2). Due to the fact that I believe that there are many different forms of truth and knowledge (Crotty, 1998), and that this knowledge depends on the person experiencing it (Guba & Lincoln, 1994), it thus follows that I needed to attempt to gather the perspectives of participants from their point of view (Bogdan & Taylor, 1975), interpreting, explaining and bringing meaning to the phenomenon in question (Anderson, 1998). The research methodology and associated method, crucially, must reflect the aims of the research

question, thus contributing to the study's quality (Punch, 2006). In line with my epistemological position, the following research question was formulated:

*How do teachers encounter, conceptualise and understand their experiences of working with children with life-limiting conditions in special schools?*

Within this research question additional objectives and supplementary research questions were developed (see section 1.3) with the aim of collecting as rich and as detailed data as possible (Silverman, 2013). As my epistemological position and theoretical perspective are now established, it follows that a research methodology that fits with both should be adopted. It is my belief that the research approach of phenomenography offers me the opportunity to explore the ways in which teachers experience the phenomenon of teaching children with life-limiting conditions in special schools.

#### **3.2.4 Phenomenography**

Phenomenography is a research approach developed in the 1970s in Sweden (Åkerlind, 2008; Marton, 1981; Stenfors-Hayes, Hult & Dahlgren, 2013), to combat some of the limitations of a quantitative methodology in education (Marton, 1986) and was based on the argument that...

...in order to make sense of how people handle problems, situations, the world, we have to understand the way in which they experience the problems, the situations, the world, that they are handling or in relation to which they are acting.

(Marton & Booth, 1997, p. 111).

Phenomenography was first developed primarily within the areas of teaching and learning to explore the variation in understanding of educational concepts (Larsson & Holmström, 2007) and how learning can move from one way of understanding a phenomenon to another (Stenfors-Hayes et al., 2013). However, it has since been used within healthcare research, in particular to examine understanding of experience (Barnard, McCosker & Gerber, 1999; Stenfors-Hayes et al., 2013). As the research question (see section 1.3) and associated context within this study concerns not only the education of children with life-limiting conditions, but also teachers' experiences of children's complex medical needs, it was this use of

phenomenography in both the education and healthcare literature that formed part of the appeal of this research approach.

Phenomenography, in line with the interpretivist paradigm, recognises the importance of ‘subjective knowledge’ (Barnard et al., 1999, p. 215) and the value that this has for qualitative research. It identifies that this knowledge can be varied, rich with meaning and understanding, ultimately leading to a greater understanding of how and what we experience within our world (Stenfors-Hayes et al., 2013).

#### **3.2.4.1 Objectives of Phenomenography**

Phenomenography aims to “identify the qualitatively different ways in which different people experience, conceptualise, perceive and understand various kinds of phenomena” (Richardson, 1999, p. 53). Crucially and rather uniquely, phenomenography does not focus solely on the perspectives of individuals, instead, it aims to explore the variation in the experiences of participants (Sharma, Stewart & Prosser, 2004), whilst still preserving the essence of the participants’ own discourse (Barnard et al., 1999). This focus on the similarities and differences in the way individuals understand and experience their world is distinctive (Barnard et al., 1999) and of importance within the current research study. As seen in Chapter Two, there has been a national increase in the numbers of children with life-limiting conditions now entering education, resulting in large numbers of teachers now educating such children. Due to my epistemological position, I believe that there cannot be one objective way of experiencing this phenomenon. Therefore, utilising a research methodology that aims to explore the similarities and differences between individuals experiencing the same phenomenon was deemed crucial.

A key feature of phenomenography is the use of a second-order perspective. With this perspective “the researcher is oriented towards describing people’s ways of seeing, understanding and experiencing the world around them” (Yates, Partridge & Bruce, 2012, p. 99). In other words, ways of understanding the phenomenon in question are examined through the participants’ own experience, rather than through the interpretations and experiences of the researcher (Marton & Pang, 1999, as cited in Yates et al., 2012). This is in stark contrast to the first-order perspective which Marton (1981) argues involves describing facets of a phenomenon, as opposed to describing individual experiences of those aspects of

the phenomenon. Put more simply, the first-order perspective can be seen as an attempt to describe the world “from the outside”, whereas the second-order perspective is “from the inside” (Marton, 1981, p. 177). This emphasis of the second-order perspective is seen as a particular strength of phenomenography (Marton, 1981) and further reinforces the view that understanding, and experience, is formed through complex relationships between individuals and the world (Yates et al., 2012).

#### **3.2.4.2 Categories of Description and the Outcome Space**

Within phenomenographic research, the researcher aims to identify the “different ways of understanding” (Larsson & Holmström, 2007, p. 56) as seen on the collective level throughout their research data (Marton & Booth, 1997). These different ways of experiencing and understanding the phenomenon in question, emerging from the data, are known as ‘categories of description’ (Marton & Booth, 1997). Although it is believed that there are an infinite number of ways of experiencing a phenomenon at the individual level, researchers also acknowledge that through the process of creating meaning on a collective level, what results is a limited number of categories of description (Ekeblad, 1996; Yates et al., 2012). Marton and Booth (1997) develop this further by specifying three distinct criteria for determining the quality of categories of description. Specifically, these categories of description should be limited in number, in addition to being hierarchically related to one another and illustrating something unique about the referential and structural aspects of how the phenomenon is experienced (Marton & Booth, 1997; Yates et al., 2012).

Phenomenography aims to explore the similarities and differences between experiences of a particular phenomenon (Richardson, 1999) and arrive at a finite number of categories of description (Marton & Booth, 1997). However, phenomenography does not stop at this description. Instead, phenomenography aims to determine how these different ways of experiencing a phenomenon are related to each other (Stenfors-Hayes et al., 2013). Researchers should look for the underlying meaning in order to determine relationships between concepts (Marton & Booth, 1997). Frequently, these ways of experiencing a phenomenon, or categories of description can be hierarchically structured in the ‘outcome space’ (Larsson & Holmström, 2007; Stenfors-Hayes et al., 2013). The outcome space can



be defined as “the complex of categories of description comprising distinct groupings of aspects of the phenomenon and the relationships between them” (Marton & Booth, 1997, p. 125). However, Åkerlind (2005b) emphasises caution when determining the structure of the outcome space. She argues that in the search for hierarchical relationships between categories of description, researchers should not ignore data that cannot and does not fit into logical, hierarchical relationships. As Åkerlind (2005b) states, the structure of the outcome space does not always have to form a linear hierarchy including all categories of description.

It is this identification of the categories of description in addition to their often-hierarchical relationships within the outcome space that comprise and represent the overall findings of a phenomenographic study (Larsson & Holmström, 2007). An identification of categories of description within the outcome space in relation to teachers’ experiences of working with children with life-limiting conditions is therefore the aim of the present research.

#### **3.2.4.3 Limitations of Phenomenography**

Like other qualitative approaches, phenomenography is criticised for its lack of scientific rigour when attempting to gain understanding of the experiences of a phenomenon (Richardson, 1999), and in particular for its emphasis on interviews as the single method of data collection (Abrandt, 1997). Much of this criticism stems from refuters of the interpretivist paradigm who believe that there is one, objective reality and truth that must be uncovered scientifically (see section 3.2.1 for a discussion of the criticisms of these paradigms).

One way to limit the influence of the researcher within phenomenographic research, and therefore address a further criticism of phenomenography, is for the researcher to ‘bracket’ their preconceived ideas and experiences in order to focus on the experiences from the point of view of the participant (Abrandt, 1997). Ashworth and Lucas (1998), through a review of empirical studies, identify a number of presumptions and opinions that must be bracketed by researchers before undertaking phenomenographic research. Firstly, knowledge about a phenomenon must be bracketed if it has been gained from a review of existing literature, other ‘authoritative sources’ (Ashworth & Lucas, 1998, p. 422), or from a researcher’s own beliefs, views and experiences. In addition, beliefs which would determine a

specific research method, for example, the desire for generalisability, must also be bracketed. Importantly, the bracketing of prior assumptions and beliefs should be conducted continuously and not merely at the outset. This is due to the risk that hypotheses and theoretical interpretations could be constructed too early in the data collection phase, influencing the direction in which the researcher travels. Thus, important aspects of the phenomenon could be missed. Ashworth and Lucas (1998) also advise phenomenographic researchers to bracket their quest for causation when studying a phenomenon as well as the need for 'objectivity' as these are not aims of phenomenography as a research approach. What must be kept in mind is that the primary goal of phenomenography is to uncover the participants' experience of a phenomenon and not the researcher's own expectations (Ashworth & Lucas, 2000).

Despite these specific presuppositions that must be bracketed (Ashworth & Lucas, 1998), it is important to note that a 'presuppositionlessness' position, where everything is perfectly bracketed, is not required nor preferred (Ashworth & Lucas, 2000). Indeed, conducting phenomenographic research with some presuppositions left unbracketed can be beneficial in terms of accessing the participants, being 'let in' to their lifeworld and in determining an ease of conversation (Ashworth and Lucas, 2000). For example, when discussing sensitive topics, it may be useful to leave some views and experiences unbracketed to develop empathy and a shared understanding between the researcher and participant. Furthermore, if a researcher bracketed everything they already knew about a phenomenon prior to the commencement of a research interview, the discussion would lack direction. Some presuppositions must therefore remain unbracketed in order for the interview to be guided by the researcher. However, this must be done cautiously in order to gather the sole views of the participant as they experience the phenomenon in question. This is an area which needed careful consideration throughout the interview and data analysis process due to my close relation to the field of study.

A further criticism of the phenomenographic approach is that many authors believe it requires several researchers working as part of a team to complete effective data analyses and to confirm the categories of description discovered (Åkerlind, 2005a; Walsh, 2000). Within the current study this is not possible nor desirable, due to the constraints of an individual doctoral thesis project. It is possible to conduct phenomenographic research alone, as many have done previously (Green, 2005; Jackson, 2009). Indeed, this centres around the issue of replicability and reliability

and therefore the question of “would another researcher examining the same data come up with the same results if he or she were studying the same data?” (Marton, 1994, p. 148). Supporters of phenomenography would argue that as the categories of description emerge as the researcher discovers them in the data, replicability is not necessary (Marton, 1994). Ensuring that my methodological decisions are explicit and justified within this research report, in addition to supporting my categories of description with illustrative quotations from the data so that other researchers can recognise the different ways of experiencing the phenomenon (Marton, 1988) should alleviate and address some of the issues of researching alone.

#### **3.2.4.4 Towards a Research Method**

As phenomenography is concerned with gathering participants’ own experiences and perspectives, it follows that an appropriate research method is needed to suitably gather a breadth and depth of experience. Within phenomenography, this typically takes the form of semi-structured interviews that utilise a range of open-ended questions (Marton, 1986; Stenfors-Hayes et al., 2013), to gather and understand the individual’s perspectives, views and experiences of a phenomenon (Bruce, 1994). Although Marton (1994) acknowledges other research methods are also suitable for a phenomenographic approach, for example, group interviews, observations and written responses, the similarity in these approaches ultimately brings about the same outcome, that of oral and personal accounts of experience (Richardson, 1999). In keeping with the qualitative paradigm and more specifically within phenomenography, it was thus decided that a semi-structured interview approach would be utilised (see sections 3.3.2 and 3.4.1 for a discussion of the interview design and process).

Within the phenomenographic interview approach, the need for reflection and sensitivity is highlighted (Barnard et al., 1999). The main aim of the phenomenographic interview is to allow the participant to reflect on their experiences of the phenomenon from their own point of view (Barnard et al., 1999; Marton, 1994). Although the use of some open-ended, predetermined questions can help to focus the discussion, the interview should follow the discourse of the participant, with the use of probes to allow the participant to explain their understanding of the phenomenon further, within whichever aspect of the

phenomenon they choose (Marton, 1988; Stenfors-Hayes et al., 2013). The interview should therefore reflect a conversation between the researcher and participant but be based around a specific phenomenon (Mishler, 1986).

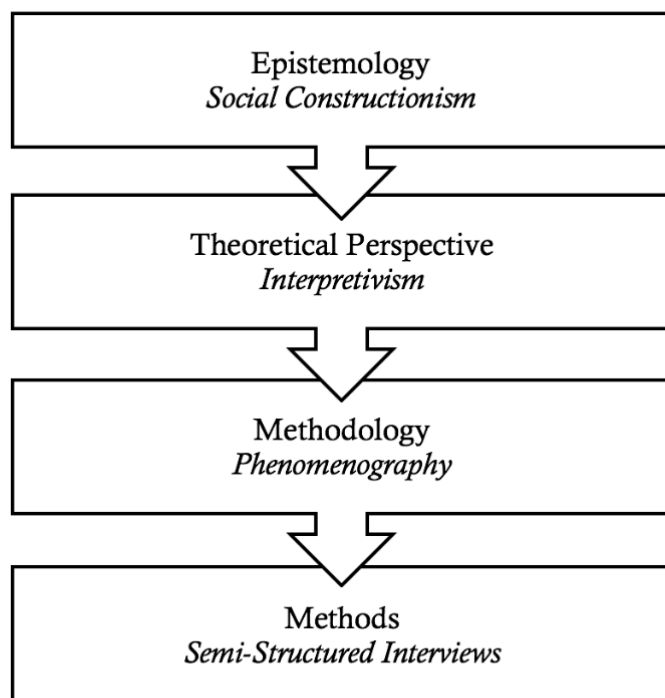
Whilst conducting a phenomenographic interview Marton & Booth (1997) identify two different levels of understanding that a participant will express; that of the internal and external horizons. The internal horizon can be seen as the “inter-relationship between ‘parts’ that make up the phenomenon” (Reed, 2006, p. 4), whereas the external horizon is how these ‘parts’ relate to the context of the phenomenon in question (Reed, 2006). According to Marton & Booth (1997), the internal horizon is a description of the phenomenon that is clear, accepted, in focus and based on understanding. In contrast, the external horizon is more vague and pre-reflective, that which may be outside of conscious awareness (Reed, 2006). For example, participants may discuss an issue which they had not actively considered or may not have the words to express clearly. It is therefore the researcher’s role to encourage the participant to reflect on their experience and bring that which may rest on the margins of awareness into the fore (Reed, 2006).

These types of discussions require sensitivity and careful prompting from the researcher to supportively allow participants to explore the “outer boundaries of their experience and understanding” (Barnard et al., 1999, p. 222). This is of particular importance when discussing sensitive topics such as student death as in the current research, due to the differing levels of consciousness that may be experienced when dealing with traumatic events such as the death of a child.

One of the main considerations when conducting a phenomenographic interview is not to lead the responses of the participants (Barnard et al., 1999), something which I needed to be consciously aware of given my own experience of this field. The focus of the interview should be solely on the experience of the participant and their understanding of the world. As such, within any probing questions, researchers need to be careful not to introduce any ideas, experiences or concepts, which the participant has not already discussed (Åkerlind, Bowden & Green, 2005). In order to do this a relaxed and accepting attitude needs to be adopted by the researcher (Barnard et al., 1999).

### 3.2.5 Summary

Given the above justification of my epistemological position, ontological standpoint and theoretical perspective, the research approach of phenomenography was chosen as the most appropriate to address the research question. Figure 3.1 summarises the theoretical and epistemological underpinnings of my research (the four elements) and demonstrates how each methodological choice has informed one another (Crotty, 1998).



**Figure 3.1:** The Four Elements of this Research. (Adapted from Crotty, 1998, p. 4).

## 3.3 Research Design

### 3.3.1 Participant Selection

Due to the phenomenographic nature of the study, and the primary aim of describing the qualitatively different ways of experiencing a phenomenon, it follows that only those who have direct experience of such a phenomenon can participate in the research process (Barnard et al., 1999; Yates et al., 2012). As a result, and in line with this approach, a purposive sampling method was utilised. Purposive sampling has been defined as “judgemental sampling that involves the conscious selection by the researcher of certain subjects or elements to include in the study” (Crookes & Davies, 2004, p. 232). Utilising a purposive sampling method in this way therefore allows the researcher to gain “information-rich cases...from which

one can learn a great deal about issues of central importance to the purpose of the research” (Patton, 1990, p. 169), in order to develop a deep understanding of the experiences of the phenomenon. The identification of participants in phenomenographic studies is therefore non-random (Åkerlind, 2005b; Booth, 1997).

Due to the demands of the research question (see section 1.3), conscious decisions were made about the characteristics of the target participants. From the outset I decided to only include teachers who have direct, current experience of teaching children with life-limiting conditions in special education classrooms. Teaching assistants also have valuable experience of caring for such children, however, I felt that their views may be qualitatively different to that of teachers, perhaps in part due to them not having overall responsibility for these children whilst in the classroom. Gaining views of teaching assistants and other professionals such as school nurses would be interesting in further research. Moreover, I decided to focus this research further by only sampling teachers who are currently teaching in special schools. As a teacher in a special school myself, I have experienced the change in the severity of medical need experienced by children (Asprey & Nash, 2006) now entering my school. Examining the views of mainstream teachers may provide interesting results, however with the introduction of the new medical guidance for schools (DfE, 2014), I feel that researching the views of mainstream teachers would be more beneficial in the future, once the guidance has been fully embraced and implemented within mainstream schools.

As a result of this decision-making process, the following selection criteria were applied when recruiting potential participants:

1. Professional qualifications – teachers who had obtained Qualified Teacher Status through a recognised training route were included.
2. Current teaching experience – teachers who are currently teaching children with life-limiting conditions or had taught children with life-limiting conditions in the previous academic year (for those interviewed during the school holidays).
3. Teaching placement – teachers were included in the study only if they were currently teaching in special schools. This did not include hospital schools or pupil referral units.

To recruit participants from across the UK, an invitation to participate was published on the Severe Learning Difficulties (SLD) Forum. This online discussion group is...

...for professionals involved in the education of learners with severe, profound and multiple difficulties. It is intended to provide a forum for the sharing of ideas, views and information and to encourage on-going professional development for practitioners, researchers and others concerned with the education of these learners. (DfE, SLD Forum Info Page).

The SLD Forum is widely used by a range of practitioners and prolific researchers in this field and therefore was considered an effective way of reaching potential participants with the required characteristics for this study. Following invitations to participate, thirty-one expressions of interest were received. Of those expressions of interest, one was declined due to their location in Australia, two because they held SLT positions and were not currently teaching children with life-limiting conditions and a further respondent was declined due to their position as a researcher (and not a teacher) in this field. Eligible respondents who met all of the above criteria were sent the participant information sheet and consent form (see Appendices 2 and 3). After a further expression to participate from respondents, their headteachers were sent further information (see Appendix 4). Once consent was obtained from both the participant and their headteacher, a date and time for interview was arranged.

The research literature surrounding phenomenography rarely states a specific sample size for conducting qualitative research. Instead, researchers in this field suggest that sample sizes need to be necessarily substantial in order to gather information-rich descriptions of experience, yet suitably manageable given the significant amount of data that is gathered (Stenfors-Hayes et al., 2013; Yates et al., 2012). Trigwell (2000) quantifies this further with the recommendation of fifteen to twenty participants to reasonably uncover variation in experience. Elsewhere in the literature the idea of 'saturation point' is used to determine the size of a research sample (Dunkin, 2000; Sandberg, 2000; Trigwell, 1997). This means that sampling continues until "no new or relevant data seem to be emerging regarding a category [and] the category is well developed" (Strauss & Corbin, 1998, p. 212). Guest, Bunce and Johnson (2006) suggest that data saturation is commonly reached after twelve interviews, by which point no new themes are beginning to emerge. For this

study, saturation occurred after sixteen interviews whereby the majority of themes began to recur in a similar manner. Two further interviews were then conducted to ensure that saturation had been fully reached. After the eighteenth interview it was clear that no new themes were emerging, and data collection was ceased.

Eighteen teachers from across the UK agreed to participate in this study and a date and time for interview was successfully arranged. In line with the selection criteria all participants were currently teaching children with life-limiting conditions in special schools within the UK. Only one male teacher agreed to participate in this research, which is reflective of the current demographics of teachers throughout the UK (DfE, 2017). Participants varied in age and length of teaching experience. Brief summaries of each participant as well as their geographical location can be seen in Appendices Five, Six and Seven respectively.

### **3.3.2 Interview Design**

As previously determined, the use of semi-structured interviews is widely adopted as the research method of choice within phenomenographic research and was the research method chosen for this study. In line with this approach, I felt that an interview method would enable me to gather insights and detailed experiences from participants (Denscombe, 2007), as well as being able to clarify any misunderstandings and ensure that what the participant is saying is exactly what they mean (Denscombe, 2007). Ideally, I wanted to conduct these interviews face-to-face as it would allow me to gain more information about participants' experiences from their point of view. Face-to-face interviews would also allow me to pay close attention to body language, which I felt was of great importance given the sensitive nature of the topic at hand, in addition to helping to build trust and rapport, something that may not be possible via telephone. In reality however, it was not always geographically and practically feasible to conduct all of my interviews face-to-face in person (see section 3.4.1).

Once decided on an interview method, it was important to identify the exact type of interview I wished to utilise. There are many different types of research interview, ranging from formal, structured interviews involving closed questioning, to unstructured, conversational interviews that flow in a manner determined by the participant (Fontana & Frey, 2008). It is clear from the qualitative framework I



have chosen, in addition to the phenomenographic approach, that at least a semi-structured interview method was needed to conduct “an in-depth exploration of a particular topic or experience” (Charmaz, 2006, p. 2). It was important that opportunities for gaining the participants’ point of view were maximised and that insights were gained into what each participant deemed important within their world (Bryman, 2012). The idea of an unstructured interview was not considered advantageous due to the specific nature of the phenomenon in question. Within the research area there are potentially numerous areas for the interview to go ‘off-topic’ (Bryman, 2012). Therefore, I felt it necessary to create a semi-structured interview, whereby I could create an interview guide, outlining specific areas that I wished to cover (Bryman, 2012) should the interview go ‘off-topic’. I felt that this was of particular importance, especially if the interview was disrupted or if the participant became overly distressed.

The interview guide (see Appendix 8) was adapted from the interview questions used by Durrant et al. (2014) and constructed in relation to the research questions, aims and objectives (see section 1.3). As Entwistle (1997) advises, the phenomenographic interview guide should start with the concrete experiences and then move towards the abstract. With this in mind the interview guide used in this research began with exploring the current ‘concrete’ experiences of teachers, by asking them to describe their current teaching role and students they teach, before moving on to the abstract, their thoughts and feelings about those experiences. Asking participants to reflect on concrete examples of their experiences in this way encouraged participants to avoid superficial descriptions, instead, focusing on their direct experiences and understanding (Larsson & Holmström, 2007).

In adopting the semi-structured interview approach, I still had the flexibility to probe for further information, clarify misunderstandings or re-word things to ensure sensitivity (Denscombe, 2007). I felt that it was this type of interview that was most suited to this research question, within a qualitative, phenomenographic perspective.

## **3.4 Research Method**

### **3.4.1 The Interview**

The research method chosen for this study was semi-structured interviews in line with the phenomenographic research approach. Data was therefore collected in the form of semi-structured interviews that lasted between thirty and one-hundred minutes. Initially, it was intended to conduct these interviews in the participants' schools, or in a location more comfortable to them. However, it became clear from my sampling method and from the teachers who expressed an interest in participating, that travelling to meet each individual participant to hold a face-to-face interview was not feasible due to the geographic location, workloads and availability of both myself and the participants (Sedgwick & Spiers, 2009). To illustrate this point, the geographic locations of all participants can be seen in Appendix Seven.

From the outset, face-to-face interviews were preferred and were offered as an option, in keeping with the fact that face-to-face interviews are often considered the 'gold-standard' of interviewing because of their heightened validity and rigour (McCoyd & Kerson, 2006, p. 390). However, as it became clear that organising a time and suitable location with some participants was not feasible due to their work commitments or geographic location, other interview methods were introduced. There is a growing body of evidence within the literature that highlights the importance and relevance of using modern technologies to access a geographically dispersed research sample (Burns, 2010; Opdenakker, 2006), with researchers often utilising more than one interview method. It was this process I found was needed within the current research to access as many participants as possible, from a range of geographic locations. Due to the fact that I still wanted aspects of the face-to-face interview to remain, for example, the ability to read body language and recognise when participants were becoming distressed, I felt that utilising online, video technology such as Skype or FaceTime would bridge this geographical gap and provide greater flexibility in terms of when the interview took place (Deakin & Wakefield, 2014).

Research into the use of online video technologies for research interviews is limited but growing, with some researchers reporting issues related to the building of

rapport (O'Connor et al., 2008). Bearing this in mind I considered my interview guide carefully in order to introduce myself and share something about my day once an internet connection had been established. This was helped by the fact that many of the Skype or FaceTime interviews were conducted during lunch hours, non-contact time or just after school, ensuring that rapport could be built relatively easily by sharing my own experiences and asking about the participants' day so far.

Other criticisms of this online interviewing approach centre around the loss of body language, in particular the subtle non-verbal cues that participants and interviewer may display (Hay-Gibson, 2009; O'Connor et al., 2008). I found despite these concerns, the use of video interviewing, particularly when internet connections were well-established, meant that the majority of these subtleties could be picked up. In fact, some of the participants did become upset throughout the course of an online video interview which I felt I was able to pick up on and offer breaks relatively easily. The physical detachment in these scenarios however was felt and whereas in a face-to-face interview, a hug or physical reassurance might have been offered, this was not possible over the internet which I found difficult, particularly when participants were visibly upset. This supports the view of Mann and Stewart (2000), who question whether an emotional connection can be formed when communicating online. I would argue that due to the shared experiences of myself and my research participants, as well as the level of professional empathy I have for these teachers, it is possible to connect emotionally to a certain degree. Not being able to physically comfort someone who is visibly upset was something I had not considered before conducting online interviews.

A further criticism is that the use of online video interviewing may cause some participants to feel embarrassed or uncomfortable when being filmed. Yet this criticism could also be applied within face-to-face interviews in that audio recording may also affect the participants in terms of their awareness that their views and opinions are being recorded (Al-Yateen, 2012). Although the use of online video technologies may have initially affected some of the participants and indeed myself, as the interview progressed, it was clear that participants became less aware of the videoing and recording aspect of the interviews and were much more relaxed. Again, the building of rapport as a teacher who has commonality of experience of the participants may have helped in keeping interviews relaxed, regardless of interview method.

One of the main considerations when using online video technologies such as Skype or FaceTime is the stability and speed of the Internet connection (O'Connor et al., 2008). FaceTime was the preferred method in terms of its greater stability in connection and use of mobile Internet in addition to Wi-Fi, however, its use depended on the interviewer and participant owning an iPhone. Skype appeared to be the preferred method for many of the participants with FaceTime used as a backup if the Skype connection failed, an incident that occurred on more than one occasion. At times during the interviews, connection was lost, or the picture froze or buffered for a few seconds. In addition to lack of connection, some interviews conducted online were interrupted further by pets, family members, children or visitors to the door. It is important to note however, that these interruptions are not exclusive to online interviewing. Indeed, throughout the face-to-face interviews, minor, unexpected interruptions included building work, telephone calls and people entering the interview space. These disturbances interrupted the flow of the interview (Deakin & Wakefield, 2014), however, by referring to notes or further probing questions, participants were able to get back on track and meaning was rediscovered.

Three of the participants were not geographically located so as to facilitate a face-to-face interview, nor comfortable or able to use online video technologies to participate in their interviews. In these cases, a telephone interview was utilised. Although the use of telephone interviewing does not provide video of the participant, it is still perceived to be a valid alternative to face-to-face interviews where geographical reach is an issue (Holt, 2010; Weinmann, Thomas, Brilmayer, Heinrich & Radon, 2012).

Despite concerns with online video technologies, Denscombe (2003), argues that there is no difference in the quality of responses gathered when using these methods. Cabaroglu, Basaran and Roberts (2010), also found no significant difference in the data gathered via online methods as opposed to traditional face-to-face interviews. I would argue that this is the case within the present study. In addition, the use of online video technologies to interview participants enabled greater flexibility in terms of time and location of interviews (Deakin & Wakefield, 2014), but also greater security for me as a sole researcher given that I did not have to travel to unfamiliar locations to meet unknown participants face-to-face.

As the methods of conducting semi-structured interviews have now been established, it is important to consider the actual process of conducting the interview. When completing a phenomenographic interview it is important to be as relaxed as possible and to show a genuine interest in what the participants have to say (Stenfors-Hayes et al., 2013). In exploring interview conduct further, particularly when conducting phenomenographic interviews, the guidelines produced by Ashworth and Lucas (2000) were useful. These can be seen in Figure 3.2.

- Make minimal use of questions prepared in advance.
- Use open-ended questions.
- Engage in empathic listening to hear meanings, interpretations and understandings.
- Consciously silence his or her concerns, preoccupations and judgements.
- Use prompts to pursue/clarify the participant's own line of reflection and allow the participant to elaborate, provide incidents, clarifications, and, maybe, to discuss events at length.

**Figure 3.2:** Phenomenographic Interview Guidelines (Ashworth & Lucas, 2000, p. 302 - 303).

Firstly, the interview guide (see Appendix 8), provides the opportunity to ask minimal questions that are suitably open-ended to allow the conversation to flow. If further questions or probing were needed these arose from the discussion and were not pre-determined. For the majority of interviews this worked well. Within one interview however, the participant's answers were short, and they often paused as if waiting for the next question. This meant that more questions were asked than in any other interview. As a result, the conversation did not flow freely and reflections on experiences were limited. Secondly, empathic listening was utilised which helped to ensure all interpretations, reflections and understandings were heard. This was aided by the fact that I had 'insider status' and shared understanding of the medical conditions and experiences they discussed.

In relation to Ashworth and Lucas' (2000) fourth guideline, about silencing my own concerns and judgements, is the idea of not leading participants or allowing my own knowledge and experience to affect my interpretations of what is being

said (Stenfors-Hayes et al., 2013). Despite the importance of not leading the participants, I made the conscious decision at the outset of the interviews to share my teaching background and current teaching experiences. I felt this helped to focus participants on the essence of the phenomenon, but also helped to develop trust and rapport (Booth & Booth, 1994). I felt that participants were much more likely to want to explain their experiences to someone they perceived would understand and who had 'been there'. With this in mind, I needed to be careful throughout the whole data collection and analysis process that I focused my attention on describing the way the phenomenon is experienced, explained and understood by the participants from their own perspective. It could have been very easy to explain things in more detail using my own prior experience and views (Sandberg, 1997).

In response to the final point in Ashworth and Lucas' (2000) interview guidelines, a variety of probing questions were used to ensure that as rich a description of the phenomenon as possible was gleaned throughout. Abrandt's (1997) strategies of repetition, requests for clarification or elaboration and confirmation were used to probe effectively. This allowed me to gain a better understanding of the participants' experiences of the phenomenon (Stenfors-Hayes et al., 2013) and meant that I needed to continuously interpret what was discussed in order to probe for further information where and when I felt was necessary (Sjöström & Dahlgren, 2002). Interviews were conducted in this way until I had exhausted all lines of enquiry and had a good understanding of the phenomenon as experienced from the participants' point of view (Booth, 1997).

All participants were sent copies of the participant information sheet and consent form electronically before taking part in the interview process (see Appendices 2 and 3). Signed copies of the consent form were gathered before the face-to-face interviews took place and verbal consent was also sought as the online interviews commenced. A small number of participants became upset throughout the course of the interview, particularly when talking about students who had died, whilst others seemed to suggest through their body language that they were becoming uncomfortable with the topic of conversation. At these points participants were offered a break which all refused. Further verbal consent was then sought to ensure participants were happy to continue with the interview. For the purpose of this

research report, all participants and children referred to throughout the data were given pseudonyms.

All interviews were digitally audio recorded for the purpose of transcription. This was reiterated to participants at the outset of each interview and all agreed to the recordings. Initially, within the first few interviews, I attempted to write notes alongside conducting the interview, however, I found this distracting and felt it interrupted the flow of the interview, potentially leading me to miss vital information (Willig, 2008). Participants also seemed to find the excessive taking of notes off-putting, in addition to me referring to my interview guide whilst they were talking. Some participants took this as a cue that I was ready to ask my next question and therefore cut short what they were saying. As such, in later interviews, as I became more relaxed and familiar with my interview guide, interviews were more conversational in nature and I relied on the digital recording, as well as some brief notes taken throughout the interview, rather than on extensive field notes.

### **3.4.2 The Analysis**

Data analysis within phenomenography involves the “comparison of data obtained from a group of participants in an attempt to describe the experience of the phenomenon in terms of the essential meaning of the qualitative variations” (Barnard et al., 1999, p. 215). The phenomenographic literature outlines a variety of guidelines to data analysis, however there is no specific analytic process to follow (Barnard et al., 1999; Kvale, 1983; Säljö, 1988). The process of data analysis used within this study is described below. Firstly, an account of the transcription process is given, followed by a detailed description of the Four Stages of Analysis (Schröder & Ahlström, 2004) used in the analysis of the transcript data.

#### **3.4.2.1 Transcription of Interview Data**

All, eighteen interviews were digitally recorded onto a digital MP3 device. After each research interview I began the process of transcribing the digitally recorded data verbatim in line with the phenomenographic approach (Larsson & Holmström, 2007). Commencing transcription after each interview not only meant that I did not have to wait until all interviews were completed before beginning the monumental task of transcribing (Bryman, 2012), but also enabled me to become more aware of emergent themes throughout the data collection process (Bryman,

2012; Lofland & Lofland, 1995). As such I was able to follow up emergent themes in later interviews or probe further where I felt a theme of interest was emerging.

Transcribing the data verbatim, complete with pauses, hesitations and fillers such as 'erm' and 'er', was a conscious decision that I felt enabled me to gain a deeper understanding and insight into what the participant was feeling and thinking when answering a question (Halcomb, & Davidson, 2006). For example, it may be that answers involving lots of pauses, hesitations and fillers could be an indication that the participant is nearing the external horizon of understanding (Marton & Booth, 1997) and therefore struggling to find the words to reflect on their experiences. Furthermore, an increased presence of hesitation and fillers could be a sign that participants are reflecting further on their experiences and bringing understanding from the margins of awareness to the fore (Reed, 2006).

All interviews were transcribed by myself, without the use of an external, professional transcriber. Each transcript ranged from 7,000-10,000 words. In addition, once fully transcribed I checked each transcript alongside its digital recording to ensure complete accuracy in what was said. Although this took countless hours, it was of considerable importance given that I could immerse myself in the data from the outset of the data analysis phase. Once the transcripts were completed and checked, they were uploaded to NVivo in order to begin the in-depth data analysis.

#### **3.4.2.2 Data Analysis**

Throughout data analysis, the description of the phenomenon should be closely related to the participants' own language, rather than language used by the researcher to interpret their descriptions. As such, the results of the data analysis should be purely descriptive in the form of categories and outcome space (Barnard et al., 1999). Crucially, these categories of description and resulting outcome space should emerge from the data and not from pre-determined categories so as not to miss important conceptions within the data (Marton, 1986; Sharma et al., 2004). Due to the lack of consensus surrounding a single method of data analysis within phenomenographic research (Barnard et al., 1999; Dahlgren & Fallsberg, 1991; Säljö, 1988), the Four Stages of Analysis described by Schröder and Ahlström

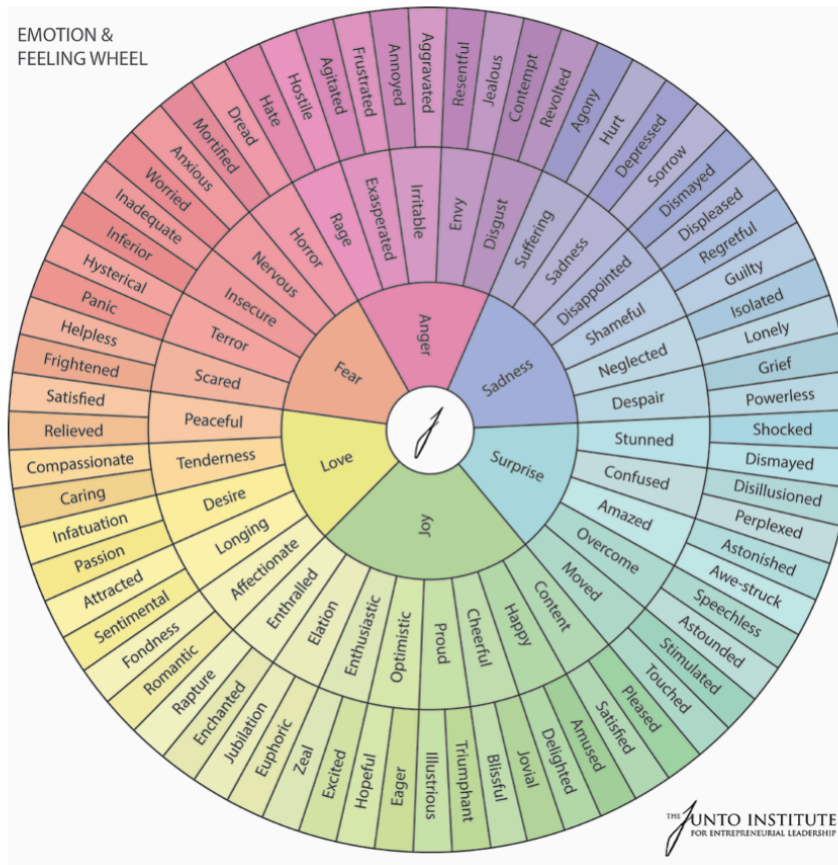


(2004) were adopted. This method of analysis was used as it appeared to be a series of logical steps in order to arrive at a collective description of experience.

The first stage of data analysis involved reading each transcript a minimum of three times to gain an overall picture of the data. As each transcript was read, I made notes on aspects of the phenomenon in question, marking passages of interest and any sections that were deemed irrelevant to the research question (Åkerlind, 2005a). Within this phase of data analysis, I moved to the use of NVivo to begin coding different statements. Each transcript was coded in turn, adopting an emergent approach with codes emerging from the data rather than any preconceived ideas that I had (Sharma et al., 2004). Importantly, this 'in vivo' method of coding (Strauss, 1987) ensured that I used the exact wording of the participants in my codes (Bazeley & Jackson, 2013), ultimately meaning that I did not miss any important conceptions that had been discussed.

Once the transcripts had been read thoroughly, had been coded using an in vivo method and I felt that I had a good understanding of the essence of each transcript I moved onto the second phase of data analysis; that of comparison. Here, different statements related to the phenomenon were compared and initial conceptions began to form (Schröder & Ahlström, 2004). It was at this phase when the method of in vivo coding became problematic. For example, as I had coded aspects of experience in the exact way the participant had expressed it, I was left with a huge number of codes that expressed a similar viewpoint (Bazeley & Jackson, 2013). As such, in the process of identifying similarities and differences between the statements, it was necessary to recode statements to identify similarities and differences of experience.

One of the main areas where this issue with in vivo coding was encountered was in coding the many different types of emotions that were expressed within the data. For example, participants expressed their sadness with varying terms such as upset, sad, tearful, distressed and so on. To make these numerous codes more manageable I began the process of recoding by utilising the Junto Emotion Wheel (Chadha, 2016) (see Figure 3.3).



**Figure 3.3:** The Junto Emotion Wheel (Chadha, 2016).

Within the emotional intelligence literature there are numerous variations of an emotion wheel, however it was the wheel used by the Junto Institute, based on the work of Ekman (1992) and Parrott (2001) that resonated with me. Firstly, the main categories of emotion seemed to fit best with those experienced by my participants and the steps towards the secondary and tertiary emotions seemed obvious and straightforward. This is in contrast to the work of Plutchik (2001), whose primary emotions of ecstasy, vigilance, rage, loathing, amazement, grief, terror and admiration, within their emotion circumplex, seemed too complex and abstract for the findings of this research. The Geneva Emotion Wheel (Sacharin, Schlegel & Scherer, 2012), was also discounted due to the complexity of their high or low control, unpleasant or pleasant categorisation of emotions.

Using the six broader categories within the Junto Emotion Wheel (Chadha, 2016), I also created a seventh as I made the conscious decision to split ‘surprise’ into both negative (shocked, dismayed, disillusioned) and positive (amazed, touched, astonished). This meant that I was better able to manage the extensive list of different emotions that arose from the data, whilst still keeping the essence of what

was said in the individual extracts and codes. Where emotions were discussed that were not categorised within the emotions wheel, for example, 'distraught', a dictionary was referred to and the essence of that emotion categorised accordingly. For example, the definition of distraught is; "greatly upset, nearly crazy with grief or worry" (Oxford English Dictionary, 1997, p. 148). Therefore, as the two words 'upset' and 'grief' were mentioned a decision was made to categorise 'distraught' as 'sadness'. The categorising of emotions mentioned throughout the interviews continued in this way until I was left with the seven broader categories as seen within the Junto Emotion Wheel (see Figure 3.3).

In the third stage of data analysis the statements and codes identified in earlier phases were grouped into preliminary descriptive categories (Schröder & Ahlström, 2004) or 'pools of meaning' (Marton & Booth, 1997). These initial categories were constantly grouped, regrouped and renamed in order to make sense of the data on a collective as well as individual level. For example, statements and codes related to what teachers believed to be the most important aspect of education for children with life-limiting conditions were grouped under the initial category 'teaching priorities'. Numerous mind maps were created showing how conceptions could be linked and the similarities and differences that existed within them.

In the fourth and final stage of analysis the preliminary descriptive categories were scrutinised on an individual level and as part of the whole (Schröder & Ahlström, 2004) to form more substantial categories of description. Aspects of the phenomenon discussed in the data were continually scrutinised to search for meaning and structure. Further mind maps and graphical depictions were created and edited to explore the links between (and not just within) the categories of description within the outcome space (Marton & Booth, 1997).

In practice, it became apparent that these stages of data analysis as described by Schröder and Ahlström (2004) were not simply a linear sequence. Instead, analysis was very much an iterative process, constantly moving between stages of analysis, exploring transcripts, in addition to the grouping, regrouping and renaming of codes, statements and descriptive categories until arriving at the outcome space.

### **3.5 Ethical Considerations**

When designing a research project, it was imperative that the ethical guidelines of the British Educational Association (BERA, 2011) were strictly adhered to. These guidelines stipulate that voluntary informed consent, openness and disclosure, the right to withdraw, any detriment arising from participation and privacy should be carefully obeyed. No incentives were offered for participation in this study.

Participants who expressed an interest in this research did so because they wanted to be part of a process that highlighted the needs and experiences of teachers in this under-researched area. In addition to these BERA (2011) guidelines, I also felt it important to consider establishing trust and rapport when conducting ethical research, particularly when exploring sensitive topics. This research gained full ethical approval from the University (see Appendix 9).

#### **3.5.1 Voluntary Informed Consent**

According to BERA (2011), voluntary informed consent involves ensuring that “participants understand and agree to their participation without any duress, prior to the research getting underway” (p. 5). All participants were sent a copy of the participant information sheet and consent form detailing the full aims and requirements of the study (see Appendices 2 and 3). In addition, due to the requirements to discuss children and experiences within a specific school setting, consent was also gained from headteachers (see Appendix 4). I felt that this was important given the sensitive nature of the research topic and the possibility that individual children, some of whom have died, would be discussed.

As previously discussed (see section 3.4.1), some of the interviews were conducted online using video technologies such as Skype or FaceTime. This meant that obtaining signed, written consent was not possible at the outset of the interview. To overcome this challenge, participants were sent copies of the participant information sheet and consent form before the interview took place and, before commencing the interview online, verbal affirmation that the participant had read the information sheet and consented to take part in the study was gained. As Deakin and Wakefield (2014) outline, obtaining this consent at the outset is crucial when interviewing online, however does have a slight impact on the building of rapport before the interview. Personally, I did not feel this impact on the building of rapport, as I attempted to establish this rapport before commencing the formalities

of the research interview through conversation about mine or the participant's day. In fact, I felt that obtaining verbal consent in this manner before asking my first question focused and settled myself and the participant into the research interview.

In relation to the digital recording of interviews, all participants were made aware throughout the participant information sheet that the interview would be audio recorded for the purposes of transcription and data analysis. Again, for the participants being interviewed online or via the telephone, it was important that I reiterated this point as they were unable to see the audio recording device (Deakin & Wakefield, 2014). Further verbal consent in relation to the audio recording of the interview was therefore gained from all participants before commencing.

### **3.5.2 Openness and Disclosure**

The full aims and objectives of the research were outlined to participants in the participant information sheet (see Appendix 2). In addition, I was open and honest with participants about the sensitive nature of the research topic and that some of the areas discussed may be upsetting. I thus felt that I was as open as possible throughout the research process and that participants knew exactly what was expected from them, before commencing the interview.

### **3.5.3 Right to Withdraw**

It was made clear from the outset and throughout the participant information sheet that participants could withdraw from this study at any time, without specifying a reason and with no negative effects. If participants became distressed at any point throughout the research interview, they were again offered the opportunity to stop and/or reconvene at a later date. As Deakin and Wakefield (2014) argue, the right to withdraw is perhaps easier throughout online interviews as opposed to face-to-face interviews, whereby the participant could refuse to answer an online video call or simply end the connection if they no longer wanted to participate. This did not happen throughout my interviews and all participants were happy to continue their participation in the study.

### **3.5.4 Detriment Arising from Participation in Research**

BERA (2011), clearly state that "researchers must make known to the participants...any predictable detriment arising from the process or findings of the

research” (p. 7). It was made clear from the outset that some participants may find the topics discussed in the research interview upsetting due to the sensitive nature of discussing children who have died or who were nearing end of life. Participants fully understood this. As a researcher, I carefully monitored the body language of participants and offered breaks if participants were showing signs of distress or upset, in addition to securing additional consent that they were happy to continue with the interview. At the end of the interview I ensured that participants were given details of further sources of support if they felt they had been affected by what was discussed, or if they needed any further information. This was in the form of a charity website or leaflet whereby further support was signposted. Participants were grateful for the opportunity to discuss their experiences including chance to talk about students who had died, often for the first time since their deaths. Many participants expressed that they felt it was a beneficial and almost therapeutic exercise.

### **3.5.5 Privacy**

This ethical guideline states that participants and their data should remain confidential and anonymous throughout the research process. As such, interview data was anonymised, and each participant given a number at transcription. In addition, the names of children, staff members and school nurses discussed throughout the research interview were given pseudonyms using a random name generator. As the research field is relatively narrow, with often only one or two special schools within a specific geographic location, and indeed only one or two classes for children with Profound and Multiple Learning Difficulties (PMLD) within a school, all names and specific locations of schools were also kept confidential to ensure that no one can be identified from this research report. Only demographic details including length of time in special education, a general geographic spread, and previous teaching experience were included in the analysis.

All transcriptions of the digitally recorded data were stored securely with their participant numbers on a personal, password protected computer to further ensure the confidentiality of the data.

### **3.5.6 Trust and Rapport**

In addition to these BERA (2011) guidelines, it is important to consider establishing trust and rapport in conducting ethical research, particularly when exploring sensitive topics. In establishing trust, I felt an approach was needed which sees trust as a moral status (Booth & Booth, 1994). Specifically, throughout this approach, “trust is dependent on the actions and attitudes of the researcher which must both validate the researcher’s identity and...show that the subject is valued” (Booth & Booth, 1994, p. 417). Primarily, I am an educationalist, however participants may not see me as such. To them, I am a researcher, present to explore distressing topics. To overcome this, I needed to build a relationship, explain about my role and teaching experience, research and the part the participant can play in both of these areas. In addition. I needed to listen and show interest in their roles and teaching experiences. I felt in this way, a positive relationship was developed to benefit and support both parties.

Like ethical considerations, some researchers believe that developing rapport is fundamentally different when interviewing online as opposed to interviewing face-to-face (Hay-Gibson, 2009). Yet others have found that despite these differences, the development of rapport did not affect the quality of the interview (Denscombe, 2003). In the same way as Deakin and Wakefield (2014) outline, rapport within this study began through initial emails to determine a suitable interview time and share some of the aims of the research. In addition, the simple sharing of my experiences or an aspect of my day, as well as showing an interest in the experiences of the participants from the outset of the online interview, enabled effective rapport to be established relatively quickly and easily.

### **3.6 Ensuring and Enhancing Rigour in Qualitative Research**

Ensuring the quality of research within the qualitative paradigm is as important as in quantitative research, however the criteria for evaluating such quality are different, in part due to the diverse nature of both paradigms and associated assumptions (Sin, 2010). Within quantitative data, the criteria of validity, reliability and generalisability are largely adopted, however, as Lincoln and Guba (1985) explain, these concepts cannot be meaningfully applied to qualitative research. Instead, Guba and Lincoln (1981) outline four criteria to assess the quality of qualitative research, that of; credibility, transferability, dependability and

confirmability. Table 3.1 shows how these four criteria compare to the concepts of validity, reliability and generalisability in scientific research, demonstrating how qualitative research can prove its trustworthiness in a similar way to quantitative approaches.

**Table 3.1:** Scientific and Naturalistic Terms Appropriate to the Four Aspects of Trustworthiness (Guba, 1981, p. 80).

<b>Aspect</b>	<b>Scientific Term</b>	<b>Naturalistic Term</b>
Truth value	Internal validity	Credibility
Applicability	External validity Generalisability	Transferability
Consistency	Reliability	Dependability
Neutrality	Objectivity	Confirmability

Elsewhere in the research literature it is clear that an element of disagreement exists among scholars and researchers. Indeed, there are numerous other criteria that researchers have introduced to attempt to assess the quality of their research (Creswell & Miller, 2000; Mays & Pope, 2000; Spencer, Ritchie, Lewis & Dillon, 2003). Many of which involve long lists of ways in which researchers can ensure their findings are valid, including through triangulation, respondent validation, reflexivity, peer debriefing and disconfirming evidence (Creswell & Miller, Mays & Pope, 2000).

Morse, Barrett, Mayan, Olson and Spiers (2002) state that the careful consideration of validity and reliability should be evident throughout every aspect of the research process and not just in relation to the research findings, to show quality and rigour within qualitative research. In line with their approach, and utilising Guba and Lincoln's (1981) model of credibility, transferability, dependability and confirmability, trustworthiness was ensured throughout. Each criterion and how they have been applied in the present research will be discussed below.



### **3.6.1 Credibility**

As shown within Table 3.1, credibility most closely relates to the scientific term 'internal validity'. Validity within research refers to truth, specifically to whether the research findings accurately represent the phenomena they are describing (Hammersley, 1998). In relation to qualitative research, credibility is concerned with the "confidence in the truth of the findings, including an accurate understanding of the context" (Ulin, Robinson & Tolley, 2005, p. 25). Within phenomenography, researchers look for conceptual meanings expressed in the data (Sin, 2010). As the main method of data collection used within phenomenography is interviews, researchers are able to explore further an individual's expression of the phenomenon and therefore establish meaning. Clarifying and confirming the exact meaning of an expression with the participant, throughout the research interview therefore enables credible data to be obtained (Sin, 2010). Corbin & Strauss (2008) further stipulate that researchers must provide clear evidence of methods of data collection and analyses in order for others to establish how the research findings were made. It is this transparency throughout the whole research process, from sampling to final data analysis, that I strive for and that I hope is evident throughout this research.

### **3.6.2 Transferability**

Transferability is most closely related to generalisability within quantitative research. Generalisability is concerned with how well the findings from one study can be representative of or transferred to a wider population (Sin, 2010). However, it can be argued that the issue of generalisability is not useful or desirable within qualitative research due to differing epistemological and ontological standpoints in addition to the many variables that cannot be fully controlled (Bassegy, 2001; Larsson, 2009; Schwandt, 1997). Within qualitative research it is more useful to think of generalisability in terms of transferability; "the extent to which findings can be used or applied in other contexts" (Sin, 2010, p. 309). Within phenomenography, some researchers have argued that the qualitative findings obtained have brought about changes in how phenomena are perceived within education (Johansson, Marton & Svensson, 1985; Bowden, 2000). It can be argued that due to the unique, collective descriptions of experience, in addition to the wide geographical spread of participants, that the research findings here could usefully be applied or transferred to others who teach children with life-limiting conditions. It

is in this manner that ‘fuzzy generalisations’ can be made (Bassey, 2001). A fuzzy generalisation is “one that is neither likely to be true in every case, nor likely to be untrue in every case; it is something that *may* be true” (Bassey, 2001, p. 10).

Therefore, within the current study, it may be possible to make fuzzy generalisations. For example, it could be said that teachers who work with children with life-limiting conditions *may* feel *x*, *y* and *z*, and they *may* be effectively supported by *a*, *b* or *c*. In essence, the findings from this research could be used to contribute to a wider understanding of the phenomenon in question (Shenton, 2004). Studies that aim to replicate my findings, whether they are supportive or not, could contribute to the wider understanding of the multiple realities of teaching children with life-limiting conditions.

### **3.6.3 Dependability**

Dependability, according to Guba (1981), is most closely related to the scientific term ‘reliability’. Reliability within quantitative research is the extent to which the research findings could be replicated if another study were to be conducted using the same methods (Burr, 2003). Replication within qualitative research is not generally an aim, due to the belief that realities and truths are constructed or interpreted by individuals at a specific time and within a specific context (Marton & Booth, 1997). Indeed, Marton (1986) and Säljö (1988) argue that the outcome space emerges rigorously from the data within a given study at a specific time and place and as such does not need to be replicable. It is in this manner that other measures of quality and credibility such as peer-review and member checking (Creswell, 2014) are irrelevant in phenomenographic research due to the importance of the researcher in interpreting meaning, and the emphasis on the collective experience (Sandberg, 1997).

To transfer this quantitative concept into something of relevance within qualitative research, the term ‘dependability’ is used (Guba, 1981; Guest, MacQueen & Namey, 2012). Dependability is defined as “whether the research process is consistent and carried out with careful attention to the rules and conventions of qualitative methodology” (Ulin et al., 2005, p. 26). This is also supported by Sandberg (1997) and Ashworth & Lucas (2000) who identify that researchers can demonstrate reliability by acknowledging their own biases and preconceptions to understand experiences from the participants’ own point of view. Ensuring that the

research report is written with justification of my methodological decisions, in addition to effectively bracketing my prior assumptions (Ashworth & Lucas, 1998), will ensure dependability within my research.

#### **3.6.4 Confirmability**

Confirmability is most closely related to 'objectivity' in scientific terms (Guba, 1981). Qualitative research acknowledges the role of the researcher in the interpretation of findings and as such complete objectivity is unachievable (Bryman, 2012). However, qualitative researchers can ensure confirmability within their research by bracketing prior assumptions, making clear any prior views or beliefs and not allowing these to impact on the findings (Bryman, 2012). Following Ashworth & Lucas' (1998) guidelines of presuppositions that should be considered (see section 3.2.4.3) will guarantee that confirmability is evident throughout my research process and findings.

### **3.7 Summary of Methodology**

This chapter has rooted the study within a qualitative, interpretive paradigm and within a phenomenographic research approach. The decisions made throughout this research process have been outlined, explained and justified in relation to the research literature. It has described in detail how the research sample was obtained, the data collected, and analysis performed. Finally, this chapter has discussed ethical considerations which were addressed throughout the research process and has explained how quality was ensured and enhanced throughout using Lincoln and Guba's (1985) model of trustworthiness that is most suited to this qualitative, phenomenographic research approach.

## Chapter Four: The Outcome Space

The aim of phenomenography is to determine how different ways of experiencing a phenomenon are related to each other (Stenfors-Hayes et al., 2013). By following the Four Stages of Analysis as identified by Schröder and Ahlström (2004), five categories of description were developed to illustrate the qualitatively different ways in which teachers experience the phenomenon of teaching children with life-limiting conditions in special schools. These five categories are:

1. Challenges Faced
2. Emotional Impact
3. Emotional Support
4. School Health Provision
5. Pedagogical Considerations

This chapter will illustrate and discuss the outcome space as it relates to the present study, will outline my own positionality in relation to the phenomenon in question and will conclude with a brief description of how the research findings will be presented in order to set the scene for the following chapters that aim to discuss each category of description in turn.

### 4.1 The Outcome Space

To arrive at the outcome space, logical relationships must be sought and illustrated between the categories of description (Marton & Booth, 1997). Whereas this outcome space was formed in the closing stages of the overall data analysis, it is felt that presenting the outcome space at the outset will help the reader to see the totality of teachers' experiences, how each category relates to one another, as well as to illustrate my journey of data analysis.

Figure 4.1 illustrates the outcome space for this study and demonstrates the relationships that exist between each category of description.

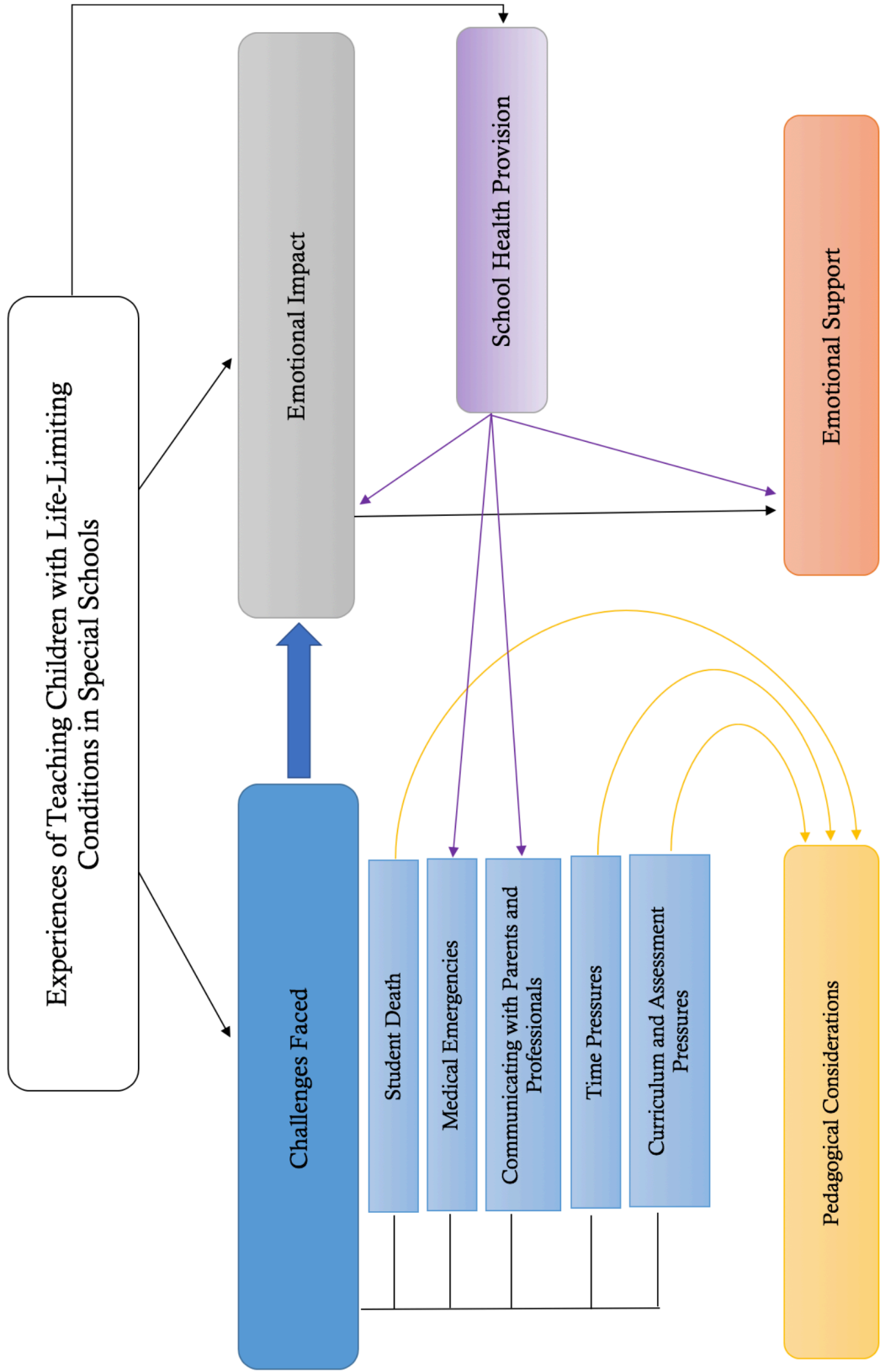


Figure 4.1: The Outcome Space

Within this outcome space, hierarchical relationships have been identified. The 'Challenges Faced' category of description was found to be the broadest and encompassed a range of different sub-categories. Importantly, these challenges experienced were tangible, experienced directly and went on to shape teachers' experiences throughout the other categories of description as illustrated by the different arrows in Figure 4.1.

Due to the overwhelming impact that student death has on teachers' experiences within special schools, the challenge of experiencing a student death is at the fore of the 'Challenges Faced' category, closely followed by the impact of medical emergencies. Teachers discussed these experiences at length and as a result, they became a huge part of their teaching biographies. The larger arrow linking the 'Challenges Faced' category to the 'Emotional Impact' category shows the direct and significant effect of the challenges faced by teachers on their emotional wellbeing. All of the challenges experienced within daily practice have a positive or negative impact on the emotions of teachers. These emotions in turn, within the category of description, impact on the personal and professional lives of those experiencing them. It is these categories together that form the basis of teachers' experiences when teaching children with life-limiting conditions. They relate to each of the other categories and are thus considered to be the main findings of this research.

The third category of description (Emotional Support) moves beyond the emotions triggered by the challenges faced, as discussed in the previous category, to reflect on how teachers seek and receive emotional support from a range of different sources. This category of description is important given the perceived barriers to emotional support received by teachers interviewed in this study and has important implications for schools going forward.

The fourth category of description (School Health Provision) is one that perhaps does not fit into a hierarchical relationship with other categories. However, it could not be ignored due to its impact on the experiences of those interviewed. The purple arrows in Figure 4.1 show how this category logically relates to others in terms of influencing how the challenges of 'medical emergencies' and 'communicating with parents and professionals' are experienced. The presence of school health provision

also impacts on the emotions of teachers and can provide emotional support. These links were felt to be important and are therefore also illustrated.

Finally, the fifth category of description (Pedagogical Considerations), extends beyond the tangible and direct experience of the challenges faced to the different priorities teachers have about what is the best educational approach for the children they teach. As can be seen from the yellow arrows in Figure 4.1, some of the challenges faced by teachers shape these priorities. For example, the fact that students die, often unexpectedly, causes some teachers to prioritise a quality of life approach rather than a purely academic style within their teaching. Similarly, the time pressures faced when trying to meet the medical, physical and educational needs of children also, consciously or subconsciously, shape the pedagogical priorities of teachers.

Overall, the Outcome Space gives a clear picture of the experiences of teachers who teach children with life-limiting conditions in special schools. Within their daily practice, teachers face a range of different challenges. Some, such as time, curriculum and assessment pressures, may occur more regularly than student death or medical emergencies, however, these experiences have a significant and lasting effect on the teachers who face them. It is these challenges and their associated emotional impact that shape teachers' biographies and influence their teaching style, outlook and wellbeing. Whereas some of the emotional impact is positive, particularly in relation to the love of the job and their students, teachers experience a range of negative emotions that have a detrimental effect on their personal and professional lives, often resulting in emotional and physical exhaustion.

In an attempt to combat the negative emotional impact, teachers seek support from a range of different sources. Some turn to friends, family and other colleagues for support, whereas others make use of the professional counselling provided by schools, often in the aftermath of a student death. Despite seeking this support, some teachers found it to be lacking. This was in terms of availability when needed, or in the lack of understanding and awareness of friends, family, colleagues or SLT. The availability or lack of school health provision also directly influence the experiences of teachers. The presence of high-quality school nursing staff reassures teachers and helps them to cope with the level of medical need they experience within their classrooms. The absence of such staff however can leave teachers

feeling vulnerable and unsure during medical emergencies. The quality and availability of nursing staff was also found to affect the emotional wellbeing of teachers within this study.

## **4.2 Researcher Positionality**

I began this research process with prior experience and intense feelings about working with children with life-limiting conditions. Upon starting my first teaching role within a special school I, like the majority of newly qualified teachers, had not considered that I may experience the death of a student nor have to deliver potentially life-saving medical care. During my third year of teaching I was given a class of children with complex needs, some of whom had life-limiting conditions. At the outset I was overwhelmed with the responsibility of ensuring these children were cared for, healthy and safe, in addition to meeting their educational needs. Primarily, I struggled with the notion that my students had the potential to become extremely ill within my classroom and even die. The weight of this responsibility caused nightmares about children having seizures and even led to sleepwalking.

As I have become more experienced and knowledgeable, much like some of the teachers in this study, I have learnt to manage these thoughts and feelings and resulting interruptions in my sleep are reserved for only the most rare and stressful of times. I have always enjoyed the challenge of working with children with such complex medical needs and since that first encounter, these children have become my passion.

Acknowledging these prior experiences, thoughts and feelings about the education of children with life-limiting conditions helped to ensure they were adequately bracketed in order to reduce bias, whilst still allowing me to develop a relationship with my participants as an insider (see section 3.2.4.3 for a further discussion of the bracketing process).

## **4.3 Research Findings**

Throughout the following chapters, each category of description will be discussed in turn. Quotations taken from interview transcripts are used to further illustrate each category of description and to support interpretive claims. All quotations are shown in italics. Pauses of under three seconds duration made by teachers are



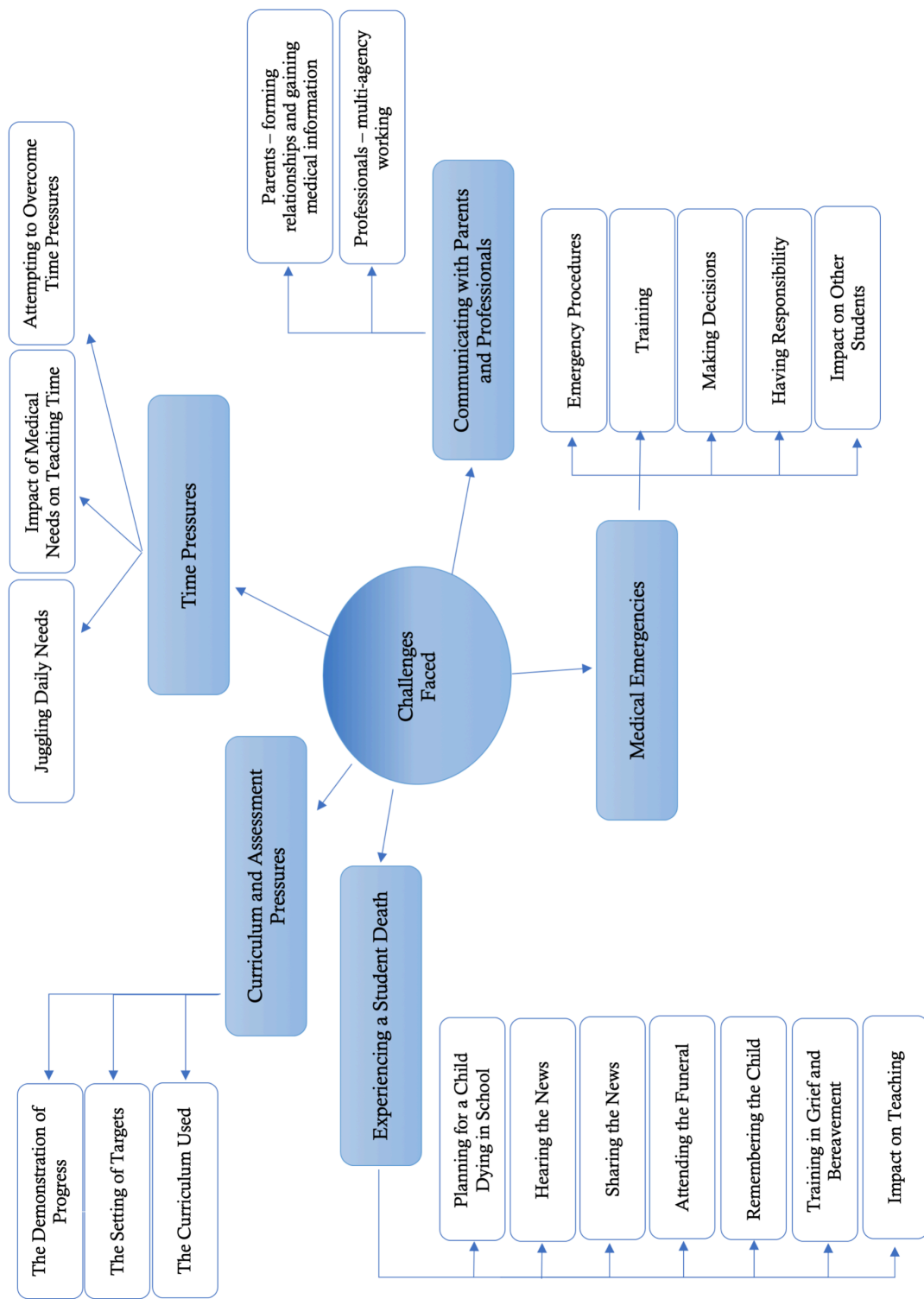
shown with an ellipsis, whereas lengthier pauses are shown with an ellipsis in brackets (...). Where sections of the transcript have been omitted for clarity, an ellipsis within square brackets [...] is used. At the end of each quotation the participant number will appear in brackets with the prefix P, for example (P2). For quotations involving both the interviewer and the teacher 'I' and 'T' are used before the presentation of speech to show effectively who is speaking. All names relating to children or staff members have been changed using a random name generator.

## **Chapter Five: Category of Description One - Challenges Faced when Teaching Children with Life-Limiting Conditions**

Teachers were found to encounter a number of challenges when teaching children with life-limiting conditions in special schools. In particular, the participants interviewed in this research mentioned a number of significant difficulties regarding:

1. Student Death
2. Medical Emergencies
3. Communicating with Parents and Professionals
4. Curriculum and Assessment Pressures
5. Time Pressures

These challenges can be seen in Figure 5.1. Each challenge identified will be explored further with specific reference to the interview data.



**Figure 5.1:** The Challenges Faced by Teachers when Teaching Children with Life-Limiting Conditions in Special Schools

## **5.1 Experiencing a Student Death**

The most significant challenge of teaching children with life-limiting conditions is the possibility that a child within the school may die. This was a challenge faced by almost all of the teachers interviewed. Some teachers had experienced the death of multiple children within their teaching careers. Others were yet to experience this eventuality but were very aware of the likelihood that this could occur at any time. At least two of the teachers interviewed had experienced the death of a child within the month prior to the interview taking place. Like with medical emergencies, this section will discuss the process of experiencing a student death for those interviewed in this study. It will begin by discussing the experiences of teachers who have had to actively plan for the eventuality that a child might die within their classroom. Furthermore, the ways in which teachers hear the news of a student death, have to share the news and ways of remembering the child including attending the funeral will be discussed. In addition, how a student death may impact on teaching will also be considered. The emotional impact of these deaths as well as the support available following the death of a child will be discussed in more detail in Chapters Six and Seven

### **5.1.1 Planning for a Student Death in School**

One of the major concerns for teachers when teaching children with life-limiting conditions was in planning for the death of a child in school. Although none of the teachers interviewed had experienced such an event, and were indeed thankful for that fact, a number of teachers expressed their concerns with what could happen in their classroom. In an attempt to manage these concerns, many teachers had consciously thought about what could and should happen in the event of a student death in school. Some had begun to put plans in place in liaison with school nurses and SLT to ensure they were prepared for any eventuality. Despite these plans, all of the teachers who had made them were fearful of a death event and dreaded an actual occurrence in school. Part of these anxieties stemmed from the thought of actually witnessing a child die as the following quotes illustrate:

*I think had it been the little boy who had a heart attack, had he passed away because we were all there literally almost in the room...I think that would have been different because we would have seen it (P10).*

*I think if it had been at school it puts a whole level of...stress and strain on everything (P14).*

However, a much larger part of these anxieties related to the processes, procedures and investigations that would occur following a death in school.

*I do yeah, I do worry about probably more because it's an inevitability and I just yeah I'd just really like it not to happen in school I think would be the main thing cos I think that would be a much harder thing to deal with then in terms of investigations and stuff I think would be really hard for a lot of our staff (P3).*

Some of the plans put in place to prepare for a death event in school included ensuring people were aware of who to call and where the child would go.

*We were talking about in terms of...you know who would call [...] so I think it definitely helped to talk about it and we talked er just about erm in particular about [...] that that's where she would go and then the rest of the children could be in the main bit of the classroom and that we would send for the school nurse and for erm the head or somebody from SLT (P7).*

Teachers felt having these conversations, although difficult, helped them to be more prepared for a death occurrence in school.

*It wasn't kind of micro managed but just so that people had a bit of an idea that there is the possibility that this could happen if it happens this is what you need to do so that people felt a little bit more prepared in some ways much the same as you do with lots of medical procedures (P7).*

### **5.1.2 Hearing the News**

Teachers discussed various ways that they heard the news of a student death. These experiences appeared to depend on the time of day or week that a student death occurred, for example whether it was in the morning, at a weekend or during a school holiday. Teachers' experiences also depended on how well SLT were able to deal with student death and as such, led to discussions about how well a student death was handled by the school as a whole. Some teachers felt their school handled the death of a child extremely well, whereas others felt there was room for improvement in order to make the experience better for all involved.

Upon the school being informed of the news of a student death, the majority of teachers identified that the child's class teacher and teaching assistants were the first to be told by the headteacher or SLT, before the news was shared with the wider staff team.

*The people in the classroom that the child was in erm are taken to one side and told first erm and then other members of staff (P16).*

These experiences depended on the time of day school received the news as gathering a whole staff group together to inform everybody at the same time was problematic, especially if children had already arrived at school that day. In those situations, some teachers described SLT visiting classes throughout the day to inform staff, or a whole staff email being sent to ensure everyone had the facts and to prevent gossip. The following teacher found that hearing the news of a student death via email was harder to handle.

*Some it's more just sort of they have to send an email I think and then it can be harder (P13).*

*I mean our headteacher always sends round an email to everybody just to inform them and to let them know that actually they need not gossip about it cos it's really difficult for the class that the child has been with you know been in and for the family you know and to make sure that they're not stood in the middle of the staffroom having a chat (P15).*

If a student death occurred at the weekend, then some teachers described being sent an email, particularly if the death was sudden and staff were expecting to see the child on Monday. Others described having such a close relationship with parents and families that sometimes teachers and support staff were told directly by parents and therefore knew a child had died before arriving for work.

*In fact, the first people who found out were the staff because the mum rang round or text [...] and they knew as they were coming into work (P6).*

*Sometimes it might be the parent who contacts me before the school does because I've got very close relationships (P13).*

Some teachers described alternative systems where special items were hung around school on the day a child had died. This meant that staff coming into school were aware as soon as they arrived that a death had occurred. Staff would then be told about the individual child following similar processes described above.

*School tend to put up [items] around the school building so you know if you see them you know somebody's gone [...] and you think oh who is it [...] then they tend to call the teachers into the staff room and tell you who it is (P10).*

A particular challenge of dealing with the news of a student death whilst at school was whether staff were given adequate time to deal with the news. This was found to be notably problematic as often staff were told about the death of a child first thing in the morning just before the other children arrived to begin their school day. Some teachers described support staff being brought in from other classes to enable the child's staff to have some time together to process the news.

*The class that the child has died from erm they get staff from another room just to go in and support that staff they pull them all out to the staff room and they tell them (P14).*

In other situations, headteachers would ensure the staff most affected by the student death were given time out to be together before returning to class.

*He wouldn't, the headteacher wouldn't just tell them and like go back he'd leave them for sort of a good 15 minutes or what have you (P11).*

However, for other staff who were not working directly with the child, often the expectation within schools was that they had to carry on with their day as there were other children who needed to have their educational, medical and social needs met. This was found to be difficult for a number of teachers interviewed.

*I do think they kind of have the expectation that you will just carry on through the day (P10).*

*Usually [the other students] are already in school so it's really hard I think it'll be so hard because you'll then have to do a day with the rest of the class [...] my colleague really struggled after Mary had died and she just walked round the school she just*

*looked awful bless her she was really like holding on all the way through the day (P12).*

In contrast, the following teacher found comfort in returning to their class to spend the day with the other children following the death of a child.

*I just want to get back in with the children [...] from experience most of us you almost have that maternal pull like I want to get back to those children that are still there (P14).*

Throughout all of the interviews, teachers discussed children who had died and their experiences following each death. There were some differences in how the news was broken to staff and this seemed to influence how well the death was perceived to have been handled by the school as a whole. Where the news was shared quickly, and staff given time to be together, the handling of the death of a child was perceived more positively.

*It's something we all knew would happen from time to time er none of us would ever wish for that to happen erm, but I think because of that the way that it was broken to everyone the way that it was handled was done very well I think yeah (P17).*

One teacher described a death which had not been acknowledged by the school as an exceptionally negative experience. This was attributed to the fact that the headteacher struggled personally to deal with death and therefore did not have the ability to support their staff team adequately.

*The headteacher at the time couldn't deal with death nothing was said in school about the fact that Matthew just disappeared, and nothing was ever mentioned about the fact that he died [...] nothing was ever said about the fact that he just disappeared, and I thought that was awful (P7).*

### **5.1.3 Sharing the News**

The above section outlines how teachers were told that a child had died, usually by SLT. Where possible it is clear that headteachers tried hard to tell the class staff first before sharing the news with the wider staff group. However, due to the exceptionally large numbers of staff that work within special schools, the wide variety of professionals that have close contact with the children and the nature of



the other children within the school, often the sharing of this news falls upon teachers themselves. This was highlighted by teachers as a particular challenge for them, at a time when emotional turmoil is high.

For the following teacher, the system within their school was that teachers were brought together and told about the death of a child before being expected to return to class and share the news with their support staff. This was found to be exceptionally hard, especially as they were given very little time to process the news themselves before having to deal with the emotional reactions of others.

*They expect us to pass that on to everybody else which...I don't know that's the best way to handle it but I can see from their point of view that they tend to be telling you as the children are arriving as well and obviously you can't have all the staff together when there's children that need to be looked after so from a logistical point of view I understand why they do it but I'd kind of like it that it wasn't all my responsibility you know cos sometimes it's upset you as well [...] you've just heard it and you've got to talk about it and deal with everyone else's reaction to it [...] it's kind of expected that you'll be ok (P10).*

Another teacher described a situation whereby they received the news about the death of a child directly from parents during the school's holiday play-scheme. This situation, although not the norm, meant that the following teacher had to take the lead role in terms of sharing the news with others. This was especially difficult for them given the uncertainty of the situation and the reactions of other people to the news.

*I really felt like I had to hold it together because everyone was so upset and so devastated and there was because it was during holiday time as well no one was really sure who's responsibility things were so I was the one who made all the phone calls to people and let people know what was happening and yeah so I think that was my main memory of it all was being very much like right I need to take control of this situation (P2).*

A further consideration when sharing the news with staff, students and other professionals within the school was in regard to ensuring that the people who had worked closely with the child were told of their death in a timely manner. One teacher discussed a situation in which the school had forgotten to inform a child's

mainstream peers that the child had died. This led to an incredible amount of upset once the mainstream peers were eventually told of the death.

*One time we forgot to tell some of the mainstream peers and because erm this pupil had been off sick for a long time I don't know a couple of months I think erm obviously they weren't coming in anymore but then when they found out they were terribly upset [...] it was just a complete oversight we just completely forgot (P6).*

To prevent this from happening, some schools devised systems whereby people closest to the child were identified before a child reached the end stages of life. This is often called 'Circles of Vulnerability' and allows for a record to be kept of the professionals, peers and support staff who have worked with the child and that need to be told as soon as possible in the event of the child's death. Planning in this way can help to alleviate the issues found by the teacher above.

*We fill in forms for each child to explain who is involved with that child erm...so sort of with the older children we did a lot of inclusion work with a local mainstream secondary school so there were a group of girls that would come over and help in our class [...] so it was important that they had support as well so we filled out this sheet of all the people that were involved even down to sort of escort and taxi services that bring children in so that if it happens...all this information is then cascaded out to the people that need to know (P18).*

Some teachers found that including extra information within their Circles of Vulnerability was of particular importance, especially if people close to the child had recently experienced personal bereavements or if hearing the news of the death of a child would trigger other feelings that school staff needed to be aware of.

*We have a big thing in our kind of circle of vulnerability with some people who will be affected because of recent bereavements that they've had that it will trigger other thoughts and we allow for that (P6).*

When sharing the news of a student death, teachers often found themselves needing to provide emotional support to their staff. Teachers seemed to intrinsically offer this emotional support regardless of their own emotional turmoil (see section 6.1.5).

*You have to support your staff...it's just like any reason you end up supporting your staff and other people when you, you're just as upset if you know what I mean and some other people who, who just know them but haven't particularly taught them or whatever and they're absolutely distraught and traumatised by it all you know so you end up turning your hat round and being the bereavement counsellor (P5).*

Having a strong relationship with support staff was seen as pertinent when providing emotional support to staff upon sharing the news of a child's death. The following teacher felt that talking with support staff was essential in helping them to deal with the death of a child.

*It's really important to talk to the staff team because some people deal with it better than others [...] I think over the years if you've built up a good team then you do have that relationship within the classroom anyway that you talk to your support staff and they would come to you with something that was worrying them in any case about lots of different things and so in this particular situation [student death] it would be natural for them to do that as well (P7).*

Whereas some teachers struggled with managing the feelings of staff on top of their own emotions, others felt that having the supporting role for their staff helped them to better deal with the situation.

*I'd have been quite happy to erm...talk it through with other people you know I think it would have been quite cathartic to me chatting to other people...counselling other people [...] that would have been quite helpful for me as well (P5).*

In addition, teachers also expressed the added challenge of informing other children in the class of the death of a classmate. This is especially problematic given the limited awareness and understanding that children with PMLD have and posed a significant challenge for teachers. For the majority of teachers, the responsibility of sharing the news of a child's death with their class lay with them. Some teachers were expected to return to class and share the news immediately, whereas others were given the freedom to choose a more appropriate time. A further difficulty in sharing the news was dealing with the questions that some of the more able children may have in addition to trying to manage their own emotions.

*So, I kind of thought how am I gonna break this...news to them and I thought oh God I'd, they want to talk about it I really am gonna cry...how do you say that your friend has died, and they're only really like 10? (P12).*

Furthermore, some teachers found difficulty in how to share the news, specifically in terms of what to say to children who may have limited or very literal understanding. When sharing the news with children it was vitally important to consider the language used when explaining that a child had died. Using the wrong language could scare children and cause unnecessary worry. For teachers, observing how trained professionals share the news is helpful in then managing further questions and offering support within the classroom.

*She encourages them to talk about death and that the person's died they haven't just disappeared erm and she's very clear that they don't get frightened about, not using stupid words like they've gone to sleep cos that's terrifying [...] it's harder for the students I think who are more cognitively able cos I think they get frightened and wonder if it's gonna happen to them (P13).*

This difficulty in explaining a death to other students was further compounded by how parents wanted the news shared with their child as well as their individual beliefs. Considering how best to share the news with children led some teachers to feel anxious and uncomfortable.

*To be honest I feel really uneasy...because having children myself I'm not sure what I would say to them because I know other people have different beliefs and that kind of thing so I'm very sort of almost vague at what happened very matter of fact and that we won't be seeing this child in school anymore but you can't go on to say anything like they've gone on to heaven or they've turned into a shining star you know because I think that's up to individual families to do that (P18).*

The following teacher attempted to overcome this by writing to parents to inform them of the death of a child first, before asking for their input in how to approach the sharing of the news with the child.

*I mean I think we've sent a letter out I think erm...just to say that that's what happened if not I think I wrote to some of the parents and just said obviously David*

*passed away erm they might have questions about it how do you want us to approach it (P12).*

When sharing the news about the death of a child within their class or within the school, teachers also faced the additional challenge of having to provide emotional support to their students. For some schools, this emotional support was built into the Personal, Social and Health Education curriculum where grief and bereavement are covered as topics. For others, specialist resources such as sensory stories or puppet boxes are used to help explain to the students what has happened.

*We have a special erm story that we tell, and we have a box on each side of puppets about a sort of animal dying and we tell the story and it talks a lot about memories and things and then we talk about erm we talk about it with the pupils (P6).*

Providing this emotional support to students was often found to be problematic due to the students' levels of understanding. Some teachers felt that as their students had such little understanding and awareness of others and the world around them trying to explain and support them through a bereavement was incredibly difficult.

*I think we try and provide these lovely opportunities for the children we'll try and provide like a little group that talks about that child but that again it doesn't translate that well because it's very likely that the children in my class will have no idea who that child was [...] their understanding of the world around them is so limited anyway trying to communicate that bereavement is very difficult (P2).*

Despite this, for some teachers, offering children support regardless of their levels of understanding was important. This was in part due to the difficulty in ascertaining exactly what children with SEND are able to comprehend and what they do take in in difficult situations.

*Yeah, I think they could do with a little bit more support, some might need a little counselling I think people assume that because students have got a special need they don't necessarily need that because they haven't got that cognitive capacity, but they do (P5).*

In some cases, teachers found themselves unable to share the news with children due to their own apprehension or heightened emotions. In these instances, specially

trained family liaison workers where available would be utilised to work with the children to help them understand the bereavement.

#### **5.1.4 Attending the Funeral**

For the teachers interviewed, being able to attend a child's funeral was dependent on a number of factors. These included whether the family would allow members of staff to attend, the school's approach to allowing people to attend the funeral and the religion or culture of the child who had died. Many teachers interviewed had attended the funeral of a child in their school with some expressing that sadly they had attended more funerals of children than those of adults.

In many circumstances, schools were found to do their best to accommodate teaching and support staff attending the funeral. Some classes would be sent home on funeral days so that all of the class staff could attend the funeral together, and often staff were not required to return to school following the funeral to ensure they had time to be together.

*As a school they're very good you know when I've been to children's funerals, I'm not expected to go back to work you know it's like no you need to have time to reflect on all that's happened (P14).*

In other instances, where cover could not be provided, only one or two members of staff would be allowed to attend the funeral, often those who had been closest to the child. This was to ensure the safety of children back at school.

*We can't always allow, if everyone who wanted to go meant that we didn't have enough staff back at school, so the children weren't safe then no (P13).*

In some cases, particularly where children were from Islamic and/or Asian families, staff were often unable to attend the funerals as they were frequently held within twenty-four hours of the death.

*We have a high intake of Asian families and their burials are usually within 24 or 48 hours so sometimes we can't get to them if it's very quick but on the whole, we're allowed two members of staff from the class are allowed to go to the funeral (P16).*

Where teachers were unable to attend the funeral, they found it quite difficult to gain closure and felt deeply for the families. The following teacher expressed their desire to attend the funerals of two children who had died to show support to the families, however, due to changing schools this was not possible, making the whole situation that bit harder:

*I found it difficult erm when I moved special schools and erm two students passed away, that was quite a difficult thing because I couldn't get to the funeral and I felt...that that would have been nice just for me to attend sort of see the family and just show them that I still care about it whereas erm that wasn't the case it wasn't possible so something like that would have been very useful to me erm you know you're always left just that little tiny thing at the back of your mind thinking I wish I'd have been able to (P5).*

Similarly, other teachers found that moving schools shortly after the death of a child or finding out that a child had died after they had moved schools, was particularly difficult to come to terms with. In these situations, often teachers were not able to attend the funerals and felt isolated with no one to speak to about the child. The following teacher talked openly about wishing they had been able to attend the funeral to gain closure, but they had managed to speak to a previous colleague which helped to ease the situation:

*I wasn't able to go to the funeral which was a shame in retrospect I wish I had gone to the funeral [...] I only found out two days before the funeral anyway so there wasn't much time to think about it and sort it out erm but I did manage to talk to one of the teachers who had been her teacher so that was good and find out what had happened (P6).*

Some teachers were invited by families to be heavily involved in the funeral itself by speaking about the child or reading the tribute. Whether staff agreed to this depended on the individual, as some felt unable to do this. Others however, felt honoured to have been asked and found comfort in sitting with support staff to plan what would be said.

*I've actually done the tribute for two or three children who've died which is a huge privilege [...] I did the tribute but I sat down with the staff team and I said ok I want you guys to help me and they came up with lots of memories, the person who'd*

*actually worked most closely with this little girl she had a few set things she wanted said didn't remotely feel able that she could do that but told me the bits that were important to her and so I included those in what I said (P7).*

Whether teachers can attend the funerals of children who have died is dependent on many factors. However, it is clear that they are able to find comfort in attending and feel a support to families when they do so. In contrast, when unable to attend, teachers often feel an extra sense of loss both for the child and for the families involved. In an attempt to combat this, many schools hold their own memorial services and have different ways of remembering children with the aim of supporting staff and students through a tremendously difficult time.

### **5.1.5 Remembering the Child**

As previously established, it is often logistically impossible to allow all staff who wish to go to a child's funeral the chance to attend. However, this does not mean that children and staff do not need the opportunity to come together and reflect on their loss. Many teachers interviewed discussed a range of ways that schools remember a child who has died which can be of enormous comfort to all involved.

One of the main ways schools remembered a child who had died was through a memorial assembly or service. Teachers spoke fondly of memorial services they had attended and acknowledged their importance in bringing the whole school together and involving the families wherever possible.

*We always have a little memorial assembly for them [...] we invite the family in after a while sort of a few months down the line when it's a bit less raw and then they have an assembly for them and...people talk about the child and we show videos and pictures and maybe sing a song they like...some families like it not all of them come but sometimes you get thirty, forty people turn up you know and it's really nice I think it is kind of closure cos not everybody can go to a funeral but everybody can go to that (P10).*

*As a whole school we have all the children all the er teachers who have taught the child over the years erm their bus guides, dinner ladies, whatever can say something about the child erm there'll be a PowerPoint with different photos on erm we'll sing songs that were the child's favourite or listen to music that the child responded to*



*things like that [...] just so erm...all of the children know that a child has passed away but it's a level that isn't too in depth (P16).*

The involvement of families within these memorial events was heavily dependent on their wishes and whether they wanted to be in attendance, however, schools made huge efforts to provide comfort and support to families. Often after the memorial services, schools would provide parents with the PowerPoints, photographs and videos used and compile a memory book for families to have from the school. It was also clear that families were not then simply cut off from the school. Many schools invited families back whenever they wished to talk about their child and to continue to be a part of the life of the school, particularly around the anniversary of the child's death. Some teachers also developed friendships with parents of children who had died and continued this long after the child's death.

*I still phone this little girl's parents who died in the Summer just to check how they're doing you know we had a memorial, a celebration assembly for them we very much continued to be part of their lives for as much and as long as they want us to be really (P14).*

Teachers appeared to be very conscious of handling the death of a child in a way that was sensitive and supportive to families. They felt this made a huge difference to parents at such a difficult time.

*If they can remember that actually everybody was really supportive, and it was done beautifully, and people did lovely things for you and to remember your child then that's going to make an enormous difference (P7).*

For schools where a number of student deaths had been experienced, annual remembrance events were sometimes held. These took the form of special assemblies or adding names to a prayer or Christmas tree. In the absence of annual events, many schools dedicated a special place within their grounds for a memorial. Again, these took many forms, for example, tree sculptures with the names of children who had died on their leaves, planting trees or flowers, a memory table or display or a dedicated quiet area of a sensory garden that was primarily for remembering children who had died.

*We have like a memorial garden and you know we have plaques for pupils and things like that so they're like part of our bereavement response (P6).*

*We've planted a cherry tree or a whole stash of daffodils or lots of different things erm you know sometimes I think it's nice to have some kind of place that is a place to remember children who've died (P7).*

In a similar way to how schools share the news of a student death, the ways in which they remember a child who has died has an enormous impact on teachers, children and families during an incredibly difficult time. Where student death is perceived to have been handled well, schools appear extremely supportive and prepared to involve everyone in the remembering of the child. Teachers in particular, remember when this is done well and find the memorial events held in school to be comforting and an important part of the school's bereavement response which in turn, helps them to deal with their loss.

#### **5.1.6 Grief and Bereavement Training**

Despite almost all of the teachers interviewed having experienced the death of a child, the number of teachers who had attended training sessions on grief and bereavement was low. Ironically, the teacher reporting having had the most bereavement training was yet to experience the death of a child. Regardless, they found the training to be useful in preparing them for the possibility of a student death and helped them to think about how they might best support those around them during a bereavement.

*We've been on some grief and bereavement training which has been really useful erm...in kind of not only sort of if they physically kind of pass away but the fact that the parents are dealing with the grief and bereavement of not having the child they thought they were gonna have that's kind of been the main learning thing [...] it's about how I can support [the staff] and not losing contact with the families (P3).*

Two other teachers reported receiving training in bereavement, but not specifically on how to deal with this bereavement as a teacher. One of the courses attended was on bereavement for pupils with SEND and the other involved working with children requiring palliative care. One school had provided inset training to staff with a specific focus on their bereavement policy.

It follows therefore that bereavement training was something that the majority of teachers in this study requested more of. One teacher felt that it would be useful given how often bereavements were experienced within their school.

*I think we could probably do some kind of training on bereavement cos I think it's something within a special school you encounter on a regular basis and so that would be useful I think you know especially for staff that have not dealt with that kind of thing before I think it's nice to know that you've got those support networks in place, who do you call when you need somebody, what kind of things could you do to support the other students and the staff so I do think some kind of training would be useful (P15).*

### **5.1.7 Impact of Student Death on Teaching**

When talking about their experiences of student death, teachers commonly discussed the impact these deaths had on their teaching outlook. Teachers often felt that experiencing a student death reinforced how fragile and precious life is and led them to care more deeply about the children in their class.

*Those circumstances really just reminded me that life is fragile [...] that nothing's a given that erm...not everybody gets to live to be old do they [...] I would say that it made me care a little deeper about what went on (P1).*

As such, some teachers described consciously providing comforting experiences to children who were nearing the end of life, ensuring that time was spent enjoying the company of others, resting, and creating a loving atmosphere for them.

*You kind of really want everything to be so lovely for her [...] we did have quite a lot of rest time that they needed and kind of just cuddles and they loved that and stories and I mean we do a lot of that anyway but I think we all kind of put a little bit more into making that nicer (P12).*

Many teachers also felt that experiencing a student death motivated them to make their lessons more fun and engaging. The realisation that children might not have long to live appeared to spur on teachers to ensure that children had a good time whilst at school and enjoyed their experiences as much as was possible given their illnesses, limitations of their condition and their medical needs.

*It does make you reflect on your practise...and I think you maybe think oh well let's make school as nice as possible you know as (...) yeah (...) as fun as possible (P11).*

This reflection was a common theme throughout many of the interview transcripts (see Chapter 9 for a more detailed discussion).

## **5.2 Medical Emergencies**

A further significant challenge identified by teachers interviewed was the occurrence of medical emergencies within the classroom. Due to the complexities of the medical conditions that many of the children discussed in this study are living with, various medical emergencies were described. These included prolonged tonic clonic seizures requiring emergency rescue medication, dangerously low oxygen levels, gastrostomy buttons that had fallen out and children who had stopped breathing. This section will discuss the procedures teachers employ during such medical emergencies and some of the challenges faced for example, making decisions, having responsibility and the impact on other students within the class. The role of the school nurses in medical emergencies will be touched upon briefly, however a more detailed discussion into the availability and impact of school nurses can be seen in Chapter Eight. The emotional impact of medical emergencies on teachers as well as the support available following an emergency will be discussed in Six and Seven.

### **5.2.1 Emergency Procedures**

Every teacher interviewed had experienced a medical emergency that required extensive intervention to ensure the safety of the child. In many cases these emergencies also required further medical input in the form of ambulance calls and hospital admissions. Each teacher expressed the challenge this posed in terms of constantly monitoring children for signs that they may need further medical input and the extra awareness they needed due to the risk of a medical emergency happening at any time.

*Students obviously can go downhill very rapidly in terms of their health so...yeah, it's difficult you have to keep an overall picture of what's going on (P1).*

Responses to medical emergencies varied depending on the child and the emergency. All teachers described having to follow a care plan that was written by medical professionals to ensure the child received the medical care they needed. Further variation in response also depended on whether teachers had access to school nurses on-site. Where school nurses were present on-site, usually the first port of call would be for teachers to call them via telephone, radio or emergency buzzer. In the absence of school nurses, many teachers would call upon SLT for support. Where school nurses were at a different site, teachers were able to telephone them for support. However, this was problematic in terms of being able to accurately describe what was going on and in gaining medical information and advice over the telephone when needed.

*You can ring them and speak to them but it's difficult isn't it if you're talking about whether somebody needs oxygen or not or do we need to up their oxygen or what do you think we should be doing at this point and then you're having to describe how somebody looks and erm and I think that can lead to inconsistencies that's the problem (P1).*

Some teachers described the need to call for additional support in medical emergencies and often talked about emergency buzzers as their 'life-lines' in such demanding situations. For one teacher however, in their current setting, the presence of an emergency buzzer caused an element of panic which they felt was unnecessary. From their previous experience this teacher felt the situation could be handled more calmly and as such disagreed with their school's emergency procedures:

*When we used to do it as a staff team in my old school anything that happened...by and large in most cases we just carried on with the teaching and a member of staff would go and get whatever was necessary [...] even emergency medication was given routinely, and you know it wasn't a big deal. Where I am now [...] you have to press the emergency buzzer you know and it's like all systems go and I'm like for goodness sake will everybody stop panicking (P7).*

Despite this disagreement the teacher quoted above did recognise that the SLT responsible for implementing the emergency buzzer procedure was doing so to

protect teachers and safeguard children given the seriousness of medical emergencies that required rescue medication or hospital admissions.

In some, less time sensitive situations teachers may decide to call parents to ask for advice first. In this way parents could avoid a visit to Accident and Emergency departments or dangerous side effects to rescue medication by collecting their child and monitoring them from home.

*Sometimes we phone parents depending on their request depending on erm what the issue is and then phone them and say [...] what do you want us to do you know do you want to come and get them do you want us to go to Accident and Emergency (P11).*

*If I'm not sure I will ring Mum because she would rather we didn't give Buccolam because it takes her two weeks to get over it so if I think she's having a funny five minutes I will get a second opinion and then we'll ring Mum if we're concerned (P12).*

A further part of the teachers' role may be to travel to hospital with the child in the ambulance, something that many had done on more than one occasion. It was during these times that teachers realised actually how well they knew the child and how much medical information they were able to pass on to paramedics and hospital doctors.

*Often when we go, and I have to go up to the hospital with the children because of emergency calls you know you realise when you're being able to pass on quite a lot of information you realise that actually...you know this child incredibly well you know what their seizures look like you know what their oxygen levels are (P14).*

However, despite this realisation, these times also involved a great deal of stress for teachers who doubted themselves and worried about the care that children received based on the medical information they had given:

*You get to the hospital and they're firing questions at you and then you have to think on your feet and then you're like, but did I say the right thing, if I didn't say the right thing is that gonna have led to something that they do which they shouldn't do or something that they don't do that they should have done. There's a lot of pressure basically (P2).*

Following a hospital admission, many teachers expressed the need to follow up with parents to check that the child was recovering well. This was often in the form of a telephone call or hospital visit. If children had been discharged from hospital some teachers would also go and visit them at home.

*If a child is really poorly, I'll go and see them in hospital in my own time (P13).*

However, one teacher discussed an issue this caused between themselves and their headteacher because of the dangers of becoming overly, emotionally attached to the child. The teacher did not believe this to be the case and felt that avoiding an emotional attachment was impossible due to the nature of the child's illness, the possibility that the child could die at any time and the need to provide all aspects of care whilst at school.

*I used to go and visit her in hospital and my previous head had said that she felt I was becoming too emotionally attached to this little girl and I really struggled with that, but how can you not be you know you're teaching her, you're holding her and you're thinking this is going to be the last time I hold this little girl, I listened to what they said but I still chose to go and visit cos I felt actually this little girl her parents weren't able to go and visit her and I just couldn't bear the thought of her being in hospital alone and this is my own time (P14).*

Overall teachers find medical emergency situations very strange situations to be involved in because of the fact they are caring for somebody else's child, yet their knowledge and care for the child is profound. Others continue to acknowledge that they are involved in regular medical emergency situations yet receive relatively little medical training in order deal with such situations as part of their daily practice.

### **5.2.2 Training**

Every teacher interviewed in this study had had some medical training provided for them by a healthcare professional. In most cases this was the school nurse. However, some specialist training providers were brought into schools for complex medical interventions such as changing a tracheostomy or using a Vagus Nerve Stimulator. General training was provided for common medical conditions and interventions such as epilepsy, asthma and administering medication. Other medical training appeared to be tailored to the needs of the class at the time.

*Obviously if you have a child with like an Epi-pen or oxygen or diabetes or something [...] the class that you're in all that team would have that training (P11).*

Teachers reported that training for medical interventions and emergencies was revisited frequently, often at the beginning of a school year. This yearly training was what some teachers called 'the basic stuff' such as tube feeding and administering emergency medication. As well general training, teachers reported undergoing child-specific training which required them to be 'signed off' as competent in performing the intervention by a school nurse. This was a requirement for the majority of staff within a class team including teaching assistants whose roles dictated they perform such interventions.

*So, the nurses would as part of our training they would demonstrate how to do it and they had to watch us do it ourselves erm I think it was three times before they would sign us off to say that we were able to do it (P17).*

Child-specific training in addition to the regular basic medical training ensured that staff felt comfortable and confident with the medical procedures they needed to carry out.

*I'm confident in how to administer Buccal for example I've never had to do it, but I understand the procedure we've had a lot of training on that (P1).*

The majority of teachers reported that training for the medical needs of their classes was very good and they were well-informed. Teachers appreciated having a general overview of their students and knowing what to do in a medical emergency. Ensuring that more than one person was trained for a specific medical need also guaranteed appropriate medical cover at all times, including in the community.

*I don't like it that one person is responsible for that because what if they're off and then it becomes a hassle erm sometimes that person might need to go to the toilet or something just at that moment when you need so we would all be trained up I'd insist on everybody in the class being trained up (P5).*

Teachers also felt they could request extra medical training from school nurses if needed. This might be if a new child joined their class or if they were working with



a child during an intervention group or lunchtime club. Having access to this training in-house from school nurses was a big advantage for many.

*I think we are lucky because we've got the nurses who can do the training relatively easily so erm yeah if we have new staff we just have to get them trained rather than having to arrange for somebody to come in, it doesn't apply for the tracheostomy training though but you know the sort of regular oral suctioning, Buccal Midazolam all that kind of stuff we can just do the training in-house (P6).*

On the other hand, despite an acknowledgement that child-specific training was necessary, some teachers found it to be tedious, especially when there were a large proportion of children in the school or class with the same medical needs.

*[The school nurse] needs to teach and observe everyone a minimum of three times before signing them off for each individual thing erm so obviously you've got one child who has a bolus a kind of the push and the pump and meds and you know making up the feeds as well there's quite a lot of different things that need to be signed off just for one person so we've got I think about 90 out of the 100 [students] that have those kind of needs to some extent that need to be trained (P12).*

As a result, some teachers found child-specific training to be incredibly time-consuming, especially at the beginning of an academic year when new students and staff enter the classroom. Nurses were also found to be struggling to ensure that everyone was trained given the time constraints of the school day, the routines of each child and levels of child non-attendance. This resulted in some classes only having one or two members of staff trained which impacted on staff/student groupings as well as some school activities.

*Well until recently we only had kind of two staff trained for each child, so it almost dictated who could do what to a certain extent [...] I think she was struggling to train everybody and to do everything else really cos that's only a really small part of her job (P12).*

*I've had some of the tracheostomy training but at the moment I can't actually do that, so I can't be on my own with him (P6).*

Teachers appeared to be satisfied with the level of medical training that was in place for them to meet the needs of the children in their classes. Some reported being well-informed about a range of medical needs and most appeared confident in performing routine medical interventions as well as the administration of emergency rescue medication, oxygen and suctioning.

### 5.2.3 Making Decisions

When dealing with a medical emergency one of the biggest challenges for teachers was making quick and accurate medical decisions that might influence the care a child received. Some teachers struggled with the responsibility of making these decisions, particularly given the lack of medical training they had received.

*It's not that I can't do it but...the nurse might walk in and take one look at somebody and say right we need to do this whereas I you know I'm still working through in my brain what the options are erm I'm not a trained I'm not trained as a nurse (P1).*

Other teachers felt they were best placed to make such medical decisions given how well they knew the child when compared with school nurses who perhaps did not know the child's individual seizure activity and warning signs as well. This discrepancy in depth of individual knowledge between nursing staff and teachers posed a challenge for one teacher who described having to accept a child being taken to hospital when they knew that it was not necessarily needed.

*The problem [with nurses] is that I find as a teacher that they don't actually know the child that well so you do end up making decisions that...leave you a little bit out there I think [...] because I know there's one boy I know him really well I know...that...when he's having a seizure and when he's not having a seizure however when he's not having a seizure there's also a chance he is having a seizure because there are other things going on so I'm fairly certain but I can't be 100% I'm not a doctor [...] so you end up making decisions [...] the other day I came back into class and there were all these people in here healthcare assistants, the nurse who was actually here erm...and they'd called for an ambulance and I was like oh you've called an ambulance he looks alright to me [laughs] and the ambulance came and once they're there they made the decision and so they took him and I went with him and during that whole situation I was like I know that he's ok (P2).*

Some teachers discussed their concerns with having to make medical decisions during emergencies, especially with very little medical training. Many talked about second guessing themselves following an emergency which impacted on their emotional wellbeing (see Chapter 6 for a further discussion).

*I think inevitably you do think did I make the right decision should I have, it's often around the administration of Buccal Midazolam stuff like that should I have done that you know (P6).*

The need to make such medical decisions in emergency situations appeared to depend on teachers' perceived levels of responsibility during these times. The presence of a school nurse, SLT and other medical professionals appeared to determine who had overall responsibility within the classroom during an emergency.

#### **5.2.4 Responsibility**

Many of the teachers interviewed discussed the need for heightened awareness at all times due the possibility of a child deteriorating quickly and unexpectedly. In addition, all teachers identified the fact that a medical emergency could happen at any time which could potentially end the life of a child within their class. Given this possibility, many teachers discussed their feelings of responsibility during emergency situations. For some, the responsibility for the medical care of the children in their class lay with them, for others they felt the school nurses, where present, had overall responsibility. This is important given the availability of school nurses within the sample (see Chapter 8).

Some teachers appeared to deal with these feelings of responsibility better than others. One teacher discussed the need to take risks in order to provide opportunities for children regardless of their level of medical need, however, in doing so they were acutely aware of being thorough in ensuring they had everything they needed in case of a medical emergency whilst in the community.

*We do do some risky things with the students it's never stopped me erm taking risks in the sense that we go out of the environment [...] you reduce risks don't you if you know that things were brewing we have not sent students out because there's been seizure activity going on [...] the other side of that is I'm quite particular about*

*checking and double checking that we've got what we need before we go you know that we make sure that everything is in place (P1).*

Despite this, the teacher quoted above did acknowledge their constant awareness that something could go wrong and that the children in their care could become dangerously ill very quickly. One way they attempted to overcome and account for this awareness was in ensuring safeguards were in place, procedures were followed, and staff were directed where needed.

For other teachers, the feeling of being responsible for children with such complex medical needs was overwhelming and led one teacher to consider whether they were prepared to deal with this responsibility anymore.

*I have some very poorly children erm, so it is a massive, massive responsibility and there are times when I just think actually I don't know if I want this responsibility anymore cos it's a lot you know especially when you've got kids that are being taken to hospital [...] sometimes there are days when I think I don't want to do it anymore (P15).*

Some teachers reported that they did not think about their levels of responsibility on a daily basis, perhaps for self-preservation purposes given the significance of the above teacher's feelings regarding their responsibilities within their classroom.

*I've never really thought about it to be honest because that's just what you do you're there you know the children have got medical problems and as long as you know the routine that you have to follow it's just part of the job [...] if you thought about it too much you'd get really scared (P16).*

*Yes, it's a massive responsibility but I kind of don't really think about it I kind of sort of get on with it (P18).*

The presence of school nurses could help to alleviate these overpowering feelings of responsibility. Teachers who were able to call upon school nurses in a medical emergency were more likely to attribute overall responsibility to the nurses as soon as they arrived. This was reassuring for teachers as they were able to allow the nurses to make some of the more difficult medical decisions.

*I might be the only teacher on-site but it's fine because there's the nurses so actually when it comes to the scary decisions to make are the medical ones and they make those (P3).*

*When things are getting a bit too scary, I know the nurses are there to support (P14).*

Another consideration depended on teachers' level of training. Some teachers highlighted that they were unable to be trained to meet certain levels of medical need. For example, in one school only SLT were allowed to give rescue medication, in another, teachers were not allowed to be trained to deal with tracheostomies. These decisions were made by school nurses and SLT and were in place usually to ensure the safety of both teachers and children. In these situations, teachers did not deem themselves to have overall responsibility for the medical needs of their students. However, this posed a significant challenge given the perceived duty of care teachers have. One teacher stated that they would intervene medically in the absence of nurses in an emergency:

*We're not trained but if for some reason the nurses didn't come, and the child's heart had stopped I wouldn't stand and watch them die I would do something and take the consequences later [...] which would be worse you know being told off for having done something or being told off for not having done something (P10).*

Another teacher also highlighted the challenge of having overall responsibility for their children yet not having the adequate training to be able to meet their care needs.

*Yeah, it's my responsibility I guess to make sure that it all happens and that it's all done it is a bit of a weird one because obviously when I wasn't signed off for certain children I knew what the plans were and the meds and things that had to be done but I wasn't able to do it so I did feel quite weird about having that responsibility but not actually being able to carry it out (P12).*

This is a dilemma faced by a number of teachers when comparing their duty of care to their level of medical training to meet the very complex medical needs of this group of children.

### 5.2.5 Impact on Other Children

Due to the varying procedures involved in dealing with medical emergencies, differences were also found in how far these emergencies impacted on the other children within the class. Teachers described two main scenarios; the first that they would try to maintain the learning of others at the same time as managing the medical emergency, and the second, that due to the nature of the emergency and the number of people required to ensure the safety of the child, the learning of others would stop, and the rest of the class would need to be removed.

One of the main factors in determining whether learning could continue for a class during a medical emergency, depended on their cognitive abilities. One teacher described a class who, due to their low cognitive abilities and therefore their lack of understanding of others, did not seem aware of a medical emergency taking place and thus learning sessions could continue.

*Lessons will carry on for the rest of the class I think because we've got sort of the ability level that we've got the children's cognition is not as high...they don't tend to fuss about someone else not being well (P10).*

The same teacher also described a previous scenario where more able children were more aware of what was happening and therefore, to prevent interruptions to learning, screens were put up around the poorly child or the class needed to be moved elsewhere.

*I think last year when I had the class who were slightly more able...and they were more aware of you know if somebody wasn't very well you tended to sort of maybe put one of the screens up or something, just so children weren't constantly just like oh so and so is not feeling very well at the moment and then we'd just carry on (P10).*

In other emergency situations the learning of others had to stop so that staff were able to deal with the emergency safely. This scenario appeared to happen more when school nurses were not on-site, perhaps demonstrating the impact of not having access to a school nurse on the learning of others.

*Well then everything just stops, and the emergency takes place and usually if it's an emergency requiring an ambulance then normally my TAs take the rest of the*

*children well my room's not that big but the other end of the room and then whatever has to happen just has to happen in the other corner (P4).*

For other children, particularly those sharing classes with the most vulnerable of children, medical emergencies have become part of their routine and they have become used to interruptions to their learning.

*They're very used to it sadly (P13).*

*I mean it amazes me how [...] generally when something goes on the rest of them all just sort themselves out and you're like oh that's great thank you as if they know (P3).*

For some teachers, there seemed to have been a culture change within schools in how medical emergencies were dealt with, possibly due to the increase in such emergencies within special education classrooms. Whereas previously, everything would stop, and all of the class staff would be involved in the care of the child. Now teachers are describing efforts to deal with the emergency quietly whilst maintaining the learning of others. This may be due to a school-wide change in emergency procedure approach, levels of teacher experience and confidence, or just an acknowledgement that if everything stopped every time a child had a seizure then children would not have access to a high-quality education because of the frequency of such events.

*I think again in the past there was a bit of a culture that if a child had a seizure everything stopped and erm you know like you'd have four members of staff over there with the child [...] we're now much better I think at you know whoever's working with the child will deal with that child and a second person will call the nursing team if that's appropriate or will go and collect the meds from the medical box [...] we try and maintain the learning for the rest of the children because you know the kids are so complex if everything stopped every time a child had seizure you wouldn't get anything done (P8).*

In summary, teachers have to deal with a variety of medical emergencies regularly within special education classrooms. All teachers discussed the need to follow emergency care plans and procedures during these times which helped them to ensure the child received the appropriate level of medical care in a timely manner. Teachers also discussed the need for an individual response to each emergency

depending on the child, the emergency and the wider situation. This meant that teachers had to be prepared to make vital medical decisions sometimes in the absence of school nurses and with limited medical training. There were differences in how medical emergencies were managed within the classroom in terms of the learning of other children. Some teachers tried hard to maintain the learning of the other children by dealing with the emergency quietly or by removing the child or the class, whereas others described situations where the whole class would stop until the medical emergency was under control.

### **5.3 Communicating with Parents and Professionals**

Communicating with parents and professionals was also found to be challenging for teachers of children with life-limiting conditions in special schools. Specifically, many teachers identified building relationships as a particular challenge when communicating with parents, as was gaining medical information. When communicating with professionals many teachers felt that challenges lay in having access to the right professional at the right time as well as ensuring that multi-agency working was effective for all involved.

#### **5.3.1 Communicating with Parents**

Communicating with parents was found to be a huge part of the teaching role, especially when caring for children with life-limiting conditions. However, forming these relationships was highlighted as problematic given that many of the children who attend special schools come to school on local authority transport. As such, special school teachers do not have access to the traditional, daily parent/teacher contact at the school gates and must therefore work harder to build positive relationships with parents.

*You don't find that you get to know the parents cos all our children come in on buses so it's not the same as mainstream where you see everybody every day [...] we don't really have that (P10).*

Within the data, similarities were found in that many teachers tried hard to form strong relationships with parents, yet these relationships were often variable. Teachers consistently found that parents were split into two groups; those who wanted to relay everything to school and were incredibly involved in their child's



education, and those who did not want to communicate or participate with school. Both groups posed challenges for teachers. For the former, teachers were given a wealth of information by proactive parents and were often contacted by them for regular, lengthy periods of time during the school day. For the latter, teachers found huge challenges in terms of gaining information needed about their child.

*Some parents are very private and don't particularly want that interaction and other parents will tell you everything you need to know and more and personally I prefer that type of parent who will tell me everything I need to know and more because then I can filter what I think I need [...] some parents don't tell us anything about the wellbeing of their children erm they arrive at school and they just arrive, and they might be tired or clearly not 100% but we don't have any idea why (P1).*

Variations in teacher/parent relationships were not found to be dependent on the needs of the child, with some parents of children with very complex medical needs not wanting to be involved in their child's schooling. However, some teachers did identify differences in the teacher/parent relationship depending on how old the child was. For example, teachers expressed that parents of older children were more difficult to engage than parents of younger children. This was perceived to be due to parents of younger children struggling to let someone else care for their child. For parents of older children, teachers felt that they were less engaged with education but felt this was similar to what would happen with typically developing children in mainstream education more generally.

*I think those with older children I didn't see the parents as much I think yeah erm...I'll see the parents you know when you expect to see the parents, they'll be here but with the younger children they are just starting off with their school career, parents find it quite hard letting go so we still have parents now who are still coming in everyday with their child and are reluctant to leave their child in someone else's care (P18).*

*It's a bit hit and miss they tend to start very engaged in the early years erm and as the children get older and older, they become less and less engaged in their education and erm I think that's kind of a natural process anyway which happens with typically developing children (P8).*

Despite these variable relationships, teachers continued to try to form relationships through a variety of means. Some teachers discussed speaking to parents on the telephone if they had worries or concerns, commencing parent mornings so that parents were invited into school regularly, as well as teacher home visits. Furthermore, almost all teachers discussed the use of the home school book as vital for sharing information about appointments, events in the school day and medical information such as seizure, food and toileting logs. Despite the perceived importance of home school books, parental use of these books was again, variable.

*Some parents they read it and you get messages about something they've done that week or a hospital appointment just keeping you up-to-date and then there's other people who obviously never look at it and the only contact you get is if there's something to complain about (P10).*

Teachers valued the importance of trying to form strong relationships with parents for a number of reasons. Perhaps, quite simply, teachers felt that having relationships with families ensured they could make their teaching relevant and meaningful for the child. For example, when speaking to the child about particular family members, or by sharing news with family and classmates. Others felt that forming strong relationships with parents helped them to offer emotional support if needed, as well as the building of trust which was seen to be crucial when caring for children with life-limiting conditions.

*I feel my door's always open for parents to be in the class [...] it's a huge trust thing for them to hand their child over with such complex needs (P13).*

In addition, teachers felt that having strong relationships with parents also gave them a better understanding of the bigger picture surrounding the child and the demands that were placed on parents. This enabled them to offer targeted support where necessary, something perceived to be a large part of the teaching role. Teachers found that parents often needed emotional support, particularly if their child was having a difficult time health-wise. Despite the lengthy periods of time this may have taken, teachers saw the importance of supporting parents through such challenging periods.

*I used to have one Mum that used to phone me every day and just to say that she'd had a really bad night and she was having a really bad morning and sometimes you know she'd be on the phone for 20 minutes [...] it's difficult sometimes because you really don't need that 20 minutes sometimes at the beginning of the day when you're trying to set up but if it means that they've calmed down and they're not so upset or angry then you feel like you've done something good for the day (P15).*

Listening to parents appeared to be a huge part of the emotional support offered by teachers. Teachers were often best placed to give this emotional support due to their understanding of what parents were going through. Parents were able to vent their frustrations and concerns without having to explain themselves due to teachers' in-depth knowledge of the child. This posed challenges for teachers however, who often found themselves subject to angry or frustrated parents.

*You know I think we're probably one of the few people who know their children as well as they do I don't think there are many other people that would know their child as well as we do and so sometimes we can be on the rough end of like their frustration with the system with the frustration of like you know doctors or not equipment being provided [...] actually you know my child as well as I do so you know I might just have to rant at you (P14).*

Emotional support is also offered to parents through the facilitation of peer support networks. For some teachers, setting up parent coffee mornings was of vital importance to ensure that parents were able to support one another. Being able to meet with other parents may also alleviate some of the isolation that those with children with life-limiting conditions can experience.

*I want to start with parent mornings in school as well and just try and get them networks with each other I mean it's one thing talking to me about stuff but if they can get more like peer support from other parents, I think that's really important (P3).*

Despite these attempts at forming strong relationships and offerings of emotional support, some teachers experienced barriers to communication with parents. Most commonly these barriers involved parents whose first language was not English. One teacher identified this area as a priority in terms of the professional development of themselves and their staff and discussed the need to continue to try to form relationships even if it seemed like they were not getting anything back.

*That's the kind of thing that I've found...most challenging [...] I suppose just because someone can't communicate with you doesn't mean that they don't want to communicate with you I think is the key thing...and you still need to give people the opportunity in fact it's even more important that that opportunity is made (P1).*

Additionally, gaining the correct medical information from parents can be a huge challenge for teachers. This can be made more difficult by parents with English as an additional language as the following quote illustrates:

*Working with parents where English can be a barrier or culture can be a barrier sometimes, we try to check in terms of making sure the medication is right and they're trying to track down where things might be going wrong you know there's a feed being missed here a medication being missed there so that can be quite tricky (P3).*

However, difficulties and miscommunication when discussing vital medical information were found even when English was not an additional language. Parents of children with life-limiting conditions have to attend many medical appointments and much of the information discussed also needs sharing with schools. This can provide a challenge as some of the medical information can be forgotten or misunderstood by parents which can prove confusing and upsetting for teachers.

*I mean one pupil was going to have a spinal rod operation and he had really severe scoliosis and was really quite unwell erm and the parents had been told something which they'd understood from the conversation they'd had with the consultant that there was something like a 5% chance that the operation would be successful erm, but it turned out that was incorrect but you know that was very upsetting on a personal level (P6).*

Some schools have attempted to overcome this issue by developing the role of family link workers who could attend medical appointments with parents if there were concerns. Family link workers were found to help parents understand what was said but also accurately feedback to the class teacher any outcomes or changes to medical regimens that were needed. However, communication with medical professionals in this manner is not always so simple and can also cause challenges for teachers.

### 5.3.2 Communicating with Professionals

Communicating with professionals including medical professionals and social workers is another huge part of the teaching role within special schools. This section will refer to communication with professionals outside of the school building (see Chapter 8 regarding medical professionals in school).

When discussing communication with other professionals, one of the major challenges highlighted was ensuring that parents and children had access to appropriate services when needed. This was a source of frustration for teachers who wanted to help parents with practical equipment such as wheelchairs but who were met with services that were struggling and unable to adequately meet demand.

*Trying to get appropriate wheelchairs can be a nightmare. I've had one of the boys this year and they sent him out of clinic with a chair that was [...] he didn't fit [...] he was arching his arms back and getting bruises and I rang and I was like it's not right and they were like oh no there's nothing we can do and I was like no we can't it's a child that can't communicate who's really poorly and it's not acceptable being in his chair that doesn't fit (P3).*

*Dealing with social workers can be a problem sometimes erm, not having one is often a very good problem, getting one that is not very good is often a problem (P3).*

One teacher highlighted the fact that these children were often saved at birth and then left without the adequate support or services to access equipment, resources and information needed as they grew older.

*I do find it difficult that parents have to fight for everything for these children, so the baby is born profoundly disabled, somebody's saved a baby at birth which is lovely but then there isn't the infrastructure in society to support that baby and so parents are left with this massive fight you know fight to get into a school like this or fight for this and fight for that to get equipment (P13).*

Teachers acknowledged that there were a huge number of professionals involved in the care of children with life-limiting conditions and some outlined positive experiences in terms of EHCP meetings which enabled all professionals to come together and share information. Some teachers valued the historical knowledge this gave them which enabled them to build a bigger picture surrounding the child.

However, there were some teachers who found that this information was not shared as freely as they would have liked, or as freely as they had experienced in the past which again was a source of frustration.

*I find it frustrating because there's a lot of stuff I know about medical stuff but where I am now [...] they don't share the information with our staff [...] I used to know everything that was known about the child (P7).*

Despite these challenges, there was evidence of positive communication with a range of professionals. At schools that were predominantly for children with complex medical needs positive links were made with children's hospices and a range of medical services were on-site or close at hand, so referrals could be made quickly. Some teachers spent long periods of time discussing medications with school nurses or consultants to ensure that the children in their care were getting the best possible outcome. This was felt to be of importance given the difficulties children have in communicating if they feel unwell or are experiencing side effects to their medication.

*Sometimes it really helps to be able to talk with consultants erm about things directly you know she will talk to the teachers if you've got queries and questions [...] I think particularly of the difficulty our pupils have in communicating it's often hard for medics to know what effect their medications are having erm and maybe recognising the side effects that you feel it's causing (P6).*

Overall, teachers felt that communicating with parents and a range of professionals was a vital part of their teaching role and many tried hard to form strong relationships with all involved. However, challenges were faced when forming relationships with parents and in terms of gaining accurate medical information when needed. Additional challenges were faced in ensuring that parents had timely access to essential resources and equipment. Where other services were deemed to be lacking, this was a source of frustration for teachers.

#### **5.4 Curriculum and Assessment Pressures**

Moving away from the medical side of the role, similarities and differences were identified in terms of the curriculum and assessment pressures cited by teachers as a particular challenge within the teaching aspect of their role. These pressures were

found to be within three specific areas; the curriculum used, the setting of targets and the demonstration of progress.

#### **5.4.1 The Curriculum Used**

Participants in this study discussed a range of curriculum approaches used within their schools, with some still required to teach the National Curriculum whilst others were at various stages of the process of redeveloping and creating their own curricula.

Of those who were still required to teach to the National Curriculum, issues were raised around the appropriateness for children with PMLD. Many discussed the relevance of subjects such as History, Geography and Modern Foreign Languages for children who are working at the earliest levels of development. In particular, participants questioned the abstract nature of the topics that they had to teach and the struggles they had in making these abstract concepts relevant to their children.

*I'm not a great fan of the National Curriculum for those children [...] I just don't think for those children at our school I don't think it's appropriate (P16).*

One participant could see the relevance of the National Curriculum for more able children with SEND, who may go on to achieve national qualifications. However, for children with life-limiting conditions, the focus on a curriculum that prepares children for examinations and a future independent life in society was not deemed to be the priority:

*Personally, I get hung up a bit on people forcing these students into a National Curriculum when they don't fit it...these students are not about to do GCSEs [...] I don't see the need for it, it should be about making their life more comfortable and worthwhile (P5).*

This 'forcing' of children into a National Curriculum that is not fit for purpose nor relevant to a child's immediate needs, was a source of frustration for some teachers who were still required by their schools to teach to its guidelines. The following quote illustrates this frustration and adds weight to the argument that subjects within the National Curriculum are too abstract for the needs of this group of learners and therefore require considerable adaptation.

*I'm currently working in a school where I don't agree with the curriculum the children are doing [...] we still have to do Modern Foreign Language, Geography, History and I'm like for heaven's sake History is what have we just done, Geography is where do I have to go for swimming and I'm sick of playing games (P7).*

This frustration was attributed to a discrepancy in what teachers thought best for their students and what they were directed to teach by SLT. Indeed, many discussed life-skill and communication elements of the curriculum to be of utmost importance in addition to providing a breadth and depth of experience. This was in contrast to the subject-specific nature of the curriculum that was required to be taught within their schools (see Chapter 9 for a further discussion).

*I think we try and fit a lot of work in er to meet the needs of the National Curriculum and erm my feeling is that sometimes we could modify it a little bit I want the students to have breadth and depth of experience [...] it's important that the children are exposed to different cultures like we do French er but to me it's not important that they do it every week but er that's not what I'm directed to do [...] but I'm not in charge so erm...yeah that's something that I find difficult (P1).*

*I'm still governed by you know things that I have to teach and things that I have to do so [...] I still have to do things on my curriculum and I still have to make sure those targets are met for you know management all those kinds of things (P15).*

This discrepancy and its associated frustration between what teachers perceive as important to teach within their classroom and what they are directed to teach was even described in terms of an element of 'conflict' between teacher and SLT, particularly when the teacher placed greater emphasis on life-skills elements within their daily practice.

*School expects you to work on your core business which in some schools is your Maths and your English [...] so that can lead to conflict not conflict, but you know you might have sensitive discussions around erm your curriculum and stuff like that (P5).*

Despite these discrepancies and frustrations, some teachers described SLT who were more open to the idea of changing the curriculum to meet the unique needs of children with life-limiting conditions, with some currently involved in the re-writing of their school's curricula. One important consideration however is the expertise



and knowledge of the headteacher in such situations. Different headteachers bring varying levels of skill and experience to their leadership roles. Those that do not come from a PMLD background possibly lack the knowledge needed to produce a rich and varied curriculum for those children. The following quote provides an example of this situation. Here, the participant describes a headteacher that, although experienced, does not have a comprehensive knowledge of the learning needs of children with PMLD and has therefore adopted a spirit of teamwork and cooperation amongst staff with the necessary strengths in this area.

*We are really trying to push for something different our Head is very experienced and she is very relaxed in that she'll let you do what you know is right because she trusts you to know your students...but her kind of background is more ASD than PMLD and she'll say oh I don't really know what to do with these students you know what you're doing so I think she'll go on our recommendations (P12).*

Indeed, participants throughout the interviews perceived the ability to change curricula and move away from a National Curriculum that is inappropriate for children with life-limiting conditions lying with SLT and specifically the headteacher. Those headteachers that were reluctant to change and move away from the National Curriculum were seen more negatively, particularly due to the current movement towards curriculum change within PMLD research and practice.

*I think a lot of it actually is to do with the headteacher because when you go to all the current conferences about PMLD and the 21<sup>st</sup> Century curriculum [...] I think there's a general agreement amongst a lot of people that your priorities for PMLD are communication, physical development, PSHCE and erm what have I left out oh cognitive (P7).*

This suggests that teachers do recognise the need for change and are seeing the beginnings of this change in the wider educational environment, particularly when it comes to the curriculum and what children with life-limiting conditions should be taught. Whereas previously teachers may have directed their frustrations at the Government or Ofsted, instead, in line with the current political climate, teachers are recognising the ability of schools to change what they teach, but place accountability for making this change firmly with the headteacher.

*I know people who've changed their curriculum and Ofsted have been quite happy (P7).*

A further criticism of the National Curriculum identified by participants and a further reason why schools were pushing for curriculum change stemmed from the inability to demonstrate the smallest levels of progress. Many teachers felt that the National Curriculum did not provide opportunities for students to make and demonstrate their own individual steps of progress. This was perceived to be partly due to the abstract nature of the subject-specific content that children working at the lowest developmental levels were unable to understand (see section 5.4.2).

*I mean we are as PMLD teachers in the process of re-evaluating our curriculum [...] we need something a bit more...I think that has the breadth in because there is still places where they're not going to move (P12).*

*We're kind of at a crossroads at the moment [...] we're trying to develop ways that we can actually show those tiny steps of progress (P15).*

Of the schools that had developed their own curricula, elements were drawn from a variety of existing programmes. It appears that schools have been able to use different aspects of programmes that work for the individual needs of their students to create a curriculum that provides breadth and depth in addition to life-skills and therapeutic elements. Therefore, schools may not need to spend a huge amount of time and resources in developing a completely new curriculum for their students. Instead, adaptations to and the collation of existing programmes can provide the basis of a broad and relevant curriculum for children with life-limiting conditions.

*We've taken MOVE we've taken stuff from play kind of play research, intensive interaction erm stuff about daily routines things about communicating (P3).*

One of the main considerations for those who had been involved in the creation of a new curriculum was in ensuring the emphasis of the curriculum was kept on the needs of the child.

*The children are at the centre of all of it we talk about the curriculum we talk about adapting the National Curriculum to be honest the children are the curriculum (P9).*

This emphasis was highlighted as a continual process, particularly as the needs of this group of learners are individual and unique. As the following quote illustrates, what may work for one class, may not work for the next. What is an important skill for one student, may not be needed by another. Teachers therefore need to have the flexibility and freedom to adapt their curriculum to suit the individual and changing needs of their students from term-to-term and year-to-year. This flexibility and freedom must be provided by SLT to ensure that teachers are able to offer the best and most relevant educational experiences for their students.

*All I do is kind of balance everything and I look at the student and last year I had three students who needed the more of the physical and emotional erm and the experiential side of life so...I adapted my curriculum to suit that (P5).*

In addition to adapting the curriculum, an important consideration for teachers was the functional benefit of what they taught. Teachers of children with life-limiting conditions are best placed to identify their immediate but also future needs. They are aware of what each child is capable of and what they most need to live as independently as possible. For some children, independence may involve participation in supported living, whereas for those who need round the clock care, it may involve being able to demonstrate preferences or show anticipation of care routines. Teachers therefore highlighted the importance of functionality in curriculum design.

*I don't disregard the Maths and the Literacy side of it I do it where it has a function so we look at and an example was there if we go shopping it's about looking after their money and erm sign vocabulary and recognition things like that [...] if you take the National Curriculum I can do everything like that erm but do it in a more functional beneficial way really (P5).*

Looking at the curriculum from the perspective of whether it meets the changing and unique needs of children with life-limiting conditions, in addition to whether it provides any functional benefit, highlights the inadequacies of the National Curriculum which aims to provide educational experiences for all children regardless of need. It is clear from the views of teachers that the National Curriculum is not their preferred curriculum model and that the 'forcing' of these

children into a model that does not fit is a huge source of frustration and is particularly challenging for teachers within their daily practice.

#### **5.4.2 The Setting of Targets and Demonstration of Progress**

One of the main aims of education for any child is to set a range of targets which both students and teachers work towards in order to demonstrate progress. Yet for children with life-limiting conditions, teachers face a number of issues and challenges when setting targets and showing progress. For typically developing children educated in mainstream, there will be a logical line of progress and development that teachers can follow to create targets. Indeed, it can be easily decided that because a child has mastered a specific skill, they can logically move on to the next. For children with life-limiting conditions however, there are a number of different factors that might interrupt this line of development and therefore make the setting of targets and demonstration of progress incredibly problematic.

One of the main challenges faced by teachers was the impact of the child's medical condition on target setting and progress monitoring. As previously alluded, typically developing children may follow a set trajectory throughout their education, yet for children with life-limiting conditions this trajectory can be spiky and, in some cases, regresses. For example, students who have degenerative conditions are unable to achieve logical next step targets and thus make linear progression, as the following quote illustrates:

*It might be that that skill isn't appropriate anymore because they've lost...their vision totally or because they've got more seizure activity going on or whatever, so we need to think about what a meaningful next step for this young person is, so we can be very child-centred (P13).*

Indeed, regression due to epilepsy and increased seizure activity was highlighted by a number of participants as detrimental to the ability of children to make progress, especially where a deterioration in their seizure control had led to a loss of cognitive and physical skills.

*Some students whose conditions particularly around epilepsy where their progress has slowed, their academic attainment has slowed and in some ways regressed because*

*their condition's changed [...] so they might have lost motor control for example [...] or their ability to communicate has changed so they have lost speech erm they've lost the ability to get up and go and pick things up that they want for example or to take part in activities that they want to take part in, things that we know in the past that they've enjoyed they've not been able to do (P1).*

In addition, a child's attendance and participation within educational sessions was highlighted as a challenge when demonstrating progress. For many of these children, particularly when approaching end of life, specialist respite care or hospital admissions can impact on attendance. Furthermore, when they attend school, their engagement with their learning may be further hampered due to periods of time asleep or participating in medical care routines.

*Some days they might just need to sleep all day, some days there'll have so many seizures their attendance isn't going to be as good (P3).*

It thus follows that careful consideration needs to be given to the setting of targets to ensure that they are achievable and demonstrate progress, however small. One-way this was approached was to adjust expectations to create maintenance targets whereby being able to maintain a skill already acquired is seen as progress for children with deteriorating conditions.

*I think we've come to a point now where we've you know Mum's quite accepting and the whole school is quite accepting that a maintenance target is appropriate [...] that's taken the pressure off the class teacher erm and the staff in the class trying to you know demonstrate something that isn't necessarily going to happen (P8).*

*They can make progress against themselves so [...] they may not make progress conventionally as in they don't work in a linear way, we can't expect a child to go from this to this but actually being able to maintain a skill could be progress for a child who has got a degenerative illness (P13).*

An important factor in overcoming this challenge was reported to be the expectations of SLT in the amount of progress these children were required to make. Many teachers reported that SLT were understanding of the challenges that demonstrating progress poses for teachers when working with children with life-limiting conditions and had adjusted their expectations accordingly.

*I mean the Head and things they're aware that you know we have so many seizures it's knocking them back all the time and then they have to kind of maintain where they are but erm they do recognise that maintaining where they are is actually progress given some of the health needs that individuals have (P12).*

Realistic expectations from SLT in this way appeared to alleviate some of the challenges and frustrations with the system, with many teachers reporting that due to realistic expectations they were no longer stressed by having to demonstrate progress that might not exist.

*I think we're really lucky our school is really understanding of how these things impact on the children [...] I think from the point of view of their expectations of us achieving academically with them yeah, they're very understanding (P10).*

*I think there's a reality as well of [...] throughout the day if I've got a child that's feeling unwell if they're tired or whatever that's fine on their recording sheet we just put off task, asleep, seizure, whatever it is and that's ok you know there's no pressure (P14).*

A further challenge when discussing progress was the system or tool that was used to measure and demonstrate progress. Like with the National Curriculum, many participants felt their assessment systems were not fit for purpose, particularly when measuring the very small steps of progress that these children make. One of the main criticisms of existing P-Level assessment systems was on their linear and narrow nature. Participants found these systems frustrating as they did not show the full extent of the progress that was made.

*I don't...feel that we've got the right system because obviously we have to put figures and things like that onto the system, but it doesn't [...] show the progress that they make not lateral it generally yeah [their progress] doesn't go upwards it goes that way and they're so teeny-tiny that you know sometimes it's really hard to show what we can see as their teachers (P15).*

*By their very nature they were quite spiky in the different aspects of their learning erm so and the early P-Levels being what they are it wasn't always erm reflected the children weren't always reflected in those levels (P17).*

In addition, one participant identified that, like the National Curriculum, the P-Levels were created nationally for all children with SEND. However, due to the unique and individual needs of children with life-limiting conditions, assessing individuals on these nationally created levels was problematic. Specifically, the following participant highlighted the issues with using the same assessment system and progression guidance for all of their pupils regardless of need.

*It just wasn't working for our pupils at all especially our more able pupils because we were comparing them with cohorts of pupils that they were nothing like and it was just very unfair [...] you were comparing you know our pupils with kids who were running around and had ASD erm and actually their learning profiles are bound to be really different if you can't move and you can't see (P6).*

Similarly, another participant highlighted the broad nature of assessment statements within the P-Levels and how these were not applicable to children with physical or sensory impairments. Using such an assessment system therefore meant that on paper, the child did not look like they had made progress, when in fact the opposite was true.

*I mean, all the Maths things at the moment the statements require her to pick things up well she can't do any of that or pick something or to drop it or roll and she can't do those things (P12).*

Instead, some participants had been involved in creating their school's own assessment systems which were more lateral in nature and allowed for greater coverage at the lowest developmental levels.

*We developed our own set of levels basically they're based loosely on the P-Levels erm [...] but they just covered a lot more erm for the children working at the earlier levels [...] actually I found those really good [...] so that was a positive change really (P17).*

*We've got a new assessment system which the first part is based on Routes for Learning and the second half we've developed ourselves to try and show that lateral progress really for those pupils (P3).*

Despite the potential of these new systems, some continued to struggle with the nature of such systems and the pressure from SLT to show progress. Whereas,

some SLT were realistic in their expectations and understood that some children would not make much progress, others appeared to be very data driven and expected to see progress from all children regardless of need. This proved frustrating for teachers who felt they were doing their best but with a curriculum and assessment system that was not fit for purpose.

*The Deputy Head that we had was erm very progress driven very data driven and expecting to see a lot of progress from all children [...] so that became a bit of a battle sometimes trying to explain to her that actually...a lot of the children I was teaching might make progress horizontally but not necessarily vertically (P17).*

Again, this highlights a possible lack of expertise and knowledge in the area of PMLD from SLT and the pressures that this can have on teachers. Words such as 'battle' and 'conflict' were found throughout the interview transcripts to describe the relationships teachers felt they had with SLT in terms of assessment data and curricula.

Many teachers preferred to prioritise informal recording of progress and experiences, for example, in evidencing 'wow moments' or experiences children had particularly enjoyed rather than whether they could perform a mathematical skill or understand an abstract concept. One teacher linked this to the functional elements of what they taught, further emphasising their perceived importance of life-skills within the curriculum:

*I want that student to do something that they find particularly difficult you know...they might be able to count to ten but erm they can't get themselves out of their chair and onto a seat [...] I'm very proud of the fact that that student can get themselves out of their wheelchair and onto a chair independently rather than the fact that erm they know that erm a hexagon has six sides or whatever (P5).*

For others, recording of experiences and key moments throughout the week was seen as a priority for the family, especially if children were nearing the end of life. One teacher described the joy that parents displayed when hearing about the tiniest amount of progress they had seen within their child, regardless of whether this could be seen on paper by other professionals:



*On paper she's made such little progress you know academic progress she was sleeping an awful lot yet for her parents they just were, so they said we can't believe how much progress she's made [...] the fact that Lucy was flicking her finger on her drum the parents saw that as a great thing (P14).*

Furthermore, providing memories for families was highlighted as of great importance for children nearing the end of life, memories that could not be gleaned from progression data on a computer system.

*We kind of talk about the need for making memories for Mum and for family [...] we've started last year erm something called a learning journal which is basically a scrap book for each child erm which is about three photos per week of just all being different activities they're doing and that goes home at the end of the year [...] there's that extra awareness that for this particular child erm how important that's gonna be for her parents and siblings (P8).*

Recording such experiences, particularly for children who are not able to demonstrate progress due to their deteriorating medical condition, was also felt to be important to ensure their time at school was seen as equally important as others. The following teacher felt that without such assessment procedures in place, the child's time at school would not remain a focus for staff and their access to experiences and activities within the classroom could be at risk.

*I think we feel it's important to continue those assessment processes and for people to be recording her responses to ensure that she's that her time at school is seen as the same amount of importance I think there's a fear that we said oh well for this particular child you don't need to record anything about how she's responding or what she's been involved in you know there's a danger that she could then become less of a focus for the staff in the class (P8).*

In summary, teachers discussed the challenges they faced in trying to fit their children into a curriculum and assessment system that were not appropriate or fit for purpose. Some teachers had been involved in the writing of their school's own curricula or assessment system which had provided some relief from the frustrations of nationally created systems. Others described the conflict or battle they experienced with SLT who placed what was perceived to be too great an emphasis on academic progress and abstract subject content. There appears to be a

discrepancy in the priorities of teachers and those of SLT in this area which is a cause of much frustration.

## **5.5 Time Pressures**

Finally, in relation to all of the above challenges, teachers experienced a range of time pressures on a daily basis, specifically in terms of 'fitting it all in'. Teachers described having to juggle the daily needs of their children and the impact this had on their teaching time. Some teachers discussed ways in which they had attempted to overcome these time pressures in terms of timetabling, adapting their teaching methods and providing structure within their classrooms.

### **5.5.1 Juggling Daily Needs**

Teachers found themselves having to juggle many aspects of their children's lives including their educational, social, medical and welfare needs. For many teachers this proved a significant challenge and one that arose frequently within the interview transcripts.

*Sometimes it's just difficult to fit everything in (P1).*

When faced with a class of children with life-limiting conditions many teachers began with collating a timetable of all of the different daily care routines needed. These involved positioning, personal care, physiotherapy, tube feeding, medication, amongst others. Many teachers found that once these needs had been timetabled, the time left for educational input was minimal:

*When I've got the students I kind of looked at what I needed to fit in in terms of meds, medical stuff and with physio and all of that as well I kind of started with there's my timetable what do I need to fit in kind of when I need to do the meds and enteral feeding and things erm in terms of the routine stuff and then added in the physio and then added in the whatever and kind of looked at what time I had left for teaching [laughs] (P12).*

For some teachers, especially if they began teaching this group of learners as NQTs, the amount of medical, physical and educational needs these children had was overwhelming, suggesting that teachers new to the role require some support in terms of managing their time effectively.

*When I first started teaching...I was how are we meant to do anything with all this medical stuff going on all we'll ever do is feed them [laughs] (P2).*

This was also found to be the case of experienced teachers new to special schools who, in contrast to mainstream, struggled with the fact that they could not spend the whole day teaching because of the demands that medical and positioning needs had on their time. At first, for one teacher new to special education, this was a shock and something they took time to get used to:

*I felt a real pull when I first started between the care needs and the teaching [...] at the end of my first day I remember like meeting up with people and they said oh how did your first day go and I said oh god I only taught about an hour and a half for the whole day and they said well-done that's amazing! [laughs] and I was like woah this is a slightly different world (P8).*

This difficulty in managing time and fitting in all of the daily needs of students was not something found to be an issue just for NQTs or those new to special education however. Many established teachers found managing time difficult and often described this as a 'juggling act' or something that needed to be balanced throughout the day.

*I suppose as a teacher it's difficult to get the balance of...medical needs erm education, physio and all of that sort of thing that I really, I find has an effect on your classroom practice, how you organise and structure your day (P11).*

One teacher described the impact of the National Curriculum as contributing to time pressures experienced. As previously discussed (see section 5.4.1), many teachers felt the National Curriculum was inappropriate for their students, due in part to abstract subject content. The teacher quoted here found that having to teach French every week exacerbated the time pressures experienced within their weekly timetable. It is clear that this teacher felt that that time could be used more effectively by meeting other perhaps more therapeutic needs whilst still meeting the demands of the National Curriculum more flexibly.

*The time pressures can be built in around the curriculum model [...] I think we try and fit a lot of work in er to meet the needs of the National Curriculum [...] in reality...you don't have there aren't enough hours in the day to meet all of those*

*needs...and for example yep it's important that the children are exposed to different cultures like we do French er but to me it's not important that they do it every week (P1).*

A further compounding factor in juggling daily needs was the access to facilities and staffing levels. Teachers found that children could not all go to the bathroom at convenient or appropriate times such as lunch time due to staffing levels and space. This is particularly pertinent given that the majority of children with life-limiting conditions discussed in this study are wheelchair bound and doubly incontinent, therefore requiring at least two members of staff to hoist and change them. In addition, gastrostomy feeds can be notoriously slow and where pumps are not used, a simple feed can take a member of staff in excess of forty minutes. Often, these feeds are required at specific times throughout the day and not necessarily at lunch time. All of these issues mean that fitting in the daily needs of multiple children within one classroom can be a significant challenge.

*I suppose you have to work the students' day around so many needs that's the difficulty is balancing what facilities you've got so they can't all just go to the bathroom at the best time (P1).*

*Personal care especially for the older children erm some of the children that I've worked with have brittle bones or erm have to be really careful when you're handling them so then that can take two of your teaching assistants out for twenty minutes to half an hour [...] then you have to think about ok well what I am going to do with my eight other children who all need support as well (P11).*

It is clear that the sheer quantity of daily needs children with life-limiting conditions have, poses a significant challenge for teachers. The impact of such needs on teaching time within the classroom is also problematic as identified by teachers in this study.

### **5.5.2 Impact of Daily Needs on Teaching Time**

Many teachers identified a range of medical, therapeutic and personal needs that had to be met before they considered children to be in a position that was conducive to learning (see Chapter 9 for a discussion of teachers' priorities). These additional, but essential needs had a considerable impact on teaching time.

*I think because their medical needs are so great it has a real impact on the amount of time you can actually spend teaching (P10).*

Teachers, by their very nature, wanted to prioritise teaching within their classrooms, however many found the physical needs of their children needed to be met first. For some teachers, ensuring that children were comfortable and positioned correctly became a priority due to the pain that can be experienced if a child has not changed position for some time or is positioned incorrectly. Again, as with personal care routines, the repositioning of children can be time and staff intensive, impacting further on teaching time throughout the day.

*I think the focus is on learning, but I think that you can't expect a child to learn if they're in pain or uncomfortable or miserable [...] I'm a bit passionate about making sure that children are positioned properly and comfortable [...] you can't expect anybody to be ready to learn anything if they're in pain (P7).*

In some schools the responsibility for conducting medical interventions such as administering medication or gastrostomy feeds lies with the school nurses or healthcare assistants. Whilst some teachers valued this as it meant they could focus on educational needs, others felt that the constant interruptions further impacted on the quality and quantity of their teaching time. These interruptions were emphasised by a number of teachers, particularly when a quiet, focused learning environment was required.

*It's like teaching in a major terminal there's always someone in your room [...] the nurses, the carers, are in and out getting their medication cos they have to fetch their own medication and then they're coming in and putting the feeds on they come in they take the feeds off it is really hard to keep a routine going (P10).*

For other schools, the responsibility for conducting medical interventions lay with the class teacher and support staff. Some teachers highlighted issues, particularly on days when the medical and care needs of children were high. Teachers felt that on those days their role was more of a caring or nursing one rather than an educator. For some, this apparent 'dual role' was difficult to accept given their lack of medical training or background.

*I mean sometimes as a teacher with the PMLD children you sort of tend to think that you're not actually a teacher you're more like a nurse (P16).*

*It becomes a logistical nightmare to stop the care taking over [...] it can just dissolve into a whole day of care (P8).*

Similarly, another teacher who tried hard to prioritise their teaching role, felt that if the care needs of children were taking over their day, it would start to impact on their emotional wellbeing, as the following quote illustrates:

*If I was the teacher and it was happening all the time, I'd be beginning to panic thinking that you know I'm actually letting the kids down now because they're not getting enough teaching [...] more than one day I'd start feeling quite anxious (P8).*

It was not just routine medical interventions that teachers identified as impacting on teaching time. Additionally, teachers identified unexpected medical needs such as seizures, as a factor that also impacts on the quality and quantity of their teaching (see section 9.2 for a further discussion). Teachers discussed the impact of small seizures that do not require more extensive medical intervention, not only because children experiencing them could not participate in lessons, but also because of the staffing needed to monitor them. Specifically, teachers described monitoring and logging of seizure activity as a significant need within the classroom and one that can interrupt their teaching time.

*The seizure management takes up quite a lot of the day erm if he's having a bad day with them that's someone that kind of needs to be with him 1:1 pretty much all day (P3).*

It is clear, therefore, that medical, care and therapeutic needs can have a huge impact on the quality and quantity of teaching time. However, teachers identified strategies that they had used to attempt to overcome these pressures and ensure that the teaching of these children remained at the fore.

### **5.5.3 Attempting to Overcome Time Pressures**

One common theme when discussing how teachers dealt with the wide range of needs within the classroom was flexibility within timetabling and teaching. Teachers had to accept that lessons may not go to plan due to medical emergencies

or changes to feeding regimens, as well as unexpected toileting. In other cases, children might come in to class alert and well, in which case teachers needed to optimise this learning time.

*I just feel you have to be incredibly flexible so I can come in with a day planner and each child has got their own individual learning plans but by 5 minutes in you might have chucked it out the window you know what I mean, you've got to be able to think I'm on plan B now and then I'm on plan C now because they may not be able to do something because they've had a seizure they may not because there's something wrong with them or they may not because they're in pain or there's you know or they may be having a particularly good day then you draft that and do something else as well (P13).*

One teacher felt that being flexible was an essential quality needed to survive when teaching children with life-limiting conditions:

*You have to be flexible enough as a person to be like okay well that lesson didn't happen because Fred was having a seizure, so you have to be okay with that because if you're not then...it's not suited for you I don't think (P11).*

As well as having numerous lesson plans that can be changed on a moment's notice, teachers discussed how they had changed their approaches to meet all of the daily needs of the children in their class. Some teachers had abandoned whole class teaching at specific times throughout the day as they found that some children would miss whole sessions due to for example, needing their gastrostomy feed, needing to sleep at the same time each morning or needing to go to the bathroom at those times. This meant that children would miss out on huge amounts of teaching time throughout the average school day ultimately impacting on their progress. One teacher discussed a carousel teaching method they had introduced to overcome these issues. This method involved working individually or in pairs with children, from comprehensive, individual timetables that ultimately optimised their learning time.

*The problem was I was finding with whole class sessions that there were some children they were never in the session because they'd have bowel movements, they had gastro [...] that's why the carousel because when the child is awake and in an alert state you can optimise their learning time whereas before I felt that you know I*

*may be doing literacy at 9 o'clock and they always have a seizure at that time and they always miss out, so it feels like I now work around the child's alert state (P14).*

Other teachers described a more fluid, child-led teaching approach which enabled them to optimise the learning of some children, whilst dealing with the unexpected needs of others.

*It's all very fluid cos it has to be child-led so if someone's in pain they need to go and be sorted out if they have a seizure, they have to again or if they need the bathroom unexpectedly, so it is fluid (P13).*

A number of teachers highlighted the importance of optimising learning time to ensure all of a child's needs were met. One teacher described how ensuring that planning and structure was in place throughout the day enabled these needs to be met in a timely fashion. They described how this meant needing an overall awareness of what was going on at all times as well as a need to direct support staff where necessary. This approach however, sometimes caused conflict with their support staff.

*You're constantly having to consider many, many factors and it is like juggling or spinning plates [...] the main thing is planning, structure, directing staff [...] what I've learnt taking over the class is there was quite a lot of efficiencies that needed sort of tightening up [...] to make sure that the students get the most time to be able to fit in physio as well as do their work and have their pump feeds and go to the bathroom and all of those things it's the little bits erm you know I did get frowned at a few times for getting 10 minutes work out of Jasmine erm just before lunch but otherwise we wouldn't get any work out of her (P1).*

One experienced teacher refused to let the care needs of their children take over the educational nature of their classroom. In doing so they had developed strategies and skills to ensure that medical, personal and therapeutic interventions were completed as quickly as possible and without unnecessary interruptions to the learning of the wider class group. This appeared to work well for this teacher and may have resulted from their vast prior experience as well as their personal outlook.

*Well as far as is possible we just try to incorporate them into what we're doing so it's as little fuss as possible because the primary purpose of my classroom is a school and*



*not a hospital [...] if these things have to be done then they have to be done but I really believe very strongly that if you've got a child who suddenly requires huge amounts of suctioning in the middle of a really quiet group activity you can't just do it then (P4).*

In summary, children with life-limiting conditions have a huge amount of needs that must be met within the classroom to ensure they are ready to learn effectively. These medical, care and therapeutic needs are extensive, have a significant impact on the quality and quantity of teaching time within the classroom and pose a significant challenge to the teachers in this study. In attempting to overcome this impact, some teachers have adapted their teaching practice, abandoning whole class teaching sessions, optimising individual learning opportunities, promoting flexibility and directing staff to ensure that the teaching of children with life-limiting conditions remains the focus of their daily practice.

## **5.6 Summary**

Throughout all interviews, teachers identified a number of different challenges that they faced when teaching children with life-limiting conditions. These challenges did not appear to be related to one particular area but were found across the whole teaching experience. These included curriculum and assessment pressures, in particular whether the curriculum used was relevant and meaningful to children with life-limiting conditions, as well as whether appropriate targets could be set and used to measure progress. Furthermore, ensuring that the child's medical, physical and positioning needs were met alongside this demonstration of progress meant that teachers felt under immense pressure to fit everything in to their day. Often, they grappled with the fact that on some days, dependent on the needs of the children, teaching took a much lesser role than the medical or caring side of the role which conflicted with their teaching identities.

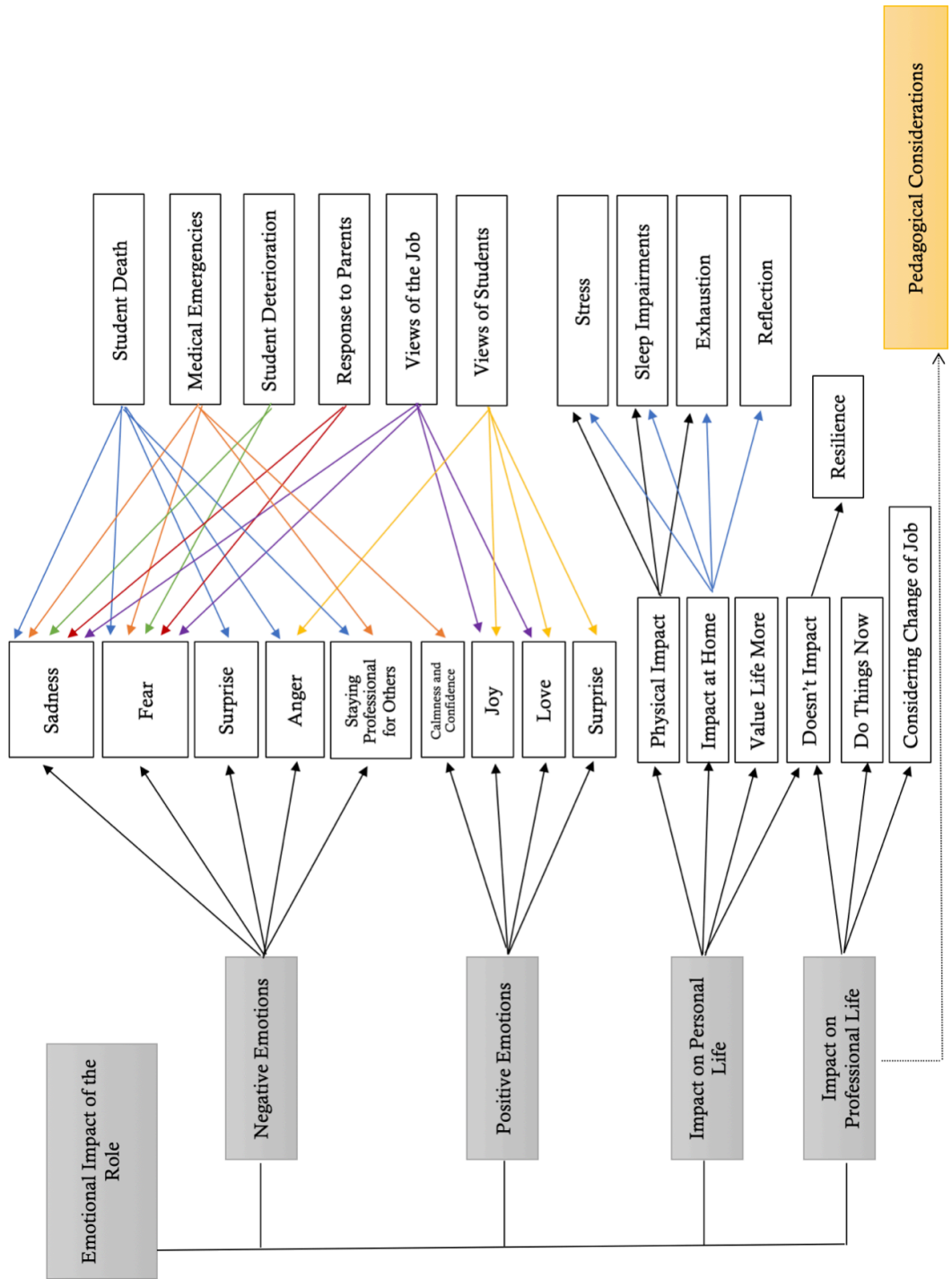
Away from traditional teaching pressures, teachers of children with life-limiting conditions also faced a number of other challenges, especially in relation to the medical needs of these children. Dealing with medical emergencies, communicating effectively with a range of professionals, as well as experiencing the death of a student were found to be significant challenges for teachers. Many teachers felt that these situations were handled well by their schools and most saw them as par for the course, however, others disagreed with processes and

procedures and felt that more could be done to ensure these challenges were handled in a more positive way. Teachers felt they were well-informed regarding the medical conditions of their students and spoke highly of the medical training they received in order to perform medical interventions and deal with medical emergencies. However, most teachers reported the absence of training in grief and bereavement. In view of how often teachers in special schools encounter the death of a child, many felt that having some training in this area would be useful.

Given the identification of these challenges, the following chapters will explore how these challenges impact on the teachers themselves. The next chapter in particular focuses on how the challenges identified here affect the teacher on an emotional level. Subsequent chapters will explore whether teachers are adequately supported to meet these challenges effectively in addition to how a teacher's philosophy is shaped by the needs of the children they teach.

## **Chapter 6: Category of Description Two - Emotional Impact**

Teachers of children with life-limiting conditions experience a wide variety of challenges associated with the education of children with the most complex of medical needs (see Chapter 5). It thus follows that this challenging role has an effect on the personal and professional lives of the teachers involved. This chapter aims to explore the negative and positive emotions experienced by teachers who teach children with life-limiting conditions. Discussions of emotions within the interview transcripts were categorised using the Junto Emotions Wheel (Chadha, 2016) (see section 3.4.2.2) and will be explored in further detail. This chapter will also examine the positive and negative effects these emotions have on the personal and professional lives of teachers interviewed from their own unique perspective. Figure 6.1 illustrates this category of description, showing how the emotional categories of sadness, fear, surprise, anger, joy and love from the Junto Emotions Wheel (Chadha, 2016) have been used.



**Figure 6.1:** Emotional Impact of the Teaching Role

## 6.1 Negative Emotions

Teachers discussed their responses to a variety of situations within their teaching role in a number of different ways. They discussed a range of emotions that were categorised into either positive or negative emotions using the Junto Emotions Wheel (Chadha, 2016). Using this wheel teachers discussed the negative emotions of sadness, fear and anger. In addition, the emotion of 'surprise' was interpreted to be both positive and negative (see section 3.4.2.2). Teachers also discussed the need to remain professional in certain situations as having a negative impact on their emotional wellbeing. Each negative emotion will be discussed in turn with specific reference to the situations that triggered them.

### 6.1.1 Sadness

The main reason why teachers experienced sadness within their role was due to the death of a student. Even if the student was not a member of their class, teachers experienced sadness at the loss alongside the entire school. Many teachers attributed this to the fact their schools were often small and as such they knew all students well. For the majority of teachers this sadness was felt strongly and many discussed being 'upset' and 'devastated' at the loss of a child.

*Obviously when we lose a child that impacts on you emotionally [...] it brings the whole school down because it's a small school and we all know all the children and it affects everybody [...] it hit everybody even the lunchtime supervisors were in tears (P10).*

*Erm it makes you sad erm it's obviously very sad erm [...] you do take it home with you, you know [...] you might have a little cry (P11).*

The sadness expressed by teachers was not confined to the immediate aftermath of the death of a child, instead, teachers expressed sadness that lasted months if not years. For some, this sadness came in waves, often unexpectedly triggered by a memory or event, as in the following quotation;

*On World Book Day a few weeks ago erm I suddenly had him in my mind and it just caught me a bit off guard and just made me a bit emotional because it was one of those things that you know he would always come dressed up beautifully for those kinds of days (P17).*

For one teacher, sadness that was experienced a period of time after the death of a child was attributed to lack of acceptance and the inability to deal with the death at the time. Again, this sadness was triggered by an event, specifically by the bereaved parents visiting the school some time after the death of their child.

*It's not until a year later and her parents came in to visit [...] I've never gone and visited them and every time it has come up, I've always been busy and...I have been busy, but I also know now looking back that I wasn't busy I just really did not want to go I really couldn't...address it so I think I didn't deal with it for a long time and then when her parents came back in and they left and I got so upset and I had to leave [...] I made my way to the family room and I had a good cry and ever since then I've realised that actually it has had an impact a really big impact (P2).*

A further contributor to the sadness experienced after the death of a child was a personal bereavement. Some teachers discussed how their sense of sadness was heightened due to the loss of close family members in the past. Others discussed how they needed to be aware of members of staff who had recently experienced a personal bereavement, thus looking out for their emotional wellbeing during the aftermath of a student death.

*I think it probably affects me more because of my personal experience in losing my brother, I do find now if a child passes away erm or we have a sort of medical emergency in school I do, it does bring back memories (P16).*

*I think things like bereavement kind of really affects [staff] on a different level and I think as well when you are a bit older and you, I think I'm not that young, but I haven't experienced a lot of bereavement in my life and I think for them having experienced it more it touches nerves (P2).*

Dealing with medical emergencies was also found to cause sadness for those interviewed. The majority of teachers explained how they would deal with medical emergencies by following procedures and calmly doing what was needed to ensure the safety of the child. However, after the emergency, once the child had recovered or was in the care of medical professionals, many teachers explained how their emotions would then take over. For the following teachers, these emotions overwhelmingly involved sadness. This appeared to be the case despite the outcome for the child.

*At the time it's just focusing on her and making sure that she's ok erm afterwards you kind of yeah go a little bit wibbly wobbly afterwards and you have a little bit of a cry (P15).*

*Once the adrenaline has gone down erm sometimes there are tears even though the child may be ok if they've had to go to hospital then your emotions are sort of running a little bit high (P16).*

A further cause of sadness for teachers was in watching the deterioration of children in their care. For many children with life-limiting illnesses, their conditions are degenerative resulting in a loss of physical and cognitive abilities. This was particularly distressing for teachers and elicited a great deal of sadness. For some, this sadness in particular stemmed from the realisation that children could lose the ability to communicate and interact with the world around them.

*I might have had a little cry that...that she was losing her eye control because that's the only thing that she has now to communicate [...] but she can't express that anymore and that is painful to consider that she's kind of there and I'm thinking if she loses her eye gaze what on earth am I going to do to make her life worth living for her, how on earth am I gonna help her to enjoy things if she can't communicate at all (P12).*

Teachers found this especially distressing when considering whether children were upset or in pain and if the child had an understanding that their condition was deteriorating. This empathy with their students was something teachers found difficult to deal with emotionally.

*She was in so much pain [...] I would question what Elizabeth's joyful state was and I think that was hard because [...] it's horrible to see somebody in pain all the time (P14).*

*I think because she's got that understanding it makes it more difficult whereas if she was really cognitively low-level it would still be horrendous, but I think it's slightly different in a way because you know I mean she gets really scared (P12).*

Physical changes in the child were also a source of sadness for teachers witnessing them, as it was a visual reminder that the child was deteriorating and perhaps nearing the end of their life.

*Other little things like how thin certain children are that sounds ridiculous but actually when you're changing a child and you're actually moving their legs and moving their arms and you're like oh my gosh look at you you've got nothing on you even down to those tiny things are just heart-breaking (P2).*

As well as children causing sadness for teachers, those interviewed also cited parents as a potential emotional trigger. Many teachers discussed having empathy with parents. Therefore, an acknowledgement of the pain and sadness that parents were feeling at the deterioration or death of their child, was also upsetting for teachers. This was something that teachers had to face alongside their own grief and sadness.

*I think what upset me more was to see her Mum's absolute grief especially for kids here because they've had to give up work most of the parents [...] they become your total world and then they're gone (P13).*

*I think watching them get upset felt more upsetting to me than the idea of this child not being with us anymore because they were just so in pain (P2).*

Teachers were found to work very closely with parents, often over a long period of time. As a result, teachers were frequently involved in sensitive discussions around a child's deterioration or end of life care. This closeness of relationship was reported to increase the sadness that teachers experienced during a period of deterioration or after a death.

*I think that's often when it's more of an emotional pull rather than the children themselves it's dealing with the parents and their own journeys (P14).*

*It's obviously if you're familiar with the families which I usually am that's quite upsetting (P5).*



Furthermore, teachers were sometimes the closest or only source of support for parents. As such, parents were reported to vent their frustrations, fears and concerns to teachers which some found upsetting to hear.

*She was sharing to the family link worker that she wanted her [child] to die and that was quite hard (P6).*

*Sometimes I find I'm somebody parents can vent at about other services and that's really hard because you want to help and support but...you can't because of the systems (P11).*

Finally, some teachers expressed sadness when discussing the job of teaching children with life-limiting conditions more generally. This sadness was expressed through feelings of isolation, particularly if there was only one class of such children within a school.

*You can feel quite isolated with the significant health needs and quite responsible as the class teacher [...] it can be a little bit isolating really when you come from mainstream where it's just hundreds of teachers who do the same thing in a sense that er it's very different isn't it in SEN (P1).*

Other teachers felt it was very unfair that these children had such complex medical conditions. The following teacher expressed her sadness in the lack of support for children and their families, particularly given the efforts of medical professionals to save those who are often born extremely prematurely. This perceived lack of control over support services and resources for families further contributed to feelings of unfairness and thus, sadness.

*I think that's what upsets me I think what we need to make the job better is people actually saying these kids well every kid is worth to be invested in if we're gonna keep saving babies at birth then we're going to need to provide, if we're gonna make that decision then we need to be responsible for that decision you know and not just leave the parents [...] it's those things that upset me but they're not in my control (P13).*

### 6.1.2 Fear

As well as sadness, the majority of teachers discussed feeling a sense of fear for the children in their care. For some, this fear crept in during the school holidays. Teachers reported feeling worried and concerned for their students, wondering if they were healthy or had had any medical emergencies that would prevent them from returning to school after the holidays. Some teachers also feared that children may have died during the school holidays and that they would not hear about it until staff returned to school.

*I mean over Christmas I knew that two of them were in hospital and I was really worried (P12).*

*I think with the holidays particularly [...] the thing we'd always say like the week before you come back you always wonder like we did have a pupil that was meant to be starting with us in September but passed away in the holidays [...] you just think you don't know how they've been and you don't know whether they've had a bad holiday (P3).*

A significant fear during term-time for teachers was in relation to the very real possibility that a child could die whilst in school (see section 5.1.1). One of the reasons for this fear was the severity of medical emergencies that are experienced. The majority of teachers expressed fear and worry during and after a medical emergency. Fear experienced during a medical emergency was felt, particularly if a child was having difficulty with their breathing, if it was the first time a medical emergency had been experienced with an individual student or if the emergency was prolonged.

*One boy had a seizure for the first time where he went blue erm that was the first time the other day, so I found that quite heart-racing (P14).*

*Especially if things go on for a long time you do think I'm not sure whether they're going to come back from this this time erm so yeah, it's quite...heart-breaking and yeah scary at times I think (P15).*

Taking children to hospital and communicating with medical professionals and parents also provoked fear in some teachers. This fear stemmed from doubting

whether they had done and said the right thing to ensure the best possible medical care for their student.

*The ambulance people are firing questions at you and then you get to the hospital and they're firing questions at you and then you have to kind of think on your feet and then you're like but did I say the right thing if I didn't say the right thing is that gonna have led to something that they do which they shouldn't do or something that they don't do that they should have done, there's a lot of pressure (P2).*

Teachers also expressed feeling fear after a medical emergency as they reflected on what could have happened and whether they did the right thing for the child during the emergency.

*Certainly, afterwards you think oh my goodness they could have...yeah, they could have died they could have done this, that and the other (P10).*

*There are times when you go home after you know somebody might have had a seizure and you do think oh gosh what if that would have happened, what if you know worst case scenario and you know that kind of thing (P18).*

A further, significant source of fear that teachers experienced was in relation to taking children with life-limiting conditions on school trips and community visits. Teachers expressed anxiety and fear over being ultimately responsible for such medically complex children outside of the safety of the school building. Others worried that they would forget something vital that was needed to perform medical interventions or provide treatment in the event of an emergency.

*I think the hardest thing I find actually is going on a trip I actually do get quite anxious about that because you're just you know away from all those things and although I know that my staff will probably deal with most things I think because it's down to me it's my responsibility I'm signing all of the paperwork [...] I just find them quite, to be honest I find them quite anxiety provoking (P6).*

Teachers also experience fear for their students, especially if they have degenerative conditions that are affecting their cognitive and physical abilities. For some teachers, they fear having to observe the deterioration of a child, for others, they fear for a child's emotional wellbeing. For example, one teacher expressed the fear

that a child may be miserable and therefore unable to enjoy their education. This fear seemed to be enhanced when a child's inability to communicate meant that teachers were unsure of a child's emotional wellbeing.

*I worry more about emotional wellbeing more than physical wellbeing I guess I'm worried that a child's, a young child in my class who's deaf and blind and I worry about how I don't know whether she's a happy person to be honest (P13).*

Finally, some teachers feared they were not doing enough to provide the best possible education for their children. This relates heavily to the teachers' own priorities for the education of their students (see Chapter 9), however, for those who favoured a more academic approach, fear was felt if teaching time was overly affected by medical interventions.

*I think there's always for class teachers in the back of their mind that nagging fear that even though everything has gone completely wrong and that child's button came out and that child's had a seizure and that child has pooped everywhere and taken two members of staff forty-five minutes to clear them up that you really should still be teaching [...] if I was the teacher and it was happening all the time I'd be beginning to panic thinking that you know I'm actually letting the kids down now because they're not getting enough teaching (P8).*

### **6.1.3 Surprise**

A conscious decision was made to split the 'surprise' section of the Junto Emotions Wheel (Chadha, 2016), into both positive and negative emotions (see section 3.4.2.2). All teachers discussed the negative emotion 'surprise' in relation to shock at an unexpected death. Despite teachers' awareness that the children in their care had life-limiting conditions, were deteriorating and/or nearing the end of their lives, almost all student deaths came as a shock. In most cases, teachers attributed this shock to the speed in which children became very ill and died, sometimes overnight. In addition, many teachers discussed the fact that the children who had died were not the most poorly and thus their deaths were unexpected. This seemed the case for the majority of teachers, despite the fact that many of the children had complex medical needs.

*The little boy that we lost recently he's erm...he'd always been quite well he'd had periods when he'd been off with a chest infection or something, but he'd always bounce back and he was never, never really sickly you know [...] no inkling that he was unwell and then literally ok on the Friday, message on the Monday he'd been in hospital and passed away and you just ooh that was quick [...] he was just out of the blue fine one day and gone the next (P10).*

*I had erm in May last year one of my pupils er passed away very suddenly literally over a weekend and that was erm that had quite a profound effect on me really erm...it was it completely came out of the blue he wasn't a child that you know had er...had...any signs of any major illnesses or anything (P17).*

For one teacher, this shock at the death of a child had a more intense effect on their emotions than they had anticipated. The following quotation shows that these strong emotions were attributed to the fact that the child had died within an extremely short period of time, something they had not experienced before.

*He became ill in the morning and the paramedics came and took him away and he died the next day [...] I was just really, really shocked it was peculiar because it's not something I'd felt about a child dying before because normally either they go to the hospital and they sort out come back or they go in and they're there for a few weeks and then they fade away and that's what you expect [...] I have taught in lots of schools and it never happens within twenty-four hours that a child becomes ill in my room and dies the next day and I just couldn't stop thinking about it (P4).*

The surprise and shock experienced at these unexpected deaths were found to heighten the negative emotions felt throughout the school. A sudden and unexpected death was felt to be worse than a child who was expected to lose their life after a long and deteriorating illness.

*This year we had a little boy pass away who I knew [...] again he was a bolt from the blue no one expected him he just died in the night [...] the last two deaths [...] they were both such a shock nobody expected either of those two to die so I think it's kind of almost worse (P13).*

#### 6.1.4 Anger

Anger was felt by some teachers in the form of frustration at systems and processes that were lacking and perceived to be out of their control. This was often in relation to teachers not being able to provide what was needed for their children as quickly as they would like. The following quotations illustrate that access to vital services to support children and parents such as trying to get a new wheelchair, often took a huge amount of time, something many felt their children simply did not have.

*I think I find it really frustrating that...other people don't necessarily do and it's not because they're bad at their job, but other services have been reduced and things and I think it's from a school perspective I find it really hard going into the meetings and we offer everything and as a school we do go above and beyond and that's just how we are [...] I find more, most frustrating when nobody else is doing their job, well they are doing their jobs because the other job doesn't exist anymore and you think you just see the parents struggling and you can't help them it's hard (P3).*

*We've all got frustrations especially with wheelchair services...erm...yeah and just the time it takes yeah very frustrating (P6).*

A further source of frustration was the perceived lack of understanding from other teachers in the school in addition to SLT. Teachers felt that, without having experience of teaching children with the most complex needs, it was impossible to fully understand the demands and stresses of the role. Therefore, they expressed frustration and anger at the lack of support and understanding on offer.

*I think sometimes if teachers don't work in those classes, they don't kind of understand and it frustrates me slightly sometimes (P15).*

*I sometimes get frustrated when I feel that sometimes people maybe aren't aware of what we're doing maybe cos they're not in the classroom enough (P13).*

This emotional support or lack thereof from teachers and/or SLT from outside of the classroom is discussed in more detail in Chapter Seven.

### 6.1.5 Staying Professional

Although not a negative emotion per se, the need to remain professional emotionally whilst dealing with challenges such as a medical emergency or the death of a child was reported to have a negative impact on the emotions of those interviewed. Many discussed needing to 'be the brave one' or 'hold it together' to help others deal with the situation. Some teachers felt this was due to their teacher role within the classroom as opposed to the role of a teaching assistant or similar support staff.

*Yeah, I think you feel you do have to be the brave one if you like...yeah because they [support staff]...they get so upset...I don't know if they feel that they can show it more (P10).*

*I felt like I had to be very professional I felt like I really had to maintain especially for the staff [...] I had to, I really felt like I had to hold it together because everyone else was so upset and so devastated (P2).*

For others, staying professional whilst at school and dealing with the situation was something that was expected of teachers by SLT. The teachers quoted below dealt with this expectation in different ways. For the first teacher, dealing with their emotions following the death of a child was something they would choose to do in private anyway. For the second, although explicitly directed to stay professional at the time, they felt that when a death happened, they perhaps would not be able to keep their emotions at bay.

*I think the school kind of expect teachers to deal with it, but I think that's probably the way I would deal with it anyway (P10).*

*[The head] said oh you must be professional whatever happens you must stay professional and that kind of thing but just do that in your own time you must be professional, and you must be there to support [the family] which is definitely the line that I would take but I kind of think that's not always that easy (P12).*

In contrast, some teachers did not feel comfortable expressing their emotions whilst at school. In emotionally-charged situations, this group of teachers would remain professional in school and instead deal with their feelings in private, at home. Whether teachers showed their emotions in school or preferred to deal with them

privately depended very much on the individual. For one teacher, the decision to deal with emotions privately was also impacted by the affect that a distressed teacher would have on their students.

*We lost a child within the team and that was quite hard, and it wasn't even so much my own feelings it was then managing the feelings of the team erm I tend to be quite sort of private about that [...] sort of outside of school that's when I manage my feelings if you like I hold it together in work and then you go home and you're like phwoar [...] I think it's more who I am as a person really (P18).*

*Erm I'm probably somebody that doesn't deal with it in that way I might bottle it up and save it for later I'm not somebody that would express it there and then which I think some students will pick up on that and I don't think that's right (P5).*

## **6.2 Positive Emotions**

It is clear that teaching children with life-limiting conditions causes a great deal of negative emotion in those who fulfil this role. However, the picture is not always so bleak. Teachers expressed a great deal of positivity for the students and the teaching role. Specifically, teachers discussed calmness and confidence when dealing with medical emergencies and discussed their job and their students in terms of joy and love. Additionally, teachers also expressed surprise in a positive way when discussing the achievements of their students.

### **6.2.1 Calmness and Confidence**

Medical emergencies have been discussed in terms of instilling fear and sadness into those who experience them. However, some teachers expressed a calmness and a confidence when dealing with emergencies within the classroom. This calmness during emergency situations appeared to come with experience for some teachers. For others, they appeared to be calmer once they had seen a first emergency for each individual child. For example, once they had seen a child have a seizure and they knew what the individual signs were, how the child recovered and what the processes were, they felt able to deal with the next one in a much calmer way.

*I'm happy to deal with [emergencies] I guess with experience, this sounds awful, with experience and as you're dealing with it day-to-day, somethings become routine for*



*some of our students with their medical needs [...] yeah so, I wouldn't say confident, but I would say comfortable maybe (P11).*

*After [the first time] I wasn't really bothered to be honest, once I'd seen the kind of emergency kind of elements of each child I'm not bothered now (P12).*

For others, teachers had consciously decided to take jobs working with children with life-limiting conditions due to their prior experience. As a result, they expected the level of medical need experienced within their roles and appeared fairly calm and confident when dealing with emergencies.

*I feel fine [with medical interventions] I mean I'm used to it, I expect it because that was the nature of the school really (P13).*

The presence of routines, care plans and procedures helped some teachers to feel calm in emergency medical situations. This particularly helped teachers given their level of responsibility during such events. Having a set of procedures and guidelines to follow helped with the directing of support staff and acted as a 'back-up' for teachers enabling them to remain calm.

*That's just what you do you're there you know the children have got medical problems and as long as you know the routine that you have to follow it's just part of the job (P16).*

*I'm quite logical, follow set procedures when it comes to [medical emergencies] at the moment I haven't experienced anything maybe enough that would be you know who knows...but...erm...I'm alright about it (P5).*

Additionally, teachers expressed needing to be calm for the sake of the child. Some teachers explained that during a medical emergency there can be a lot of professionals in the room, especially once the paramedics arrive, and staying calm to prevent the child from panicking or becoming frightened, was a priority for them.

*While the nurse was dealing with the medical side as in the oxygen part erm we were just sat talking about things that she loved to do like handbags and clothes erm yeah so just trying to make light of the situation even though it kind of wasn't so yeah erm and then I think she ended up with about three paramedics in the room as well which*

*was a little bit much so we just kept up that banter trying to keep her not getting so stressed cos that would have just made her worse (P15).*

### **6.2.2 Joy**

One of the overarching emotions discussed by teachers throughout the interviews was that of joy. Despite the negative emotions and the challenges identified by many, teachers were fulfilled by and thoroughly enjoyed their roles. They felt lucky to be able to make a difference to children with life-limiting conditions. For the following teachers, the unique nature of their teaching role was felt to be more fulfilling than previous mainstream positions due to the holistic approach teaching children with life-limiting conditions requires.

*I think for me personally as a teacher it's been the most fulfilling personally in terms of job satisfaction erm to be able to get to know a small group of students as well and to know their parents and to try and actually do a good job in the whole picture as opposed to mainstream you're kinda dipping in and out all the time with a group of twenty-eight kids and it's a lot about the subject [...] whereas this feels like it's more about individuals (P1).*

*I think for me the joy of teaching those particular children came in being able to teach everything about them and trying to improve every aspect of their lives in whatever way was possible for us to do (P17).*

In addition, joy was expressed in terms of the children. Teachers found joy when children were able to do something they could not do before or when children demonstrated pleasure in the activities they were completing in the classroom.

*It can be exciting cos sometimes you discover somebody can start to put two words together and then three or somebody who starts to use the switches when you thought they might not be able to things like that (P13).*

*We do stuff with them and challenge them in ways we didn't expect that we would and that's really exciting (P5).*

Teachers felt that instilling joy within their teaching was a priority for them and their students. This was shown when talking about children who had died. Despite

their deaths, many teachers felt confident that regardless of their illnesses, these children experienced joy whilst at school.

*We had a little girl who died, but every day was joyful with her you know she had so many joyful things [...] three children that have died it has been a sudden seizure you know their seizures are so bad but, in the meantime, they had joy (P14).*

For many, these feelings of fulfilment and joy outweighed the negative emotions experienced during medical emergencies or student deaths. These feelings of joy seemed to instil a sense of pride and privilege in teachers and many expressed feeling very lucky that they have the opportunity to work with these children every day.

*Personally, I find it really rewarding and obviously you know when we lose a child that impacts on you emotionally and it brings you down [...] but...I think the rewards you get out of it make up for those times (P10).*

*I do feel rather privileged to be in this job as well you know you stand and think you can make a difference to these children's lives (P18).*

However, for other teachers, not even joyful experiences can help to combat the negative emotions experienced on a daily basis.

*They're all brilliant they really are and that is the good thing about it and even with all the stress there are moments in every single day when it is completely lovely, but I don't think that quite equals, this is the problem there's definitely an imbalance (P2).*

In an attempt to protect staff and students from the negative emotions experienced, many teachers consciously made an effort to promote joyful experiences. Some talked about 'being silly' to make students laugh and discussed being positive despite the severity of their pupils' illnesses. This was seen to offer some emotional protection throughout their day-to-day teaching.

*I like to think in my class there's loads of laughter, there's loads of joy erm...there's lots of silliness, because in some ways that's what helps us to get through the day you know because otherwise you could become feeling quite low [...] I do find it an absolute privilege to sit and work with these children I really do (P14).*

### 6.2.3 Love

In addition to joy, many teachers spoke about their job and the children they teach in terms of love. Despite the challenges of day-to-day teaching, the traumatic medical emergencies and the devastating student deaths, teachers expressed love for their children and their job.

*I'm always conscious that I go to school I love being with the kids at school I love everything that I do [...] it's just part of who you are, and I love it (P7).*

Some teachers discussed their passion for teaching children with life-limiting conditions, a passion they perhaps did not know existed until they were given a particular class or joined a certain school.

*I started spending a bit more time with the children with PMLD that we had er it was just something that really erm just really caught my attention and I just I really wanted to find out if I could teach them it was kind of a big challenge for me erm and it was one that I absolutely just loved, it was suddenly that was where my passion was [...] that was where I found my passion really working with those lovely children [...] I just love it (P17).*

Teachers overwhelmingly expressed love and care for their students, however, some teachers were warned of becoming too emotionally attached, particularly for the most vulnerable children. Nevertheless, for the following teachers, the severity of the child's condition in addition to the sheer amount of care that the child needed from them, only added to their feelings of love and thus their inevitable emotional attachment.

*I used to go and visit a little girl in hospital and my previous head had said she felt I was becoming too emotionally attached and I really struggled with that it's like but how can you not be you know you're teaching her you're holding her and you're thinking is this going to be the last time I hold this little girl (P14).*

*You do everything, we did everything for her literally everything [...] you literally hold these children like you literally hold them on your lap and cuddle them and you spend, she came in despite how poorly she was every single day, so you spend so much time with them [...] I love them (P2).*

Despite teachers expressing their love and care for the children in their classes, they did appear to have a professional awareness of their emotional attachment and acknowledged that regardless of their feelings, the children they taught were not their own.

*I care about them a lot [...] and also you know that's their life it's not really your life as much as you might love them (P12).*

*It's a really odd situation to be in when [a medical emergency] does happen because it's somebody else's child but you still care very deeply for them (P17).*

This was something that older teachers seemed to deal with better than younger teachers suggesting that a degree of emotional detachment was something that came with experience.

*Yes, I'm their teacher, yes, I'm fond of them some children you get closer to than others but I'm not their parent and I don't have that level of emotional involvement [...] when I was younger it was harder erm I can think of two children I got too fond of and I learned from that I thought no you just don't do that they're not yours you know you can be really fond of them but you have to just have that barrier up and I think that is something you learn from experience (P4).*

As with joy, feelings of love seemed to offer some emotional protection for teachers and enabled them to deal with the challenges they faced on a day-to-day basis. The following teacher suggests that without those feelings of love and without caring deeply for these children, the job and its associated challenges would become impossible.

*I love my job, I love it, I don't think you could do it if you didn't (P11).*

#### **6.2.4 Surprise**

Positive surprise was expressed by teachers when discussing the children they teach. The determination and resilience in the face of their life-limiting conditions, were things that teachers found surprising.

*That's what I feel is important that these kids are really seen as, I mean they're amazing, what they go through I couldn't go through half of it they're so resilient and*

*brave you know they're incredible and they teach me a lot more than I ever teach them (P13).*

The achievements of these children, some of whom have degenerative conditions, were also something that teachers were surprised by.

*They do stuff, accomplish things that they didn't expect that they'd be able to do (P5).*

These feelings of amazement at the achievements, determination and resilience of children with life-limiting conditions added to positive emotions such as love and care in addition to furthering the personal rewards and fulfilment that teachers experienced throughout their teaching role.

### **6.3 Impact on Personal Life**

It is clear that a range of positive and negative emotions are experienced when teaching children with life-limiting conditions in special schools. These emotions stem from a range of experiences such as medical emergencies, student deaths, the views of students and the job as a whole. With such a caring role and such intense emotions, it thus follows that this can have an impact on the personal lives of those experiencing them. Some teachers described how the emotions experienced whilst at school negatively impacted on their personal lives including affecting their sleep and interactions with their families, adding to stress and exhaustion.

Fear and anxiety, particularly after a stressful event such as a medical emergency, was found to impact on the sleep of teachers. Often teachers who had dealt calmly with a medical emergency at school found that once they had gone to bed they began to reflect, worry and doubt their actions, ultimately impacting on their sleep that night.

*It's generally when I've gone to bed [...] it all starts to go round in my head which isn't always ideal, but you know you're only human at the end of the day [...] if I'm worrying about a student or if I'm worrying about things that are happening then yeah it can stop me from going to sleep (P15).*

*I hope I deal with it professionally at the time but yeah, I do find that it bothers me erm you know sleepless nights thinking about it thinking well did I do the right thing or what if that had happened (P6).*

Leading on from sleepless nights, many teachers discussed feeling exhausted and the impact this had on their personal lives. Exhaustion resulted from, not only sleepless nights, but the emotional labour associated with their teaching roles. Dealing with their positive and negative emotions in addition to the various challenges discussed previously, left teachers feeling drained at the end of the school day.

*I often found that actually it would erm it's a lot, it's a lot more tiring than I would have thought it would be (P17).*

*So the demands of the job, what is tiring is the being in with the kids and the kind of emotional needs from that are hard [...] my hours aren't ridiculous it's just that I'm so tired generally by the end of the day erm [...] you might have to be dealing with emotional parents, angry parents all that kind of thing you just even if you finish at 4pm you might feel like it's 9pm (P3).*

This level of exhaustion was reported by one teacher to negatively affect their social life, as they were often too tired to go out and socialise with friends after a day in the classroom. This was something that this teacher had recently recognised after having made a conscious decision to step out of the classroom due to the emotional and physical demands of their role.

*I am so tired during term-time I'm just beyond tired and taking the step out and doing the other work has made me realise how closely that's linked to this job [...] on the days when I'm in this classroom I get...that's it like I get home and I am absolutely flat out like there's no chance [...] Fridays for me are just 7 o'clock bedtime in the hopes of getting a good weekend (P2).*

The emotional demands of the teaching role further impacted on the personal lives of teachers through reflection. As previously discussed, many teachers reflected on decisions made throughout the school day, particularly in relation to medical emergencies. These reflections were found to impact on sleep but also invaded the personal lives of teachers at other times. Many teachers discussed taking their emotions home and thinking about their students and their day for long periods when home.

*You never switch off you know and I'm quite, I try not to bring my job home but inevitably you do [...] I'd love to say I'm good at leaving [emotions] at the door but if you ask my [partner, they] would say I'm rubbish at it (P14).*

Interactions with family members were also found to be negatively impacted by the stress and emotional demands of the teaching role. The following teacher found their stress spilling over into their personal life affecting their emotions whilst at home.

*I probably do get a little bit grumpy and snappy at home erm but once I've done it and I realised I've done it I do apologise to my daughter or whoever I've snapped at so and they kind of understand that it's quite stressful (P15)*

The negative emotions experienced when a student died inevitably affected the personal lives of teachers. This was especially the case in the following quotations of teachers who had young children.

*I always need to feel when I come home like my son is 8 you know it's that need to give him a bit of an extra hug (P14).*

*I tend to tell my children that we've lost a child because they're older and they do understand you know that the children I work with are very poorly and that sometimes these things happen, so they do tend to...to be a bit nicer to me that night and maybe not play up as much as they might (P10).*

The impact of the emotions experienced on the personal lives of teachers was not purely a negative one. Some teachers discussed the emotions experienced as having a positive impact on their personal lives. For these teachers, this positive impact centred on their value of life. The children with life-limiting conditions were found to have taught their teachers to value and appreciate life more than they did before. This was found to have a huge impact for those interviewed.

*I suppose you value life more...erm and I think that you (...) you probably feel lucky (P11).*



*I'm just grateful I think, what the students give me without them realising is they make me appreciate, make me realise that I've got nothing to moan about in my life (P13).*

## **6.4 Impact on Professional Life**

The emotions experienced throughout the teaching role not only impacted on the personal lives of teachers but also on their professional lives too. For many, the impact of the emotional demands of the role influenced their pedagogy (see Chapter 9). In addition, the emotional demands and challenges experienced emphasised the need for teachers to 'do things now'. For example, the following teacher felt the need to ensure they did not wait for exciting experiences or to get new equipment for their children.

*For me it's important that we do everything now you know if we're gonna do a trip we do it and if we're gonna have this experience we make sure that we do it we don't hang about if they need new equipment I'm a terrible nagger for making sure they have things as soon as they can [...] cos they've only got a short time (P13).*

What was clear throughout some of the interviews was that the wide range of emotions experienced throughout the teaching role together with the challenges faced on a day-to-day basis resulted in teachers becoming overly stressed. For the following teacher, this build-up of emotions was becoming too much and as a result they were considering a change of job role.

*The fact is that all of these things build up and they lead to you well me feeling really stressed and I think that's a lot of because I've been thinking about taking a step out of teaching [...] that day-to-day build-up of stressful situations and heart-breaking things to watch is actually a bit too much for me I think (P2).*

Similarly, the teacher quoted below was also finding the emotional demands too much to cope with at times. This led them to question whether they wanted to continue with their current role at all.

*There are times when I just think actually, I don't know if want this responsibility anymore cos it's a lot (P15).*

On the other hand, some teachers, often those more experienced, felt they were able to adequately separate their personal and professional lives. As a result, they were found to be more resilient, lessening the impact of the emotional demands on their personal lives.

*I'm always conscious that it's different to go in as a professional and then come home where I can relax and not have to deal with it [...] it's not the same as it is for our parents who never really get a proper break (P7).*

This emotional separation seemed to be a conscious acknowledgement of the professional role of a teacher as opposed to that of a parent. Again, teachers who had more experience of this role were better able to separate their personal and professional lives which offered a degree of emotional protection.

*Well you have to keep it professional but...erm...you know when you say professional people get the idea it's very...but you know I give parents a hug some parents you have jokes with [...] you can't let it affect you...because you couldn't, you have in some part of your brain you have to keep it there maybe I might come home and tell my [partner] all about it and then that's it it's gone because I'm not there, they're the ones that have it there all the time I'm not their parents my job is to be one step removed but there in whatever capacity they need (P4).*

## **6.5 Summary**

Teachers of children with life-limiting conditions have to deal with a variety of challenges within the classroom on an almost daily basis. Facing these challenges provokes a range of positive and negative emotions for teachers. Teachers expressed feeling overwhelmingly sad and fearful when dealing with medical emergencies, student deaths and when watching children deteriorate. They felt surprise and shock at unexpected deaths which hit the whole school community in a profound way. Teachers also expressed anger and frustration at not being able to provide what was needed for students due to the lack of outside agencies.

On a positive note, teachers felt a tremendous sense of joy and love for their teaching role and the children they teach. They were often surprised by the determination, resilience and achievements of their children and some felt confident and calm in their abilities when dealing with medical emergencies.

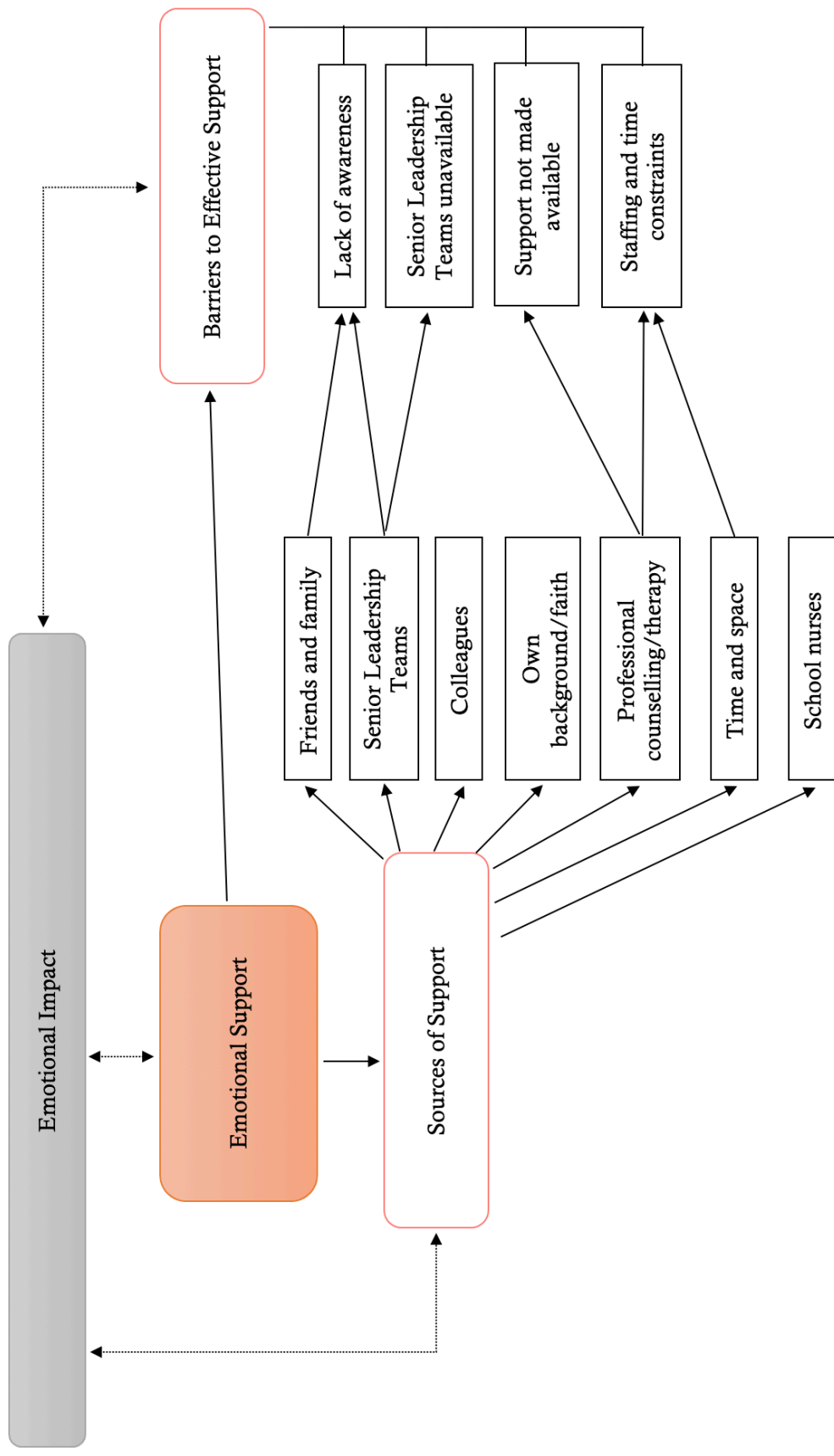
For many of the teachers interviewed, these emotions had an impact on their personal and professional lives. Most noticeably, negative emotions influenced the sleep of teachers, leading to exhaustion, stress and a desire to move away from the classroom teacher role. Only a few, more experienced teachers, felt able to effectively separate their personal and professional lives and thus were more emotionally resilient than others. The offering of emotional support is therefore essential in supporting teachers to deal with the negative emotions experienced within their role.

## **Chapter 7: Category of Description Three - Emotional Support**

Teachers of children with life-limiting conditions experience a wide range of positive and negative emotions that were found to have an impact on their personal and professional lives (see Chapter 6). Teachers attempted to deal with these emotions by seeking support from a range of sources such as friends and family, other colleagues and school nurses. Some of this support was found to be effective in helping teachers to manage their emotions, however barriers to this support were experienced, including in a lack of understanding and awareness from friends, family and SLT. Figure 7.1 illustrates the emotional support that teachers seek within their roles, as well as the experienced barriers to this support.

### **7.1 Sources of Emotional Support**

As can be seen from Figure 7.1, teachers cited a number of different sources they could turn to for emotional support when needed. Each source of support will now be discussed in more detail.



**Figure 7.1:** Emotional Support for Teachers

### 7.1.1 Other Colleagues

The biggest source of emotional support cited by teachers was from other colleagues within the school. For many teachers, other colleagues were found to provide effective emotional support due to the specific challenges faced by this group of teachers.

*I've got some really good colleagues, so we do sit and chat and you know talk about things and how to deal with things (P15).*

*I had some colleagues that I was very close to that we all worked with the PMLD classes at the school, so we were able to erm unload on each other and I think that was really important actually to have that relationship with people that understood what it was like (P17).*

Within schools that had experienced a number of student deaths, a supportive atmosphere was found, where colleagues looked out for each other through difficult times. Again, this shared understanding was reported to be one of the most important factors in effective emotional support.

*You kind of deal with it better if you're with the people who understand it so as a team you know you might as well crack on together because you find strength in each other (P12).*

This support not only involved talking to people who understood, but also included providing cover for classes who had experienced the death of a child. This cover enabled the class team to come together and emotionally support one another outside of the classroom environment. Many teachers valued this time to meet with their team, discuss their emotions, the child and emotionally support each other.

*Staff cover was provided so that staff in that room were given some time to just come together and be sad and sort of chat [...] it really helped [...] I do think that having a bit of time to acknowledge what's happened and talk to one another as a staff team before you're then put straight back into the thick of it is good [...] there was a lot of support for one another (P7).*

In addition, many teachers also turned to their colleagues for practical support in terms of meeting the students' needs, both educationally and pastorally. Again, this

was due to the knowledge and experience other colleagues had regarding the needs of the students.

*The biggest support for me has been other teaching staff in the school, people that know particular students and sharing ideas with other staff and gleaning ideas from them as well erm so that I can understand how to best meet the students' needs. There's obviously a wealth of experience and people who've known the students for years and years (P1).*

Having a colleague with experience and training in grief and bereavement was also found to be a factor in gaining effective emotional support from staff within the school.

*I have a very good teacher I work with in my department she does very good work on bereavement (P13).*

### **7.1.2 Senior Leadership Teams (SLT)**

As can be seen above, most teachers spoke positively about the support provided by other colleagues within the school. However, when discussing support provided by SLT, the response was mixed. For many teachers, SLT were incredibly supportive, and teachers found they could seek out their support when needed.

*We've got a lovely supportive SLT [...] they are good here they do like I can go to my line manager and go blah [...] they'll sit there and listen they're not like oh get out of my office at all like they're very nice and really open-door policy (P2).*

Others described proactive SLT who would come to classes to ensure that staff were supported, particularly after the death of a child.

*My line manager at the time er she came in to my class fairly regularly just to check again that we were all ok (P17).*

However, for some teachers, SLT would not be the people they would turn to for emotional support due to being unapproachable, unavailable or lacking in understanding of what it was really like to work in a classroom with children with life-limiting conditions (see section 7.2).

*I think I'd go and talk to the other teachers or the TAs because I think actually, they're more approachable than SLT are (P10).*

### **7.1.3 Friends and Family**

Many teachers interviewed discussed turning to friends and family for emotional support following a challenging day, medical emergency or the death of a child. Teachers found talking to partners, friends and family was emotionally supportive and helped them to manage their feelings. Whereas talking to other colleagues was helpful because of their understanding of the unique needs of the students they teach, talking to family members helped the following teacher due to the distance of the family member from the situation. As well as this distance, life experience in terms of personal bereavements was also helpful when seeking emotional support.

*If I really do want to vent, I talk to my Mum because she's obviously that much more removed and she's older, so I tend to talk to her if I need to really sit and say how unfair it all is and...why's it so crap for all these kids (P10).*

Some teachers found their partners to be particularly understanding and as such were able to talk to them about things they found stressful or emotionally draining. This was felt to be supportive for those involved.

*I've got a very supportive partner and very supportive family so if something has happened at school then I can sort of let it out at home and...it's fine then (P16).*

On the other hand, for some teachers, this lack of understanding of the needs of the children they taught proved difficult when seeking emotional support from friends and family outside of the school environment (see section 7.2).

*I've got a lot of friends that are teachers erm they all teach in mainstream schools and it's just I don't know it's just it takes a lot of explanation and sometimes I just don't want to necessarily talk about it to them (P17).*



#### 7.1.4 School Nurses

School nurses were a further source of emotional and practical support within the school environment for the teachers interviewed. Teachers felt that where good relationships with nurses existed, and where school nurses were available, they could turn to them for support.

*The nursing staff have been very, very supportive [...] sometimes you just want a bit of reassurance I suppose from the nursing staff that you are doing the right thing (P1).*

For many teachers the support provided by nurses may only be needed within an emergency situation and be more practical in nature, however, some teachers actively sought out nurses for more emotional support. The following teacher turned to their school nurse for support when witnessing a child's deterioration. In addition, the extra qualifications of the school nurse also ensured she was a valuable source of emotional support following the death of a child.

*I'd go to our school nurse and just see I'd got everything in place that I needed [...] I'll go away and talk about all the paperwork stuff and the diagnosis with [the nurse] and stuff [...] she's in charge of kind of grief counselling or whatever [...] she's great as a friend and professionally (P12).*

For teachers where school nurses were on-site full-time, they felt happy, reassured and supported. The following teacher understood that they may feel differently if nurses were not available throughout the school day to provide both practical and emotional support.

*I mean having the nurses on-site I wouldn't feel anywhere near as happy coming in to work without them here [...] I can see if you were in a school where you weren't supported or in a hospital or anywhere where you aren't supported, and you didn't feel like...there was the people to go to and you maybe were dealing with a lot of medical stuff you didn't have the nurses you know it wouldn't be the same (P3).*

### 7.1.5 Professional Counselling

Some teachers reported that following a student death, schools brought in professional counsellors for staff. Others reported that counselling could be made available should staff feel it was needed. Teachers appeared to feel more supported when counselling was made available without them having to request it.

*The school that I was at dealt with it very well, the headteacher was very proactive and supportive of staff and students they had counselling in place for everybody who wanted it (P1).*

*As soon as the child passes away, I think they all go for counselling erm they went as a team [...] the whole class team went together I think that was their choice erm...you're offered it either individually or as a team (P12).*

Counselling services were felt to be helpful when staff were given time to be together to remember the child who had died. The following teacher felt that having someone to take charge of the discussion was particularly helpful within group counselling sessions.

*There was another time when they actually got somebody from County erm and different classes in turn who had been involved were given time to er go [...] people were given time to talk about memories and things that they found difficult, things that they you know that they sort of celebrated about that person all the rest of it and again that was helpful [...] I think it was quite a good model in some ways to have that time with somebody to just direct it (P7).*

In addition, existing school staff with expertise in grief and bereavement were also utilised to provide emotional support to staff.

*We are really lucky we have a drama therapist who also sees staff if they need to speak about things particularly to do with work particularly to do with this and she's very available and just after Jessica passed away we had erm...some sessions with her and the music therapist (P2).*

External counselling was more likely to be offered or brought in to school following a student death. However, emotional support is often needed at other times, for example following a medical emergency or an especially challenging day (see

Chapter 6). For these occasions, some schools advertise a phone line which provides counselling support if and when needed. These are usually independent companies or charities that offer general advice and support and are not specific to teaching children with life-limiting conditions (see Appendix 1 for examples of phone line support).

*There's a phone number of someone you can talk to if you needed to so there is support if people feel they need outside support then it's there (P4).*

The following teacher found this phone line support helpful, particularly as the person on the other end of the telephone was not involved in the school or in teaching children with life-limiting conditions. The distance that gave was useful for this teacher in obtaining the support they needed;

*My last school had an independent counselling thing that you could ring up for anything I mean it didn't have to be work related but obviously quite often it was, but it was there if you needed that extra bit of support and sometimes it helps to talk to people not so close to it doesn't it? (P10).*

Some teachers valued this support, whereas others felt they were able to deal with their emotions without the need for professional input. The important thing for the majority of teachers was that the support was offered and made available for them. Teachers seemed to value having the opportunity to speak to someone if needed, but also appreciated the option to refuse this support if they did not feel it was required at the time. However, some teachers experienced issues when trying to obtain emotional support from professional counsellors within school (see section 7.2).

### **7.1.6 Time and Space**

For many teachers, having the opportunity to take some time out of the classroom following a medical emergency or upon hearing the news of a student death was helpful when trying to deal with the associated emotional impact. Teachers found this time important and did their best to try to facilitate this time for all staff involved.

*Generally, as a teacher if it's been a real emergency or something's happened...we'll take it in turns to go and have a cup of tea go and have five minutes and just you know bring ourselves back (P11).*

Unlike in the above situation, within some schools having time and space out of class was facilitated by SLT. This ensured that classes were covered, but at the same time meant the whole staff team could be together following a particularly stressful situation. Teachers found this incredibly supportive and effective in helping to deal with their emotions following an emergency.

*We're offered time out of class if something's happened in class erm we're allowed we'll be covered by management they will go into our class erm and we can have time out to just have time with the teaching assistants if we need to (P16).*

Within some schools, reflection rooms or family rooms were made available for staff needing time and space. These rooms provided teachers with somewhere quiet, away from children and other staff, if they needed time to deal with their emotions.

*I'd say that there are quite big procedures in place we've got a reflection room in school as well that if staff feel that they need to take a bit of time out they can go up there (P18).*

*We set up what we call a reflection room space that like has a candle in it and stuff and staff who aren't coping in the classroom can go there (P6).*

As a last resort for staff who are needing extra support when dealing with the death of a child, some schools allow staff to go home. This time and space at home is directed by SLT with the acknowledgement that staff do react differently to grief and bereavement, some in more extreme ways than others.

*I think that group didn't even come into school they just said they were going home...I think we expect staff to react in very different ways erm and we do allow staff to go home (P6).*

### 7.1.7 Other Sources of Support

Other sources of support cited by teachers involved finding support in their own background, speaking to parents and using their faith to help manage their emotions. Everyone deals with grief and bereavement differently but for a minority of teachers, having a background in counselling or in working in other stressful environments helped them to cope during emotionally charged situations.

*I think that maybe having worked in a hospital helps with that because we used to get phone calls saying we need this and they're bleeding and eurgh panic panic and it's like well I'll just deal with it and you just do it it's just your job and I kind of think of it like that at that point you know this is my job this is what we need to do (P10).*

*I have a background in counselling which is supportive for me (P13).*

A valuable source of emotional support can also be found with parents. Whereas many teachers might see parents as requiring emotional support themselves, the following teacher found that parents were able to provide support to staff, especially when talking through concerns regarding the child's medical condition and their life expectancy;

*I think parents are very good at helping you to understand and to manage your concerns around their children better because erm they've gone through that process [...] they've come to terms with the fact that it's life-threatening and it isn't going to last forever they're still going to be upset and what have you but it's quite good when you chat to them they tell you...they kind of explain things a little bit and you can get your head a bit more around it that helps a bit as well for me (P5).*

Finally, some teachers were able to find support within a faith or religion which they found comforting. This was particularly pertinent when dealing with emotions following the death of a child. The teacher quoted below found their beliefs in life and in God helped to shape their approach to children with life-limiting conditions and helped them to cope when a child died.

*I believe that God has a really special place for very vulnerable children and that kind of frames who I am and how I deal with things and sometimes I think actually that makes it a bit easier for me [...] but that's not to say that it's not utterly horrific and*

*painful for people as it happens it doesn't make it any easier it just...dunno it just it does change your kind of general attitude I suppose (P7).*

## **7.2 Barriers to Effective Support**

It is clear that teachers find emotional support in a variety of different ways. However, not all find obtaining this emotional support easy. Some teachers experience barriers to effective emotional support resulting in the inability to gain much needed support when required.

One of the main barriers to effective emotional support experienced by teachers was in relation to SLT. As discussed in section 7.1.2, many teachers found SLT supportive during emergencies or following the death of a child, however some teachers described difficulties in approaching SLT to request or obtain support. These difficulties included SLT not being approachable, available or present in school when support was required.

*I think...they like to think they're approachable, but they're so busy themselves...that there isn't you'd have to try and find one if you could actually pin somebody down to sit and say...but I mean you can't find them half the time just to ask them simple questions let alone to sit and have half an hour heart-to-heart (P10).*

*No, I don't think so I never know where they are, I mean I could, but I wouldn't think of them to be honest I wouldn't think of management to help me (P13).*

Other teachers felt that SLT would no longer understand the emotional strain of teaching children with life-limiting conditions as many had not taught within a classroom for an extended period of time. Some also felt that SLT lacked experience in teaching children with life-limiting conditions altogether and were therefore unable to relate to the concerns of teaching staff. Without this understanding, the following teacher felt that SLT were therefore unable to provide the emotional support they needed. This lack of understanding and support from SLT could also further negatively impact on the emotions of teaching staff in schools.

*Do you know what would help is if people above us, management actually came and taught because that would help because it would make me heard because then they've*

*done it and then when we have those conversations rather than it being my one-sided it's so awful and going away thinking oh I've just sounded like a really moany cow [...] instead of that then at least they'll be able to relate to it and I don't mean just a day either [...] I mean a week doesn't really give you a real feel but it gives you a much better feel at least and then at least when it comes to that emotional support they have a better idea of what it's actually like [...] they are so far removed that they don't really understand and a lot of them stopped teaching a long time ago and...I don't think some of them have even taught in a class like this, so they just don't have the experience (P2).*

In relation, teachers felt that receiving emotional support from their colleagues was problematic, again due to a lack of understanding. In a similar way to with SLT, teachers felt that colleagues without direct experience of teaching children with PMLD, life-limiting conditions or complex medical needs, lacked an understanding of the emotional impact of the role. This lack of understanding and therefore perceived lack of emotional support from colleagues was found to be frustrating for teachers.

*Yeah, I sometimes think if teachers don't work in those classes they don't understand, and it frustrates me slightly sometimes (P15).*

Counselling was provided or at least made available to staff should they request it in a number of schools (see section 7.1.5), however, some barriers to this support were experienced. The main barrier experienced was the absence of any counselling support whatsoever. In these instances, teachers felt unsupported and felt that the school's bereavement response had not been thought through enough.

*I don't think that enough is done in schools for bereavement [...] it might have been a throw away comment at a meeting when it was announced but there wasn't any [counselling] set up [...] I wouldn't have thought that [SLT] were introspective enough to consider that (P5).*

For other schools, counselling support is something that is being explored and considered but is not yet in place to support staff currently going through bereavements or medical emergencies.

*We don't currently [have counselling support] I know we are looking into it I know it has come up a few times and that we're looking into it erm but currently no (P11).*

Where counselling was in place, some barriers were experienced in terms of the logistics of staff participation. The following teacher felt they could not get the most from the counselling sessions provided in school due to concerns over staffing levels and cover within their class.

*Just after Jessica passed away we had erm...some sessions with her [drama therapist] and the music therapist which again should have been helpful but just fell flat the cover situation wasn't sorted out so the class were not okay and we knew they weren't okay so we were trying to concentrate on what was being offered to us but actually I was thinking I need to be in class [...] it was good that they offered them but again it just wasn't quite thought out enough to make it work (P2).*

Furthermore, the same teacher felt that the length of time counselling support is needed for is heavily underestimated by schools. For many of the teachers interviewed, counselling support was offered immediately after the death of a child and for a short period of time afterwards. However, as the following teacher indicates, not everyone deals with their emotions at the time of the death and therefore may require additional emotional support many months or even years afterwards.

*During that time, they did make it quite clear if you wanted to if you needed to leave and go and speak that was fine, but I think people underestimate the length of time that actually takes because...I didn't really need to talk to anyone then I probably needed to talk to someone two years later, probably around now (P2).*

Friends and family were cited as a source of emotional support for teachers, however, some barriers to this support were experienced again in relation to a lack of understanding. Teachers felt that for people not working within SEND or with children with such complex medical needs, it is hard to understand the emotional pressures of the role. Therefore, gaining support from friends and family can be problematic.

*I've got a really supportive partner who's just like at the time I think they found it really difficult to understand what I was saying just because they have no experience*



*of this environment, people who don't have experience of it can't relate to it, like it's an alien world to these people, like people barely know we exist let alone that these terrible things happen, so I think they find it difficult to relate (P2).*

In addition to a lack of understanding, the following teacher chose not to discuss the details of their teaching role, the children they taught or the child who had died, for fear of upsetting their friends and family, particularly those who were pregnant or with very young children.

*I do find with friends and family or especially ones who've got kids they don't like to hear these stories, the idea of their child going through anything like that, particularly two of my best friends are recently pregnant around the same time and I just steer clear of all the stories that I had mounting up cos I was like just no, let's not do that to them (P2).*

Finally, moving schools following the death of a child was seen as a barrier to receiving effective emotional support. For the teachers that had moved schools shortly after the death of a child, they found that they were unable to talk to colleagues about the child and their death in a way that they maybe would have done if they had stayed at the school. Additionally, moving schools also meant that teachers were unable to go to the funeral which was seen by some as emotionally supportive in terms of gaining closure (see section 5.1.4).

*Since I've moved schools, I haven't really discussed it that much with many people purely because it's not something that generally comes up in conversation [...] maybe I just don't choose to talk about it at my current school I think erm...er...it's not because I don't want to talk about it but I just...I've made the move to a new school (P17).*

### **7.3 Summary**

Teachers experience a huge range of emotions throughout their daily roles and in difficult circumstances such as medical emergencies or the death of a child. To help them to deal with these emotions teachers turn to a number of different sources for support. Understanding the needs and associated stresses of teaching children with life-limiting conditions was one of the main components of effective emotional support. This meant that other colleagues as well as school nurses were best placed to offer emotional support and were a source that the majority of teachers turned to.

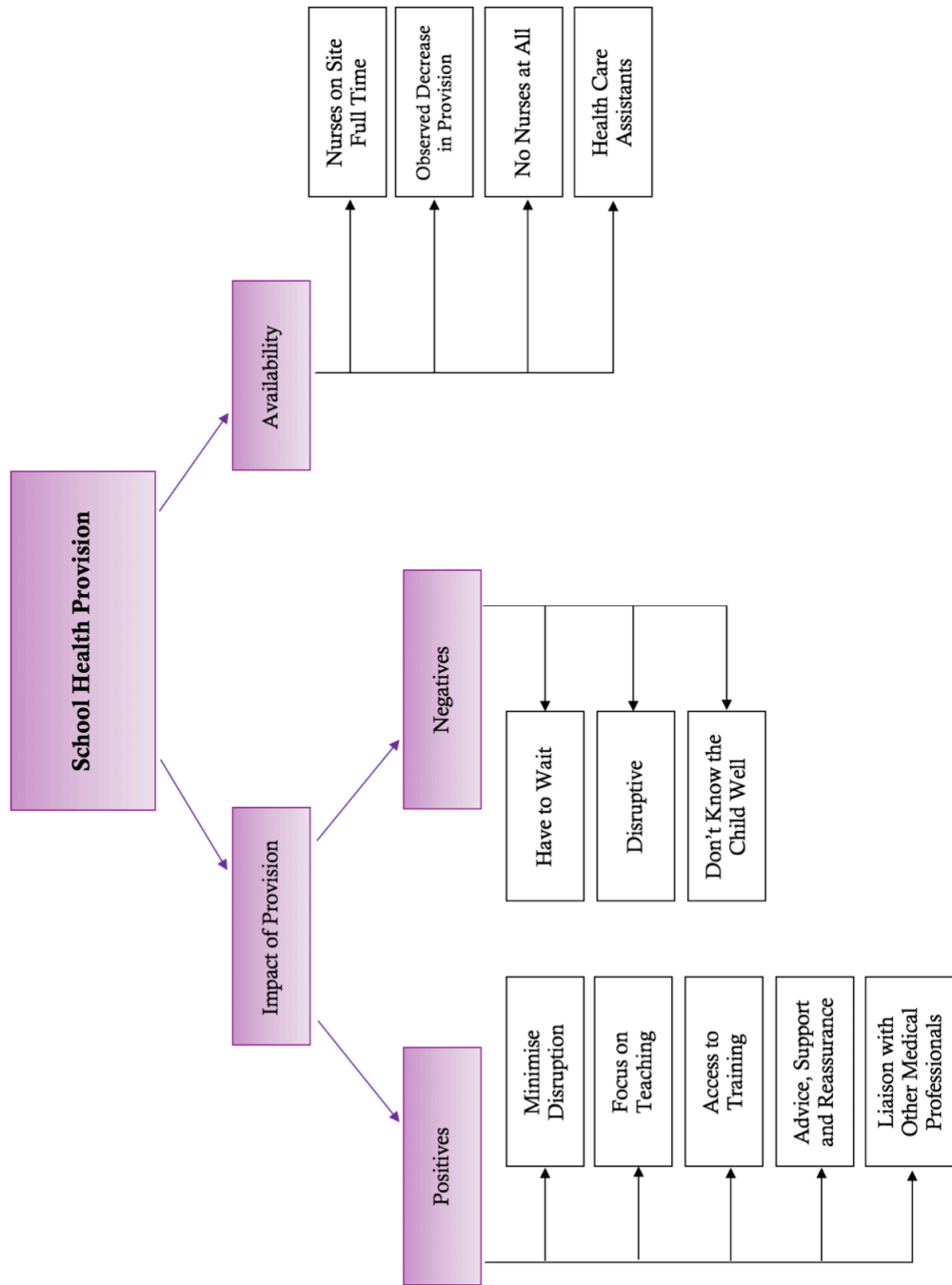
SLT were also in a good position to offer emotional support, particularly if cover was required so that teachers could have some time and space out of class to deal with their emotions. Having an awareness of the emotional needs of teachers in these situations appeared to determine whether SLT were perceived as supportive or not. SLT could also effectively emotionally support their teachers during difficult times by ensuring that professional counselling was available as and when required. Teachers felt the most supported when this counselling was made available without them having to request it. In addition, teachers often turned to friends and family for emotional support. For some teachers, the distance that friends and family had from their teaching role was helpful when seeking support.

It is clear that understanding the unique teaching role participants in this study undertake daily was crucial for effective emotional support. It thus follows that a lack of understanding was a barrier to support that was commonly experienced by teachers. Other colleagues or SLT within the school that had not recently had direct teaching experience of children with life-limiting conditions were perceived to not have the understanding needed to effectively offer emotional support. Similarly, friends and family that lacked understanding or awareness were also not the most effective sources of support. Teachers described not wanting to explain in detail the needs of the children they taught or not wanting to upset friends, particularly those pregnant or with small children.

Emotional support, particularly when involving outside agencies such as counsellors or therapists needs to be well thought through to ensure that staff can get the most from their sessions. Having someone to direct the discussion, not putting limitations on the length of time that counselling is provided for and ensuring that adequate staff cover is provided can all ensure that the support offered is as effective as possible.

## **Chapter 8: Category of Description Four - School Health Provision**

The role of the school nurse is an important one in the care of children with life-limiting conditions. For many teachers, school nurses were responsible for medical interventions such as gastrostomy feeds, administration of medication, oxygen, tracheostomies and suctioning. In addition to these daily medical responsibilities school nurses were also responsible for writing care plans for children with medical needs, supporting parents, staff and students and, perhaps most importantly, responding in emergency situations. However, despite these important roles, access to high-quality school nursing is a challenging area in the current political and financial climate. The teachers in this study described a range of different experiences regarding their access and availability to school nursing provision and its associated impact on their teaching, the care of their children and their own personal wellbeing. These experiences are illustrated in Figure 8.1.



**Figure 8.1:** School Health Provision

## 8.1 Availability of School Health Provision

There were huge differences found amongst teachers interviewed in their experiences of school health provision, in particular in terms of the availability of school nurses in their schools (see Appendix 5). For some teachers, they were lucky enough to have access to a high number of school nurses who were on-site full-time.

*We have constant nursing...we have a whole team of nurses on-site [...] about six or seven (P13).*

*We're really lucky we've got a lot of nurses on-site (P15).*

Whilst at the other end of the scale, there were some teachers who were meeting the needs of children with life-limiting conditions without the presence of a school nurse on-site at all.

*I: Do you have school nurses on-site?*

*T: I think no [laughs] not currently I know that we are looking into...getting one (P11).*

*No, we don't [have nurses], we have TAs who are paid at a higher level to do a variety of those things (P4).*

For almost all teachers, there were some inconsistencies in the availability of school nurses and some experienced times when there was not a school nurse available to them. This posed huge challenges for teachers when meeting the needs of children with life-limiting conditions. A lot of teachers had seen first-hand the decrease in school health provision, in particular the number of school nurses, which they attributed to current budget cuts and recruitment issues.

*We used to have a very good team of school nurses we had them actually based in school they were there full-time [...] and because of various cuts and changes in the NHS structure they're expecting us to do more and more (P4).*

*We do have a nursing team on-site, well we did up until when we go back on Tuesday erm they're now not full-time (P8).*

*Well I'd like it if there was nursing staff definitely all the time on-site and there isn't although that's our aim as a school but it's not always being able to do it and again, I'm sure this is a financial issue (P1).*

*I wish we had a nurse we are meant to have a nurse, but we can't find one at the moment (P2).*

In an attempt to overcome the unavailability of trained school nurses, many schools had sought other options, for example by training teaching assistants to perform medical interventions or by employing healthcare assistants either from the NHS or care agencies to meet the needs of individual children with the most complex medical needs. Many teachers described situations where care staff were specifically employed to look after the medical needs of children with tracheostomies or who had the potential to stop breathing at any time. These healthcare assistants appeared to bridge the gap between education and health in the absence of full-time school nurses.

*We've got three children with trachys and children that can stop breathing at any point er for no apparent reason they just stop...erm, those children who need higher levels of medical care have got...carers with them who are trained to look after those children and it enables those children to come to school because if they didn't have those carers with them then they wouldn't be able to come to school because we haven't got enough nursing staff to be with those children all the time and we're not medically trained to that point [...] most of the carers are not nurses they're just trained by the NHS to work with specific children (P16).*

## **8.2 Impact of School Health Provision**

The impact of school health provision depended massively on the availability of school nurses on-site. As previously discussed, there were inconsistencies across all participants in terms of the level of school nursing cover they experienced in their schools. The impact of this provision is therefore variable.

Where school nurses were on-site full-time, many teachers discussed the positive impact they had on experiences in class. For example, where school nurses were available to carry out routine medical interventions such as gastrostomy feeds,

tracheostomy changes and suctioning, teachers felt that they had more time to fulfil their roles as educators.

*Because we've got carers and we've also got nurses on-site you can afford to just pass that side of it over to someone else and you can get on with teaching the rest of the class (P10).*

The presence of school nurses or healthcare assistants on-site was also found to minimise disruption in class. Instead of losing a teaching assistant or having to stop lessons to administer medication, feed a child via a gastrostomy or complete a tracheostomy change, school nurses and healthcare assistants were able to do this without interrupting the teaching and learning of the class.

*We get someone who comes round to do that to sort of minimise disruption if you like because you lose a member of staff that then needs to go and draw the medication up then will need to come back and administer it and then go back and sign it whereas if we've got one person in school who can do that, that sort of relieves the stress on the staff (P18).*

*[The nurses] dip in and out they literally they've got like a timetable and it's 9.30 this class, such and such a child, 9.40 that class and they literally go from class to class all day doing interventions (P7).*

The following teacher discussed the long-term absence of their school nurse and the resulting impact that will have on their class and their teaching:

*The nursing thing is going to be really tricky I think coming up this term and next term that's gonna be the thing that will it really matters it dictates how we do as a class we have to spend a lot of time feeding and nursing and things if I have to do more meds and things (P12).*

On the other hand, however, having nurses complete all of the medical interventions and administration of medication can have a negative impact on the class and the child, particularly if nurses are busy and children are required to wait for their medication or intervention.

*I've had a case where I had a child with asthma and I said oh I need his inhaler and she said we're just doing our drug round I'll fetch it in an hour, oh no he needs his inhaler now (P10).*

*With the nurses you have to wait and that can really impact on things like positioning and moving the sessions (P3).*

In addition, the constant interruptions of nursing staff coming into classes to perform medical interventions can be hugely disruptive when teaching, particularly as children often need a quiet, calming and distraction-free environment.

*It's like teaching in a major terminal there's always someone in your room [...] you know the nurses; the carers are in and out getting their medication cos they have to fetch their own medication and then they're coming in and putting the feeds on they come in they take the feeds off it is really hard to keep a routine going (P10).*

A further positive impact of having school nurses on-site full-time was in enabling children with the most complex of medical needs to attend school safely. For some, the unavailability of nurses on-site meant their most medically complex children could not be in school. Thus, having nurses on-site full-time was of huge importance and had a massive impact on the education and wellbeing of children.

*We've got two children that are not allowed to be in school without a nurse being in school so if there's a nurse not available we have to let those parents know that they're not in erm, so we do have a nurse all the time (P14).*

*We are dealing with children that otherwise would not be getting an education, and everyone is entitled to an education [...] a lot of these children wouldn't be in education at all if it wasn't for the therapeutic and medical input (P9).*

One of the most positive impacts of having school nurses on-site was in terms of access to training for staff. Almost all teachers expressed how quickly and easily staff could be trained in medical interventions including the administration of emergency medication and gastrostomy feeds by the nurses who were on-site. This made a huge difference to how well their classrooms ran and the extent to which they could meet the medical needs of their children, particularly if new staff came in or if children present with new medications or require new interventions.



*Being able to get the training really quickly so they've done all the training on the job in school, we've not had to wait for someone to come in except for the really specialist stuff we've got one girl with a Vagus Nerve magnet so someone specialist came in to do that but other than that you know the oxygen training she was able to just come in and do so that's made it really easy that we've not had to...wait for other training to come in (P3).*

Teachers valued the input of school nurses where and when available. They expressed feeling lucky to have school nurses on-site, particularly in the event of a medical emergency when they could turn to nurses for support, advice and reassurance. This was of particular importance given the severity of medical need within special schools and the potential for children to become gravely ill (see section 7.1.4 for a discussion of the emotional support school nurses offer within schools).

*They're very useful to have around because you know if there is a seizure going on, you're timing it and if they're not coming around you can go and get the nurse and they can come in and take over (P18).*

As well as support and advice during a medical emergency, many teachers expressed that nurses were also able to offer support and advice in routine situations or with regards to a child's general health and wellbeing. This included being able to liaise with other medical professionals such as dieticians, consultants and physiotherapists including being able to refer a child for further medical input at a teacher's request.

*I can ring over and ask for some advice or I can try and book something or to make a referral [...] I can contact the nurses involved and ask them to make a referral (P13).*

*We've always had a nurse on hand to come and have a little look and they might even refer on, they can then go and contact the nutritionist who can then go out to the family and investigate it that way, so they can sort of pass things on if we have any medical concerns they can bring it up at the medicals that happen at the school (P18).*

Teachers also felt that a positive of having access to school nurses was in being able to have the most up-to-date medical information about the child, ensuring that they received the best care possible whilst at school.

*I think because they're on-site they can access erm like records if they've had hospital appointments or if they've been in respite and it's a healthcare respite they can see the notes of that or they know the community team, so they've got those health links out so rather than me having to ring this person or that person they're kind of that person to go to for that (P3).*

In contrast, where school nurses were not available on-site full-time, teachers felt they did not receive this level of support and reassurance around medical emergencies or routine health concerns. Where teachers were reliant on a nurse at the other end of the telephone, or a range of nurses who came into school on an ad hoc basis to provide cover, it was felt that these professionals did not get to know the children as well as if there was a full-time nurse situated at the school. This meant that during medical emergencies teachers felt more responsible for making medical decisions which left some feeling uneasy.

*We do call the healthcare assistants in in those situations or if we have sometimes we do have a nurse on-site we borrow one from another school sometimes erm, so they do come and help, the problem is that I find as a teacher they don't actually know the child that well, so you do end up making decisions that...leave you a little bit out there I think (P2).*

### **8.3 Summary**

The teachers in this study described a wide range of experiences in relation to the availability of school health provision within their schools. Some teachers were lucky enough to have access to a high number of school nurses, on-site at all times. For others, teachers were expected to care for very medically complex and vulnerable children without nursing support.

Teachers who had access to full-time school nurses found them to offer support and reassurance during medical emergencies. Medical training was easily accessible when conducted by an on-site school nurse and having nurses perform medical interventions was found by some to reduce the number of medically related disruptions within the classroom.

Where school nursing provision was unavailable or inconsistent, many teachers felt that this was due to funding and budget cuts as well as recruitment issues within the

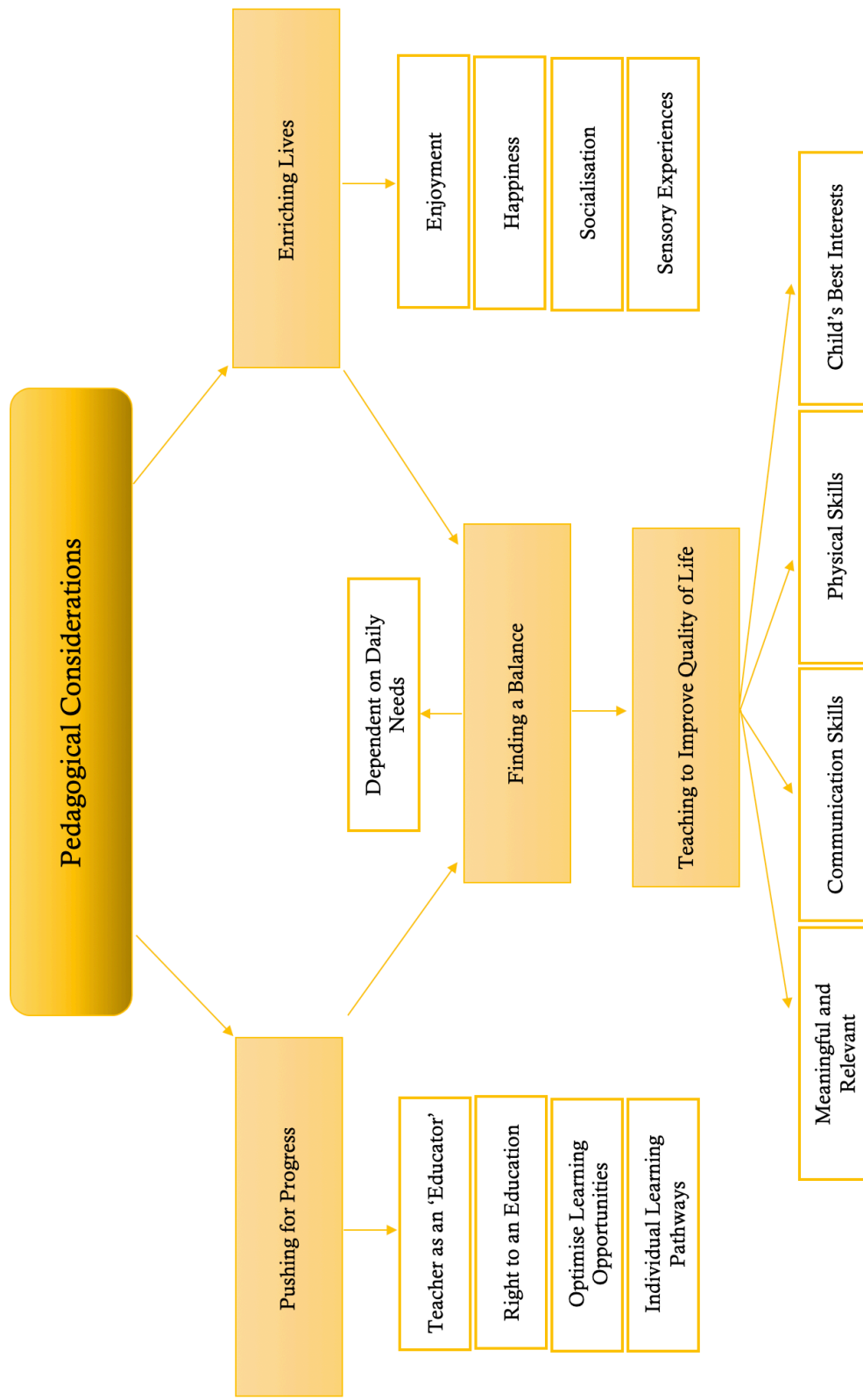
NHS. In an attempt to cover for this shortfall, many schools were found to be employing healthcare assistants from the NHS or external care agencies to care for individuals with the most severe medical need. In other instances, schools were training teaching assistants at a higher level so that they were able to carry out medical interventions such as gastrostomy feeding and the administration of medication.

On a more negative note, teachers who had worked with and without school nurses felt that having nurses carry out the majority of medical interventions was actually more disruptive within the classroom, particularly where children had to wait for vital medication. In addition, the inconsistencies in nursing provision also meant that teachers were unsure of which nurse would attend in an emergency and whether they would have a good working knowledge of the child. This led to teachers feeling as if they had to make important medical decisions without the proper support from a familiar nurse.

## **Chapter 9: Category of Description Five - Pedagogical Considerations**

Ensuring that the curriculum is relevant and meaningful for children with life-limiting conditions was a challenge identified by many of the teachers interviewed (see section 5.4) and appeared to stem from decisions made by SLT about whether to follow the National Curriculum or not. This challenge however, led to a discussion by all teachers of whether the priority within the classroom should be on academic attainment or whether a focus on ensuring quality of life would be more appropriate. The teaching priorities discussed within this chapter have been intentionally separated from the curriculum pressures experienced whilst at school as they are unique to each individual teacher and based on teachers' own reasoning and life experiences rather than decisions made by school leaders or policy-makers. There were similarities and differences in the responses of teachers to this discussion which have been illustrated in Figure 9.1.

Within the subsequent sections, each pedagogical consideration will be discussed in relation to why teachers believe it to be a priority within their classrooms and how it impacts on their practice. A discussion of how teachers attempt to marry the two in order to find a balance they are comfortable with will also occur.



**Figure 9.1:** The Pedagogical Considerations of Teachers Interviewed

## 9.1 Pushing for Progress

For some teachers, particularly those with a strong mainstream background, their main teaching priority was of an academic nature. Their identities related primarily to being an 'educator' and therefore aimed to further the academic abilities of children in their class, regardless of their levels of medical need or stage of life. As illustrated in the following quotations, some teachers found the child's condition to be a motivator for stretching and pushing them as far as academically possible.

*For me as an educator...it pushes me I suppose to do as much as I can with the students [...] we're almost 1:1 in this room so we have that provision to get as much challenge as possible for the students, as much opportunity for them to make progress [...] I don't dwell on the fact that their conditions are life-limiting I just get on with it push them to achieve I suppose that's the way that I am really (P1).*

*Dealing with the child as they are now, I want to make the absolute most of their abilities and stretch them as much as we possibly can at whatever degree (P4).*

In addition, many of the teachers who prioritised the more academic nature of the role believed that all children regardless of their levels of medical need had a right to an education.

*They've all got a right to be at school and to be educated to whatever level that they need to be (P16).*

*From an education point of view, they, they are all entitled to receive an education erm and it must be appropriate to them (P17).*

The following teacher felt very strongly that this should be the case to avoid returning to a 1970s viewpoint that children with SEND were 'uneducable'.

*I think otherwise you'd go back to the sort of...considering those children uneducable which I don't think we should ever go back there (P11).*

In relation to this, a further teacher emphasised the importance of repeating learning opportunities, particularly given that these children learn at a much slower pace than typically developing children. Thus, a pedagogical consideration for them

was in not giving up, always pushing for progress and as such providing effective learning opportunities wherever and whenever possible.

*If it looks like it's not gonna work the first time it doesn't matter you give the opportunities again and again and again a child that looks like they're not gonna develop a certain response that we're looking for who knows they might one day and it's our job to make sure we keep giving them opportunities (P8).*

Teachers ensured they were able to push for as much academic progress as possible by adapting their pedagogy to cater for the unique and individual needs of their children. Due to the vast range of educational and medical needs, focusing on individual learning pathways ensured that each child could be adequately challenged. This pedagogy also ensured that teachers could be focused on individual next steps to ensure that each child was able to reach their full potential, as the following quote illustrates:

*We've gone very much into what we call ILPs which is instead of IEPs it's Individual Learning Pathways and so we set targets that fit in really well with EHCPs because we look at 3 or 4 of the outcomes, talk about it with the parent you know what your actual priority for your pupil is, what do you want them to be able to do at the end of the next key stage or the next transfer (P6).*

Additionally, focusing on individual learning pathways ensures that the most is made of times when children are healthy, awake and ready to learn. This was something identified previously as being a challenge for teachers given the amount of teaching time lost to medical interventions, seizures and time spent asleep (see section 5.5.2)

*You know you just got to pounce on them when they're ready to learn really (P18).*

For one teacher, prioritising this academic side of teaching caused conflict with support staff who appeared to favour a more caring approach for these children. This was also expressed by another who highlighted that support staff would prefer to comfort and do nice things with children who were approaching the end of their lives, rather than focus on activities of an educational nature.

*I did get frowned at a few times for getting 10 minutes work out of Jasmine erm just before lunch but otherwise we wouldn't get any work of her (P1).*

*All of my team they just want to give the kids a lovely time they're not really there for the education they're there because they want to give the children a nice time [...] my staff would do away with the curriculum altogether I think and just take them out on walks and take them to the park and stuff (P12).*

Pushing for academic progress was seen as important amongst some of the teachers however, others disagreed that this was the most important priority within their classroom. Instead, at the other end of the spectrum, teachers placed greater emphasis on ensuring quality of life for their students.

## **9.2 Enriching Lives**

In contrast to those who expressed the desire to push for progress within their teaching, other teachers felt that because of the shortened lives of their children, their main priority was to provide the most positive experiences possible to enable children to enjoy their lives to the utmost whilst they still could.

*I think that given they've got a life-limiting condition and they've got massive medical needs my job's actually to give them as many good experiences in that time as they can and whether they make progress upon a piece of paper is kind of secondary and it doesn't stress me, I'd much rather know that I've given that child lots of experiences they might not have had otherwise and that they've had a good life (P10).*

Reasons provided for this viewpoint were the acknowledgement that for some children, their parents are unable to provide nice experiences and that due to the complexity of their medical needs and the sheer quantity of medical equipment required, children may not be able to leave the house to enjoy new and exciting experiences that may enrich the time they have left.

*It's important to make a difference to the children [...] you have the ones who you know that when they leave school they go home, and they don't leave the house again until they come back to school and those are the ones that you really need to give all those experiences to because the parents just for whatever reason can't give them that (P10).*



These teachers appeared to prioritise an enrichment approach because of the knowledge that these children would not be alive for very long. This awareness caused teachers to reflect on their practice and influenced their choice of teaching activities. Rather than prioritising activities that they knew children needed to progress academically, teachers instead focused on sensory experiences they felt the children would enjoy and gain pleasure from.

*I think you [sighs] you want to do the best job possible because you know that their lives might be short [...] you reflect on your practice and you think oh well let's make school as nice as possible or (...) as fun as possible maybe [...] so I know Annie is never gonna speak French but she might like to smell a baguette, listen to some French music...you don't know what they're taking in and I think...just because we don't know doesn't mean we shouldn't do it (P11).*

Some teachers acknowledged that ensuring quality of life for these children opposed the usual school priority of making, demonstrating and recording progress. However, despite this acknowledgement, they argued that providing such wonderful sensory experiences and the responses gained from them, was of much more importance than anything that could be recorded within progress data.

*Sometimes sitting out in the sensory garden exploring the things exploring the senses you can't plan for those times you can't tick boxes but actually you can get those amazing responses [...] we can get so hooked up on data at the end of the day we're dealing with children and actually let's make every day count (P14).*

*If it means going outside and making a mess or listening to music that they like or visiting a coffee shop that they really love to go to then I do think it's the most important thing (P15).*

One of the other main considerations when prioritising enrichment activities within the classroom, was children's happiness. For many teachers their main aim was to ensure that children were happy whilst at school, something they could do by promoting enjoyable experiences rather than pushing for academic progress that may be unattainable.

*I want them to be happy so there are other children where I might be like oh we need to do this for their own good it's not going to make them happy but we're going to*

*teach stop and wait and all those things whereas with them I'm more like everything that they can possibly want that will make them enjoy their day [...] it's what will make them the absolute happiest they can for...as long as they can (P2).*

A further aim for this group of teachers, was one of socialisation; ensuring that these children had access to people as much as possible throughout the day. For the teachers who prioritised this approach, it was felt that having people around the children would help them to be less isolated, engage further with their environment and increase their enjoyment of experiences.

*I really try to make sure they have people with them as much as possible like just someone to talk to, someone to sing a song quietly in their ear just those sorts of things [...] cos I just I feel like that for them...they can get so isolated (P2).*

*We've definitely changed the erm the emphasis of how we approach her time in school so [...] we definitely put more emphasis on her having contact with peers (P8).*

Despite these arguments for ensuring quality of life as the main pedagogical priority within the classroom, one teacher sometimes struggled with the idea principally in terms of their teaching identity. In particular, the following teacher found that although they placed importance on providing fun and different sensory experiences for children, sometimes they felt they were more of a childcare service than a teacher.

*Sometimes as a teacher with the PMLD children you tend to think that you're not actually a teacher you're more like a nurse or erm...childcare in a way sometimes because you're not actually teaching them anything, you're just giving them lots of experiences (P16).*

To overcome this feeling and in an attempt to marry the two approaches, many teachers discussed having to find a balance in their prioritising of quality of life and academic attainment within their classrooms.

### **9.3 Finding a Balance**

As previously established, there is a great deal of demand on the school day when working with children with life-limiting conditions in special schools. The requirements of medical interventions, education, physical and positioning needs

can influence the priorities that teachers have within the classroom. For some teachers, their priorities do not fall within either end of the academic attainment versus quality of life spectrum. Instead, some teachers acknowledge the importance of both and therefore attempt to balance the two within their teaching. Teachers often find themselves balancing these priorities on a daily basis and have found that this heavily depends on the needs of the children that day. For example, as the following quote illustrates, on days when children are alert and well, their priority might be in terms of advancing their academic attainment. However, on days when children are experiencing a lot of seizure activity, are sleepy or unwell, their priorities may switch to more of an enrichment approach ensuring that children are as happy and as comfortable as possible.

*I suppose as a teacher it's difficult to get the balance of...medical needs, education, physio and all of that sort of thing really, I find it has an effect on your classroom practice how you organise and structure your day [...] I'm not saying that erm their education isn't important at all it'll just be that day that might take the priority...over something else (P11).*

At first, teachers new to the special school teacher role expressed finding this balance difficult, especially given that their mainstream identities had been heavily based on their students making academic progress.

*I felt a real pull when I first started between the care needs and the teaching (P18).*

However, in an attempt to overcome this, one important aspect of finding a balance between quality of life and academic progress for these children was perceived to be in terms of ensuring their readiness to learn. Many teachers overcame this pull by recognising that children who were unhappy, uncomfortable or in pain would not be in an optimum position to learn. Therefore, their priorities within the classroom became about balancing their positioning and physical needs with academic activities.

*I think if they're not getting their physio, their stretches, their change in positions and things like that then you're not gonna be able to educate them anyway because they're not gonna be comfortable [...] once they're healthy or having the care they need in the medical side of it and they're positioned correctly and they're having their stretches so they're not getting tight and in pain then you can start to look at education (P16).*

Once teachers felt that they had found an adequate balance between academic attainment and quality of life within the classroom, some teachers took this one step further to look at the purpose of what they were teaching in a further attempt to combine the two extremes.

#### **9.4 Teaching to Improve Quality of Life**

Some of the teachers interviewed expressed their views that quality of life was more important than academic attainment for children with life-limiting conditions. However, unlike the group of teachers whose main priority was pushing for academic progress or the group of teachers who primarily focused on enrichment activities, some teachers attempted to further combine the two, by ensuring that what they taught children with life-limiting conditions was meaningful, relevant and ultimately, improved their overall quality of life.

*What we're teaching them should improve their quality of life and if it doesn't then we have to ask the question why are we doing this? (P7).*

*The way you look at quality of life for them is different so that's why I still do set targets and I still do things around you know I want them to learn to read and to do this but it's not because I feel the need to teach them something it's because it will improve their quality of life (P3).*

One of the main reasons for this viewpoint was in terms of ensuring children had the best quality of life for as long as possible. The following teacher felt this was important given the unknown medical advances that could occur over the coming years. As such, they did not feel comfortable in just providing nice experiences for their students. Instead, they wanted to teach things that would improve their lives both academically and physically, with the ultimate aim of helping them to live for longer.

*You always sort of have to think you know I'm doing this so that they can live longer so that they can move forward you know, and medicine is getting better all the time you just don't know what's going to be out there (P11).*

In contrast, another teacher felt that it was important to think carefully about what they were teaching and whether it would improve a child's quality of life given that

their lives are shorter. They felt they had to make the most of the time they had in school and did not want to waste time teaching things that were irrelevant to their shortened lives.

*Their time is so precious it takes a long time to learn and to make progress therefore we have to choose the things that we teach carefully because we don't want to waste their time (P7).*

For the teachers interviewed, similarities were found in their priority of the teaching of communication skills to improve children's quality of life. Teachers felt that if children were able to communicate with others, as well as have some control over their environment, then they would have a better overall quality of life as a result. Therefore, within their teaching, many teachers focused on ensuring children were learning to request things, demonstrate their preferences and use switches or eye gaze to communicate with others.

*You're just looking for things that are meaningful for them at the moment, so they tend to be around communication, switch use, erm environmental control erm use of eye gaze you know they tend to be targets that we hope will improve their quality of life (P6).*

In addition, the teaching of physical skills through physiotherapy, rebound therapy, personal care routines and occupational therapy was also deemed to be important to a child's quality of life. Teachers who prioritised these skills did so with the knowledge that as children got older and bigger, maintaining some independent movement would improve the lives of not only the children themselves, but their parents and carers too.

*So, having worked with the older children and knowing how difficult it can be to change some of those we can put in place some of the skills like rolling from side to side erm we can start doing that down here so that they're more able to do it hopefully when they're up the bigger end of school to make it easier for staff and parents (P3).*

Despite this, teachers expressed the need to constantly review what they were teaching whilst having the child's best interests in mind. The following teacher was not afraid to question why they were still persisting with activities that the child was not benefitting from. As such, the teacher was able to adapt their teaching to ensure

the child was getting the most out of their time at school with the aim of improving their quality of life.

*It just reached a point with him that I questioned with the physiotherapist whether it was actually good for him anymore to do it because he was definitely regressing with it we had other ways of trying to extend his legs and move his bones and his muscles erm...so sometimes I think you just have to be aware of whether you're doing something because it's written on a plan somewhere erm whether you're doing something because that child is receiving their education or whether you're doing it for their quality of life and how essential it is for them at that point in their lives yeah erm it's a tricky balance to find (P17).*

Ultimately, teachers who prioritise teaching for quality of life, do so to ensure that, as teachers, they have the most impact possible on their students. They think carefully about what they are teaching and have a continuous awareness of the needs of their students. This ensures that they are able to provide an education that focuses on the children and what is best for them given their shortened lives.

*It's all about why we're doing what we're doing what they're going to get out of it so for children where we know their learning is limited and their life is limited, it's like what are the best things that we can offer so I think that's the thing that I'm constantly thinking about when I'm teaching is, is this the most appropriate thing [...] it makes me really try and pinpoint what I want to do (P3).*

## **9.5 Summary**

The teachers in this study held a range of different beliefs about what was a pedagogical priority within their classroom. For some teachers, particularly those with strong mainstream backgrounds, their main priority and focus was on pushing the children and stretching them to develop their academic abilities. They did this with the belief that they were primarily employed as educators and that all children had a right to an education, regardless of their level of understanding or medical need. Other teachers approached their role with more of a caring identity. They believed that due to the limited nature of children's lives, their main role was in ensuring that children were happy and comfortable, and as such prioritised providing quality experiences that would enrich the lives of their students.

In an attempt to marry the two ends of the spectrum, some teachers expressed the need to find a balance between providing nice experiences at the same time as making academic progress. For these teachers, this balance depended on the daily needs of the children. Teachers acknowledged that when children were less well, their focus would be more on providing experiences to ensure children were happy and comfortable, but at the same time, ensuring that staff were ready to optimise learning opportunities when children were alert, awake and ready to learn. Another way that teachers attempted to address the academic progress versus quality of life debate was by ensuring that what teachers taught to their students actually improved their quality of life. To do this, teachers expressed the need to think carefully about what was meaningful and purposeful for their students given the limited nature of their lives.

What is clear from the ways in which teachers discussed their pedagogical considerations, is that for many, they did not appear to fall completely into one side of the debate. Almost all teachers could see both sides of the argument and found that, depending on the needs of their students, their priorities could change on any given day. All teachers however overwhelmingly, yet not surprisingly, wanted the absolute best for their students and cared deeply about their time in school.

## Chapter 10: Discussion

This chapter aims to bring together the findings of this study as presented in the previous five chapters. As the outcome space has already been illustrated and discussed in Chapter Four, within this discussion the findings will be examined in more detail, with specific reference to the existing literature and associated implications. Finally, this chapter will discuss the limitations of this study and recommendations for further research.

This study aimed to explore how teachers encounter, conceptualise and understand their experiences of working with children with life-limiting conditions in special schools. Supplementary research questions (see section 1.3) aimed to explore the educational biographies, pedagogical constructs, day-to-day experiences and actions and emotions of eighteen teachers who work with children with life-limiting conditions in special schools. As such, the discussion of the findings section is divided into five parts. Firstly, the day-to-day experiences of teachers will be explored, including in relation to the significant curriculum, assessment, time and medical challenges encountered. Secondly, the pedagogical challenges and considerations will be discussed, particularly in terms of whether teachers favour a quality of life approach over traditional academic based teaching for children with life-limiting conditions. Thirdly, how teachers experience and deal with the death of a child will be discussed. Although this was not a specific supplementary research question, the overwhelming experiences of the teachers interviewed, including the frequency with which student deaths are experienced, makes this a significant part of their educational biographies. Fourthly, the actions and emotions of teachers will be explored in relation to the impact they have on their professional and personal lives. Finally, the emotional support that schools can offer teachers will be considered, to develop resilience and help teachers cope with the difficult experiences they face throughout their teaching careers.



## 10.1 Day-to-Day Working Experiences

The teachers in this study were invited to reflect upon their day-to-day working experiences of teaching children with life-limiting conditions. In doing so they described a number of significant challenges that were encountered including curriculum and assessment pressures, time pressures and dealing with medical emergencies. The availability and quality of school health provision also proved to be a large part of teachers' day-to-day experiences when working with children with life-limiting conditions.

Within the literature and within the current political climate, specifically in relation to the Rochford Review (Rochford, 2016), there is much discussion about the relevance of the National Curriculum for children working within the earliest stages of development, typically those who have PMLD. Many believe that the National Curriculum is no longer relevant for children with PMLD and complex needs (Grove & Peacey, 1999) and are instead creating their own curricula to meet the individual needs of these children (Rayner, 2011). A range of curriculum approaches were used by teachers within this study. Some teachers were still having to teach to the National Curriculum, whereas others were at various stages of creating their own curricula to better meet the needs of children working at the lowest developmental levels. Criticisms of the National Curriculum in this study included the relevance of abstract subjects for children with little understanding of the world around them, in addition to the focus on the future, examinations and assessment. This supports the notion that the National Curriculum is no longer relevant for children with life-limiting conditions (Grove & Peacey, 1999).

The National Curriculum and the requirement to teach within it was a source of frustration for the teachers interviewed. Instead, many described wanting to teach a life-skills based approach with a focus on communication (see section 9.2). There was evidence within the interviews that curriculum change is starting to happen, with some teachers describing situations whereby they have time set aside to meet with others within their departments to look at their curriculum models. This adds weight to the work of Lawson et al., (2015) who found that a move away from the National Curriculum is beginning. As the research interviews were held around the time of the Rochford Review (Rochford, 2016) and prior to government policy changes based on Rochford's (2016) recommendations, there was no evidence of

the widespread use of the engagement materials (Carpenter et al., 2015) for assessment or as a basis for a new curriculum. Further research in the coming years would be of benefit to determine whether the Rochford Review (Rochford, 2016) has had any impact on the curriculum model and assessment for children with life-limiting conditions.

Assessment was also found to be a significant challenge within teachers' daily experiences. In a similar way to the curriculum model, many teachers felt that assessment processes were no longer relevant for children working at the earliest stages of development. One of the main criticisms of assessment models used was their linear approach. Children with life-limiting conditions often have long periods of illness, non-attendance or degenerative conditions whereby skills may be lost temporarily or permanently (Aruda & Newinsky, 2011). As such, the progress of these students does not follow a straightforward linear pattern, instead it is often spiky or can regress. For teachers, this posed issues in terms of the setting of targets and reporting of progress, a finding that replicates that of Ekins et al. (2017). In an attempt to overcome this issue, some schools acknowledged the maintenance of a skill as a measure of progress. However, this was not the case for all schools. It appears that having SLT who are able to acknowledge the impact of a child's medical condition and correspondingly adjust their expectations of progress, helped teachers to overcome the frustrations of an inappropriate assessment model.

A further criticism of assessment models, particularly around the outward-bound P-Levels was in terms of the narrowness of skills measured. Teachers found the P-Level descriptors frustrating because they did not measure the full extent of the progress that children were making. As previously stated, these P-Levels are in the process of being replaced with engagement criteria and pre-key stage standards (Rochford, 2016) and so future research could be usefully conducted into the impact of these changes to teachers' experiences of assessment for children with life-limiting conditions. Nonetheless, it was found that some teachers were still required to assess children with life-limiting conditions using assessment models that were not fit for purpose. Teachers described battling with SLT over the lack of progress for some children, suggesting that there may be a lack of understanding and awareness on the part of SLT when it comes to the areas of PMLD and complex medical needs.

Teachers discussed their preference for recording progress in more informal ways, for example with the recording of ‘wow’ moments or positive experiences. They described the need to do this to record memories for families, particularly if a child was nearing the end of their life. Others felt that recording progress or experiences throughout lessons helped to keep an emphasis on the importance of school for children who had degenerative conditions or required palliative care. It was felt by some that if recording of experiences and progress was not required, then a child’s access to school-based activities could be jeopardised. Teachers’ views on the recording of progress and curriculum models was found to be heavily related to their views on what was a priority for children with life-limiting conditions (see section 10.2).

Time pressures were found to be a significant daily challenge for teachers. Children with life-limiting conditions are characterised by a wide range of needs, for example, medication, physiotherapy, regular positional changes, tube feeding, personal care and so on. These needs are all in addition to the need to be educated. Teachers found themselves struggling to fit everything in to the school day and often had to make decisions about what was most important. According to Maslow’s hierarchy of needs (Maslow, 1943), as seen in Figure 10.1, it thus follows that without the physiological needs of students being met first, education, and therefore progress, is impossible.



**Figure 10.1:** Maslow’s Hierarchy of Needs (McLeod, 2018).

As such, teachers in this study found that they were constantly juggling the daily needs of their students. Many found that after they had met all of the physiological needs of their students there was little time left to fit in any educational activities. The requirement to teach to the National Curriculum, in addition to staffing levels and unrealistic expectations from SLT, contributed to the stresses of trying to fit everything in. Some teachers acknowledged that on some days, all they did was care for their students and battle to meet all of the medical needs that arose. For teachers with a mainstream teaching background, days spent caring for their students caused anxiety around whether they were doing their best educationally. Similarly, Durrant et al. (2014) also found that teachers in their survey were anxious about having enough time to fit in a child's educational and care needs. Indeed, the teachers with experience of children with life-limiting conditions described similar instances of days when a child's educational needs became secondary to their care needs.

To overcome these issues and attempt to fit in more educational activities, teachers described having to optimise learning opportunities and 'pounce' on children as soon as they were alert and ready to learn, regardless of the time of day. Utilising teaching approaches such as learning carousels or individual learning pathways can help to ensure flexibility within the teaching timetable to meet all educational and medical needs. Furthermore, it can also ensure that children are making progress on their unique, individual trajectory regardless of the severity of their medical condition. The use of individual learning pathways found within this study supports the work of Carpenter et al. (2010) who advise that children with life-limiting conditions require this approach in order to meet their unique and challenging needs.

Communicating with parents was another day-to-day experience that proved challenging for teachers of children with life-limiting conditions. Firstly, because the majority of children attending special schools come into school on local authority transport, the traditional teacher-parent contact at the school gate is lost. Therefore, teachers had to work hard to facilitate contact with parents in other ways. The use of the home-school journal was utilised by all teachers in this study as well as regular telephone contact. These attempts to communicate with parents refutes existing findings that communication between teachers and parents of children with life-limiting conditions is poor (Asprey & Nash, 2006; Robinson &

Summers, 2012; Rozsahegyi, 2008), though it is important to note these studies focused on the views of parents and not teachers. Relationships between teachers and parents were found to vary significantly throughout this study. Teachers often described some parents being incredibly involved in the care and education of their child, whereas others did not want to engage with school at all. This posed issues in terms of spending considerable amounts of time offering emotional support to parents who needed someone to talk to, or, on the other hand, not knowing whether a child was physically well, experiencing levels of seizure activity or why they were unusually tired upon their arrival at school. The latter concern supports previous findings that a lack of support from parents can impact on the school's ability to support a child with a medical condition (Boden et al., 2012). Variance in teacher-parent relationships was not found to be influenced by the severity of a child's medical condition. Instead, some variance was found depending on how old a child was. Parents of older children were found to engage less with school than parents of younger children.

Teachers valued strong relationships with parents and tried hard to facilitate them. In doing so, teachers often found themselves offering emotional and practical support to families. Many teachers found the giving of this support a large part of their role. Where this can be seen positively, in terms of providing a bigger picture surrounding the child, being able to target experiences to a child's preferences and providing access to practical support that may otherwise be outside of a school's remit, negative effects were also found. Due to the shared understanding that teachers had with parents regarding the needs of their child, teachers often found themselves subject to angry or frustrated parents. This was found to have a negative impact on their emotional wellbeing. Durrant et al. (2014) also found that gaining medical information from parents was difficult due to the emotional trauma they were experiencing. In addition, these findings support those from Price et al's (2013) focus groups who also found that teachers were often on the receiving end of angry and upset parents which affected their emotional wellbeing.

Gaining medical information from parents was also found to be challenging, regardless of the strength of the teacher-parent relationship. Parents of children with life-limiting conditions often have many medical appointments to attend with a number of different healthcare professionals. When reporting the outcome of these appointments, parents can misinterpret or forget vital information which was found

to upset, confuse and frustrate teachers. This finding replicates the work of Mukherjee et al. (2000) who also found that teachers within their focus groups were concerned by the medical inaccuracies parents communicated to school. Some schools in this study had developed the role of the family link worker to address these issues, for example, by attending medical appointments with parents to ensure that both parties had the most up-to-date and medically accurate information possible.

Furthermore, gaining medical information and support from other professionals was also challenging. Unlike the teachers in Durrant et al's (2014) study as reported in Ekins et al's (2017) handbook, due to the specialist knowledge of teachers in special schools, the teachers in this study were aware of the services available and which professionals to contact. However, teachers described frustration at the lack of other services or their inability to provide timely support, adding weight to the finding that demand for specialist services is still not being met (Rayner & Male, 2013). Some improvements had been seen with the introduction of EHCPs (DfE, 2015a) providing forums for professionals to come together and share the bigger picture around each child. However, some issues remained in terms of the sharing of information between professionals, with teachers reporting that medical professionals were not as forthcoming as they would like.

Medical emergencies were regularly experienced by teachers in this study and often involved a child having a prolonged tonic clonic seizure or who had stopped breathing. These emergencies usually happened quickly with little warning and therefore teachers described needing to constantly monitor what was going on with their students. This mirrors the findings of Boden et al. (2012) and Jones (2005) who also found that teachers were conducting constant surveillance of their children for signs of medical issues. All teachers in this study had medical care plans for children with medical needs within their classrooms and all reported the need to follow these in an emergency.

Child-specific training, like in 70% of the cases in Heller et al's (2000) study, was given to all teachers in this study with the requirement that they had to be 'signed off' by a medical professional before they could carry out medical interventions unsupervised. This ensured that staff felt confident in their ability to perform medical interventions such as suctioning and tube feeding and were well-informed.

The knowledge and training of special education teachers found within this study is in stark contrast to the findings within the existing literature (Clay et al., 2004; Stanviloff, 2000, as cited in Barrett, 2001; Wait et al., 2013). All teachers reported high-levels of knowledge about the medical needs of the children within their classes and all had received training on the medical interventions and emergency procedures they were required to perform. This training had a corresponding impact on their confidence levels during an emergency. Most teachers reported being able to calmly deal with an emergency by following set processes. This finding adds weight to the need for comprehensive training programmes in schools and also supports previous findings that training programmes help to raise confidence levels and decrease anxiety for teachers (Barrett, 2001; Duggan et al., 2004). Despite this confidence and calmness, teachers also appreciated the presence of a school nurse and described feelings of reassurance that the nurses could make the 'scary medical decisions' in emergencies.

The presence of school nurses able to assist in a medical emergency was hugely variable. Some teachers had access to a full-time school nurse on-site, whereas for others, their school did not, at the time of interview, have any school nursing provision (see Appendix 5). This variation in nursing provision meant that for the majority of teachers there were times in which a medical emergency occurred without the presence of a school nurse. This posed huge issues for the teachers in this study and, in a similar way to those in Esperat et al's (1999) qualitative study, caused increased anxiety. Many teachers emphasised that they were not trained medical professionals and during these times found it difficult to relay exactly what they were seeing to a school nurse via a telephone. Also, inconsistencies in school nursing provision proved challenging if the school nurse did not know the child, their symptoms and presentation as well as teachers. This led, in one instance, to a child being sent into hospital by a school nurse, despite the teacher knowing that they were well.

Healthcare assistants have been employed by some of the schools in this study as an attempt to bridge the gap between education and health. In the absence of school nurses these healthcare assistants are able to administer medication and, in some cases, are employed to work on a one-to-one basis with the most medically complex children, for example those on ventilators or requiring regular oxygen. These healthcare assistants are examples of 'hybrid workers' identified by McConkey et

al. (2007). However, the issues raised by McConkey et al. (2007) in terms of accountability and funding appear to remain.

Nevertheless, the presence of school nurses or healthcare assistants employed to manage the medical needs of children with life-limiting conditions can have a positive impact on teachers. Having other people responsible for the medical care needs of their students enabled teachers to focus on their primary role, the education of their students. Disruption within classes due to gastrostomy feeds or medication was found to be minimised as often someone would quietly come in and perform the medical intervention without the rest of the class needing to stop working. On the other hand, some teachers found that having someone extra come into their class was more disruptive, particularly if children were engaged in a quiet, sensory session. Disruption was also caused if nurses or healthcare assistants were busy and as a result, children had to wait for their feeds or medication. One teacher found this particularly dangerous when a child required their asthma medication. Despite these negatives, the presence of school nurses or healthcare assistants ensured that children with the most medically complex needs were able to attend school.

Following a medical emergency, regardless of their levels of training and presence of care plans, teachers often reflected on what could have happened and doubted they had done the right thing. This caused much anxiety after the event, suggesting that emergencies can have a negative impact on the emotional wellbeing of teachers despite high-levels of knowledge and training. These anxieties were also found in Durrant et al's (2014) study, particularly around the safe and correct administration of medicine. It may be therefore, that support is needed from medical professionals or SLT after a medical emergency. This could be in the form of a debrief or informal 'chat' about the event and what, if anything, could have been done differently. In fact, teachers may feel that they are able to have these conversations with their support staff without the presence of a school nurse or SLT. These discussions may therefore help to alleviate concerns and reduce anxieties, particularly if held on the same day, thus reducing the negative impact on teachers' sleep and personal lives.

Despite these day-to-day challenges, the majority of teachers in this study expressed love for their job and their students. They described feelings of joy when talking



about their work and valued moments which brought joy to themselves and their students. Laughter and humour were large parts of the educational biographies of the teachers interviewed. Some loved to be silly and make their children laugh, others gained pleasure from watching their children achieve. Overall, all of the teachers gained personal fulfilment from their teaching roles.

## **10.2 Pedagogical Challenges and Considerations**

When thinking about their pedagogical considerations for teaching children with life-limiting conditions, teachers found themselves on a spectrum between pushing for academic progress and enriching lives. For some, particularly those who had a mainstream teaching background, their main priority was to push for academic progress regardless of the level of medical need their students presented with. For this group of teachers, their identities were very much 'educators'. Whilst they cared about the medical needs of their students and continued to see the importance of their physical and care needs, their main aim was to push students to achieve. This was often based on the belief that all children had a right to an education, whether they were perfectly healthy or nearing the end of their lives. For these teachers, focusing too much on a child's care needs meant there was a danger of seeing children as 'uneducable' as in the 1970s. As such, this group of teachers optimised learning opportunities, whatever time of day, created individual learning pathways and prioritised repetitive learning approaches to ensure each child had the best possible opportunities to succeed. Utilising these teaching approaches acknowledges the different learning patterns of children with CLDD as identified by Carpenter and Egerton (2005). As previously discussed, due to the recent Rochford Review (Rochford, 2016) and the pilot phase of development, the widespread use of the engagement materials (Carpenter et al., 2015) was not found within the current study. Having such academic priorities, caused a degree of conflict within the classroom between teachers and support staff for two of the teachers interviewed. This occurred due to the differing priorities of teachers and support staff, with the latter group favouring more of an enrichment approach for these children.

At the other end of the spectrum, some teachers prioritised enrichment within their teaching. Due to the child's life-limiting condition, these teachers wanted to make the most out of the time children had left, by providing new, exciting and positive

experiences for their students. This replicates the findings of Durrant et al. (2014) who also found that teachers would want to make lessons fun for children with life-limiting conditions. For these teachers, demonstrating and recording progress was seen as secondary to ensuring quality of life for children, and as such, they adopted a more caring role within their teaching. This is similar to the findings of Davis (1989) and Zijlstra and Vlaskamp (2005) who also acknowledged that the curriculum may not be appropriate for children nearing the end of life. However, prioritising an enrichment approach was found to have a detrimental impact on teaching identity for one of the teachers interviewed. They found that providing fun, sensory experiences for their students sometimes felt like more of a childcare service than an educator role. This impact on personal identity can have important consequences for emotional wellbeing, particularly when looking at whether the positive experiences of role fulfilment can protect teachers from the negative emotional impact of caring teaching (Hargreaves, 1998). Furthermore, as identified by Fleitas (2003), having expectations that are prematurely low may disengage some learners and negatively impact on their experiences of education more generally.

In an attempt to marry the two approaches, teachers within this study aimed to find a balance between pushing for academic progress and providing positive experiences that enriched lives. This depended heavily on the medical needs of their students on a day-by-day basis. For example, if a child had come into school in a postictal state following an epileptic seizure, the chances of that child being alert, well and ready to learn are slim. On these days, teachers attempting to find a balance, described providing sensory experiences to ensure the child was still able to participate in the school day. Whereas on days when the child comes into school alert and well, teachers would then prioritise educational activities that enable progress to be made. Finding a balance in this way takes the pressure of teachers on days when medical needs are high, yet still protects their teaching identities.

An additional group of teachers have taken this idea further by prioritising what they teach to ensure they teach only things that will improve children's quality of life. This appeared easier for teachers who were not following the National Curriculum. For these teachers, their emphasis is not on pushing for academic progress, nor only providing enriching experiences. Instead, they focus what they teach to ensure that lesson content is meaningful and relevant with the aim of

improving quality of life. As such, much of the lesson content focuses on physical or communication needs. For example, allowing students to practise walking in their pacers or using eye-gaze technology to communicate. Making progress in these areas may not be measurable against the National Curriculum or on commercial assessment tools, but teachers felt these were the most important skills for students with life-limiting conditions to acquire. This prioritisation of life-skills within teaching continues to give teachers the 'educator' identity, but also acknowledges the caring aspects of their roles. These teachers may see the child holistically, ensuring that what they teach, has a resulting positive impact on the child's quality of life overall.

As with the qualitative nature of this study, it cannot be determined whether factors such as a mainstream teaching background, years of experience or teacher age has any impact on the teaching priorities and pedagogical considerations of those interviewed. It may be useful for schools to identify their ethos around the education of children with life-limiting conditions to ensure that conflict does not arise over curricula that are perceived as unfit for purpose. Additionally, to protect teacher identities and negate detrimental effects surrounding role fulfilment and emotional wellbeing, it may be necessary for discussions to be held between teachers and SLT to ensure that a common approach to teaching children with life-limiting conditions is developed and maintained. All of the teachers interviewed were knowledgeable and well-informed about the curriculum, assessment processes and the capabilities of their children. As such, they did not fear having expectations that were too high or too low, unlike the teachers interviewed in A'Bear's (2014) study.

### **10.3 Experiencing a Student Death**

The teachers in this study had a wealth of experience with children with life-limiting conditions as over half of the participants had worked in special schools for more than ten years. Throughout their careers, sixteen teachers had experienced a student death. Furthermore, the majority of teachers had experienced the death of more than one child, with eight teachers reporting to have experienced the deaths of 'many' children. Given the frequency with which student deaths were experienced, it was clear that the death of a child became a significant part of the teachers' educational biographies as illustrated by teachers themselves.

The experiences described by teachers, specifically in relation to the number of student deaths supports the work of Bohling and Keiser (1997, as cited in Munson & Hunt, 2005) in that the death of a child was commonly experienced amongst teachers in special schools. Given that student deaths continue to occur regularly some twenty-one years after these findings, it is concerning that awareness, training and support for teachers are still perceived to be lacking.

According to Scott (1981), teachers are ill-prepared to deal with student death. For the teachers in this study, student death was something they had to consider and plan for, particularly for the potentiality that a death could occur in school. Creating plans for a death in school, formally or informally, enabled teachers to feel prepared for this eventuality. However, in a similar way to the teachers interviewed in Durrant et al's (2014) study, thinking about and planning for a student death caused increased fear and anxiety for those involved. Moreover, many of the student deaths experienced by teachers in this study were described as 'sudden' or 'unexpected'. This suggests that despite the acknowledgement that the children they teach have life-limiting conditions, a student death is not something that teachers are fully prepared for nor regularly expecting.

Given the sudden and unexpected nature of many of the student deaths experienced, it may not be possible to fully prepare teachers for this eventuality. However, some schools created 'circles of vulnerability' as part of their bereavement response which aim to provide a framework for the sharing of the news and direction of support. These documents highlight important people who need to be informed of the death of a child, some of whom may work outside of the school environment, for example bus escorts, physiotherapists or mainstream peers. In addition, other staff members may feature on the circle of vulnerability due to personal bereavements or other issues, meaning that they might require further emotional support if and when a death occurs. Completing a 'circle of vulnerability' document as part of a bereavement response seems to mirror the findings of Munson and Hunt (2005) who also found that a grief plan can help to highlight personnel requiring additional support as well as what that support might entail.

Some of the teachers interviewed described differing responses to bereavement depending on the time of year of the death or the strengths and abilities of SLT. Having a formal bereavement response, grief plan (Munson & Hunt, 2005) or crisis

team (Jellinek & Okoli, 2012) may help to formalise a school's response in the event of a student death. Having these documents in place may have helped two of the teachers in this study; one who was unsure of what to do after directly receiving the news of a student death during the school holidays and another who felt that a student death was handled badly by a headteacher who refused to acknowledge that the child had died. In the first instance, a bereavement response would have helped the teacher to know who to contact as soon as they were given the news. In the latter, the headteacher would have had a formulated response to turn to regardless of their own uncertainties about how to handle a student death.

In support of Holland and McLennan's (2015) survey of North Yorkshire schools, many of the teachers interviewed also reported not having received any training on pupil bereavement throughout their teaching careers. For most of the teachers interviewed, bereavement training was something they felt would be useful, especially when considering the frequency with which they experienced a student death. This mirrors the findings of Lazenby (2006) who also reported that teachers would have found training on death in schools helpful. This finding shows that teachers continue to lack training on the issue of student death in schools, despite how often a death occurred. Bereavement training in schools should be delivered regularly, perhaps incorporating the bereavement policy or response plan, to ensure all staff are aware of their roles when experiencing the death of a child.

Upon being told of the death of a child, many of the teachers reported having to return to class to share the news with their support staff and students. This posed a significant challenge for teachers who had very little time to process the news and deal with their own emotions. As a result, many of the teachers described having to put their own feelings aside to remain professional for others. This replicates the findings of Lazenby (2006) and Rowling (1995), suggesting that teachers continue to have to meet the needs of a range of people before their own. To meet the needs of those around them, some teachers adopted the role of counsellor for their support staff. Due to the teacher/teaching assistant relationship within the classroom, many teachers found they had to remain strong as support staff often turned to them following a student death. Whereas some teachers found this role intrinsic and therapeutic, others struggled to handle the feelings of staff on top of their own emotions. This finding supports the work of Munson and Hunt (2005)

who also found that teachers had to deal with their own grief in addition to supporting and counselling colleagues, students and families.

Taking part in death rituals such as memorial services or funerals was found within the literature to be helpful for teachers when coming to terms with the death of a child (Bennett & Dyehouse, 2005; Ward, 1988). Being able to attend the funeral of a child depended greatly on the response of the school. Some schools decided to close for the day so that staff who wanted to attend the funeral were able. Others chose to ask the classmates of the deceased child to stay at home to enable class staff to attend the funeral or brought in supply staff for the day to cover for those wishing to attend. For some however, attending the funeral was not possible either because schools could not provide cover for staff or because they had moved schools since the child's death. For the majority of teachers interviewed, attending the funeral was an important part of their role following a bereavement. They saw it as an opportunity to support the family, say goodbye and gain closure. For those who could not attend, they were left wondering whether the family knew they still cared.

Enabling staff to attend funerals is an important consideration yet logistically complicated for SLT (Bennett & Dyehouse, 2005), especially when they must ensure the safety of children still in attendance at school. Other ways of giving the teachers in this study the opportunity for closure and reflection came in the form of memorial or remembrance services in school. For those interviewed, these services were a lovely way of bringing everybody together, including the child's family, to share memories and remember. Having a set format of these services, for one school, helped support other children develop an understanding of what had happened. These services were helpful for teachers and were greatly appreciated, supporting the work of Rowling and Holland (2000) who also found that SLT can support staff by providing time to talk and remember the child after a death. In addition, having spaces where teachers, other staff and children could go to remember, such as memorial gardens, remembrance trees or reflection rooms were described positively within this study. If schools are struggling to enable staff to attend the funeral, one way of ensuring that they have this opportunity for closure, show support to the family and help other children understand a bereavement is to hold remembrance services or memorials in school. The teachers in this study

certainly talked about them positively and described how they made a traumatic experience a little better for all involved.

#### **10.4 Actions and Emotions**

It is not just the experience of losing a child that has an impact on the emotional wellbeing of teaching staff within special schools. Teachers interviewed in this study cited a range of everyday situations which triggered different positive and negative emotions. These emotions were categorised using Chadha's (2016) Junto Emotion Wheel (see section 3.4.2.2).

One of the main emotions experienced by teachers when working with children with life-limiting conditions was that of sadness. Teachers experienced sadness following the death of a child, medical emergencies, student deterioration and when communicating with parents. For many teachers this sadness was not confined to the aftermath of a student death. In fact, some teachers interviewed described feeling overwhelming sadness years after the death of a child. This supports previous research that teachers do experience grief after a student death (Lazenby, 2006). Plante and Cyr (2011) found that younger healthcare professionals reported higher levels of grief than older healthcare professionals. Although all teachers in this study experienced grief and sadness, older, more experienced teachers appeared better able to understand and deal with these feelings. It remains unclear whether this is due to lower levels of grief as in Plante and Cyr's (2011) study however. It could be that individual personalities play a part in coping strategies or as more and more child deaths are experienced, teachers become better at identifying and dealing with difficult emotions.

Moreover, mirroring the findings of Kliebenstein and Broome (2000) and Durrant et al. (2014), teachers also experience intense feelings of grief and sadness when witnessing the deterioration of a child's condition or following an acute medical episode. These findings have important implications for the offering of emotional support to teachers. As sadness was not just confined to the aftermath of a student death and could last a considerable amount of time, SLT need to ensure that emotional support is continuously offered for staff to access when they feel it is needed.

Despite these intense feelings of grief and sadness, many of the teachers reported the need to remain professional following the deterioration or death of a child. The need to be 'brave' to support other staff appeared to be a large part of the teacher role following the death of a child. This was attributed to the authoritative role a teacher had over their teaching assistants and as a result, many of the teaching assistants turned to their teacher for support. For some, supporting others was found to be therapeutic. For others, taking on the emotions of colleagues was found to heighten their own experiences of grief. This finding supports existing studies by Munson and Hunt (2005) and Rowling (1995) who also found that teachers were expected to offer emotional support to others and often needed to put their own feelings aside to do so.

Many teachers described feeling fear for the children they taught, especially when considering the possibility of a student death. This fear was often felt towards the end of school holidays as teachers anticipated welcoming their students back into school. For some, teachers feared whether all students would return and whether they would be in good health. Medical emergencies whilst at school were also a significant source of fear and anxiety for teachers, especially if a child stopped breathing or if it was the first emergency the teacher had witnessed for an individual child. For the majority of teachers, much of this fear stemmed not from whether they would know what to do in an emergency situation (McCarthy et al., 1996), but from doubting that they had done the right thing or from reflecting on what might have happened. Ensuring that robust procedures are in place in the form of emergency healthcare plans as well as ensuring access to adequate training could help to alleviate some of this fear. However, in contrast to the findings of Boden et al. (2012), teachers in this study were extremely knowledgeable about the child and their medical condition, yet still experienced fear and anxiety. This suggests that training alone cannot eliminate feelings of fear amongst teachers.

All of the teachers in this study experienced frequent medical emergencies for numerous children within their classrooms. This is in contrast to many of the teachers interviewed in existing research where the medical emergencies discussed were often hypothetical or involving one child (Barrett, 2001; Boden et al., 2012; Durrant et al., 2014). As a result, teachers in this study did not have doubts or fears about their abilities to deal with medical emergencies. The majority of teachers felt comfortable with the medical interventions they were asked to perform on a daily



basis within their classrooms, often due to the child-specific training they had been given by healthcare professionals and the frequency with which they experienced a medical emergency. More experienced teachers reported feeling greater levels of confidence when dealing with medical emergencies, a finding that disagrees with Nabors et al. (2008), who found that special education teachers had a greater knowledge but not greater confidence when dealing with medical needs within the classroom.

The presence of school nurses was also found to alleviate some of the fear felt by teachers during a medical emergency. For emergencies where school nurses were present, teachers reported feeling reassured and were able to hand over the 'scary medical decisions' to someone more qualified. Indeed, one teacher described the presence of a school nurse as their 'safety net'. This demonstrates the importance of high-quality school nursing provision in special schools, shows the impact school nurses can have on the emotional wellbeing of teachers and adds weight to the work of Barrett (2001), who also found that excellent multi-agency working reduced teacher anxiety during medical emergencies.

Surprise was interpreted to be either positive or negative within the biographies of teachers as they explained them. Much of the negative surprise came from the sudden and unexpected nature of many of the student deaths experienced. All student deaths were described in terms of shock despite the knowledge that the children they taught had life-limiting, often degenerative conditions. This was often attributed to the speed in which children deteriorated and died, sometimes overnight or over the course of a weekend. This element of shock and surprise was found to heighten other negative emotions and contribute to the grief felt by the school.

Finally, teachers described negative feelings of anger and frustration at systems and processes outside of their control. These perceived inadequacies in social care or health agencies frustrated teachers who saw delays in care or in obtaining practical resources such as wheelchairs which would help students have a better quality of life. In addition, teachers also described frustration and anger at the lack of understanding from other teachers or SLT who did not have experience of teaching children with life-limiting conditions. A discussion of how this lack of

understanding contributes to the quality of emotional support teachers received can be found in section 10.5.

It was not just negative emotions that were expressed by teachers when thinking about their work with children with life-limiting conditions. Many teachers discussed their role and their students in terms of love and joy, a finding that supports the work of Closs and Norris (1997, as cited in Bolton et al., 2000) and Mackenzie (2012). These positive emotions when talking about their children were also evident throughout facial expressions and body language. It is clear that the children bring much joy and laughter to the teacher and to the school, something that was important even after their deaths. Like in the literature (Hargreaves, 1998; Isenbarger & Zembylas, 2006), these feelings of love and joy helped to outweigh the negative emotions experienced during medical emergencies or student deaths. Pride, privilege and feelings of fulfilment were described by many teachers as reasons why, despite the stress and emotional exhaustion, they continued to teach. This idea of personal fulfilment was also found within the teachers and healthcare professionals involved in Price et al's (2013) focus groups. Positive emotions outweighing or protecting against the effects of negative emotions was not the case in every instance however, with a minority of teachers considering taking a step out of teaching due to the negative emotions impacting on their personal lives and their overall wellbeing. As found by Howard and Johnson (2004), access to strong support networks could help to improve the resilience of those teachers considering a move away from teaching altogether (see section 10.5).

These intense emotions experienced by teachers who work with children with life-limiting conditions were found to have an impact on their personal and professional lives. Most commonly, negative emotions experienced following a medically intense day had an overwhelming impact on the sleep of teachers interviewed. Often teachers found themselves unable to sleep due to worry, doubts or reflections on what could have happened during the emergency experienced. As a result, many teachers reported feeling exhausted. This exhaustion was not only due to sleepless nights but was also a sign of the emotional labour involved in their teaching roles. For teachers, having to control the negative emotions of fear, anger or sadness to meet the needs of their other students and support their staff, is a heavy emotional investment. This supports findings in the literature that the emotional labour involved in caring teaching can lead to emotional exhaustion (Hargreaves, 1998;

Isenbarger & Zembylas, 2006). This emotional and physical exhaustion was found to have a resulting impact on the social lives of those interviewed, either within their fraught interactions with family members, or their lack of energy to socialise with friends.

Professionally, the emotional impact of the teaching role caused some teachers to consider the way in which they taught and indeed what they taught. Where children were visibly deteriorating and nearing the end of life, some teachers felt that the content of the National Curriculum was no longer relevant. Instead, they wanted to ensure that the child was happy and comfortable whilst at school (see section 9.2). In addition, teachers described the need to 'do things now' as they acknowledged that the child did not have time to wait for practical resources or exciting experiences. For two of the teachers interviewed, the emotional stressors of their role were causing them to consider a career move outside of the classroom. This illustrates how negative emotions can impact significantly on the professional lives of teachers and may be a reason for the high attrition rates in teaching more generally (Tapper, 2018).

Certain teachers in this study did not feel that the emotions triggered by daily events impacted on their professional or personal lives. These teachers appeared to emotionally separate their teaching role from their personal lives and therefore their professional identity. Interestingly, these teachers were often more experienced, acknowledged that they were not the parents of these children and thus demonstrated greater resilience within their teaching role. This finding replicates the work of Sonnentag et al. (2009), who found that those who developed 'emotional boundaries' were less susceptible to negative emotions impacting on their personal and professional lives. In a similar way, the notion that less experienced teachers in the present study are less likely to have developed emotional boundaries and separation supports the finding that teachers lack support in terms of maintaining professional distance (Price et al., 2013). Whilst it is not claimed that emotional separation should be promoted within teaching, in fact the concept of caring teaching suggests otherwise (Hargreaves, 1998), effective collaboration with other, more experienced colleagues may help inexperienced teachers develop some coping strategies and therefore greater resilience. This may in turn, lessen the impact of emotional demands on teachers' personal lives.

## 10.5 Supporting Teachers - Findings and Implications

To ensure that teachers are able to effectively deal with their own intense feelings of grief in addition to supporting others, robust support systems must be in place. The teachers in this study highlighted various sources of support that they turned to within their role. These sources varied between the formal, for example professional counselling and school-based support, to the informal such as friends, family and other colleagues. Similarities and differences existed in terms of whether such sources of support were deemed effective in helping teachers to deal with their emotions.

The most utilised source of support for teachers interviewed was talking to other colleagues about their emotions, difficult situations and how to deal with them. Some teachers found the shared understanding other colleagues had about the situation helped them to better talk through their concerns. In contrast, some teachers felt that colleagues within their school did not fully understand the challenges or concerns of teaching children with life-limiting conditions, particularly if there were only one or two classes of children with PMLD within the school. Not having an awareness or understanding of the unique needs of this group of learners acted as a barrier to effective support when discussing concerns with other colleagues. These findings are similar to the work of Billingsley et al. (2004) who found that amongst NQTs, informal support from other colleagues was of more use than more formal sources of support. Schools need to carefully consider the experience of teachers within the school, particularly if only one or two classes contain children with life-limiting conditions. If it is the case that teachers of these classes may become isolated due to the inexperience of other teachers in this area, then support should be sought from outside of school. Perhaps linking with other schools so that collaboration and support can be gained from colleagues who do share the same experiences and understanding may help to alleviate some of these issues.

SLT are conceivably, the most responsible for ensuring the emotional wellbeing of their teaching staff and in some instances, their support was perceived positively. In these cases, SLT were seen as approachable, present and available to listen to teachers' concerns. However, for other teachers, in a similar way to the work of Heller et al. (2013), the support from SLT was deemed to be lacking. This was in

part due to the lack of understanding of the daily needs of teachers teaching children with life-limiting conditions and also due to the lack of availability SLT experience as part of their busy work schedules. This finding is concerning but not surprising given the hectic and fast-paced nature of the current education climate. However, a lack of perceived support from SLT may be detrimental to the emotional wellbeing of school staff. As Kinman et al. (2011) found, perceived higher levels of social support in terms of approachable SLT and colleagues resulted in lower levels of emotional exhaustion. This is something that should be carefully considered by SLT when faced with a student death. Regular 'checking in' on staff who are struggling to deal with their emotions following a bereavement, in addition to making time to listen to their concerns, could help to prevent the more negative effects of emotional labour and thus develop more emotionally resilient teachers (Howard & Johnson, 2004).

A further way that SLT can support their staff is in the provision of professional counselling or therapy sessions. Teachers interviewed in this study felt more supported by schools if counselling was provided without them having to request it. A passing remark that counselling could be made available if required was not enough for teachers to feel supported. Some teachers also felt that having class staff members together for group counselling sessions was of greater benefit than individual sessions. Having access to an external counsellor or therapist was felt to be helpful not just following a bereavement but after medical emergencies or a particularly challenging day. Some of the teachers were aware of phone line support they could access if needed, which was often displayed in the staff room. Being able to speak to someone with some distance from the school was felt to be helpful for a few of the teachers interviewed. This mirrors the findings of Durrant et al. (2014) who found that teachers wanted to speak to someone who had experience and understanding of the requirements of teaching children with life-limiting conditions but who was far enough removed from the school to not be burdened by the teachers' worries or concerns. There are a growing number of charities that offer phone line support for staff working in this area and having access to this support throughout the year may be of use to teachers. A list of some useful sources of support can be found in Appendix One.

An additional consideration when providing counselling support is in terms of the logistics of this support. For teachers in this study, not having adequate cover for

classes and an under-estimation of the time counselling would be needed for were significant barriers to the support on offer. Teachers may find that counselling is needed some time after a bereavement, in one instance in this study, two years after the death occurred. This finding is similar to the work of Plante and Cyr (2011) who, within healthcare, found that formal counselling was a useful resource yet needed to be available more widely.

Speaking to friends and family may offer some of this required distance, as they are not directly involved in working with children with life-limiting conditions. For some teachers, this meant they could turn to friends and family for support and many found they could talk through their concerns or worries with partners or other close family members. Again, this replicates existing research that family and friends are useful sources of support when experiencing the death of a child (Lazenby, 2006; Plante & Cyr, 2011). For other teachers however, a lack of understanding of what school life was really like meant that effective support could not be obtained. Furthermore, many teachers did not want to upset or burden their friends and family with their emotional needs and stressors resulting in some teachers, like those in Lindsay et al's. (2012) study, dealing with their emotions alone. This finding suggests that the provision of emotional support within school is of great importance given that many teachers feel they cannot receive this support adequately at home.

Having time and space after hearing the news of a student death was another way in which teachers were able to attempt to deal with the emotional impact of such an event. SLT could help to facilitate this support through providing cover for class staff members so that they could be together following a student death. Having this time together could be seen as a form of 'debrief' where staff have the opportunity to discuss their emotions and memories of the child. Findings from healthcare suggest these could be helpful (Plante & Cyr, 2011; Rogers et al., 2008), and teachers in this study also found having the opportunity to be together with other staff was emotionally supportive. These 'debrief' sessions could be of a formal or informal nature and perhaps could be facilitated by school nurses or SLT to ensure that discussions are productive and questions surrounding the death are fully answered. The use of family or reflection rooms as quiet spaces where teachers could gather their thoughts or deal with their emotions during the school day was also found to be helpful.

Teachers experience a range of intense emotions following the death of a child (see Chapter 6). The ways in which schools handle these deaths can impact greatly on the emotional wellbeing of staff. Ensuring that schools have a formulated response to a student death can help them to navigate through a traumatic time and guarantee that support is made available to all staff as and when needed.

## **10.6 Reflections on the Research Findings**

As, at the time of data collection, I had not experienced the death of a student, I was most affected by the stories teachers told of their own experiences of child bereavement. The majority of teachers described periods during the aftermath of a student death that were managed 'beautifully'. Spaces created for remembrance and reflection, time given to staff to manage their own emotions and just be together. On the other hand, however, some told of situations handled less well; children not spoken of, deaths unacknowledged and time to grieve not provided. Throughout the interviews I was able to learn about how schools prepared for and navigated the aftermath of a student death through documents and procedures such as bereavement policies or circles of vulnerability. This led me to reflect on my own school's practice and the apparent absence of such policies. The knowledge gained from these interviews enabled me to discuss in particular the idea of circles of vulnerability with a colleague now responsible for our PMLD class. This proved helpful given one student who, at the time, was critically ill in hospital.

Poignantly, at the time of writing this research report, I experienced my first student death and sadly, within six months, another. Unfortunately, whilst the immediate sharing of the news was handled well by my school and, as a staff team, we supported each other, I feel we let the children, other students and families down with our approach to bereavement and remembrance in school. I feel that with a comprehensive bereavement policy and circles of vulnerability documents for our children with the most medically complex needs, we could have handled the aftermath of their deaths in a more consistent way for staff and students. I intend to use what I have learned throughout this research journey to improve this practice.

These findings and my subsequent experiences of student death have resonated with me on a deeper level. I hope this research has brought to the fore the challenges faced by teachers working with this unique group of students and I hope

it challenges senior leadership teams and training providers to consider their approaches to bereavement and support for their staff. The journey that I travelled throughout this research process has been arduous yet enlightening. As a practitioner I now feel in a better position to influence policy and practice within my own school with a view to improving support for staff and students alike.

### **10.7 Limitations**

This study was conducted using a phenomenographic approach and as a result, five categories of description were identified. It cannot be guaranteed however that these categories of description are exhaustive. Others may exist, as is the case in other phenomenographic studies. What can be assured however, is that these categories of description accurately describe the experiences of teachers who work with children with life-limiting conditions at the time of interview. Eighteen teachers who teach in special schools across the country were interviewed. Given the wide geographical spread and the number of different schools that teachers came from, it can be argued that fuzzy generalisations (Bassey, 2001) can be made from these findings (see section 3.6.2).

In line with the phenomenographic approach, purposive sampling was utilised to ensure that each participant had experience of teaching children with life-limiting conditions in special schools. The participants were sourced from an online forum for professionals working with children with SEND. Despite all participants having experience of the phenomenon, the use of the online forum to access participants may have introduced a degree of sampling bias. For example, the reasons behind the use of the online forum by participants were not explored. It could be that the teachers on the forum used the online community to access emotional or practical support. As such, teachers who use the forum may be qualitatively different and have qualitatively different emotional needs and experiences, than those who do not. In addition, only one of the participants in this study was male. Despite this being representative of the male to female ratio in teaching more generally (DfE, 2017), the absence of more male teachers may be a limiting factor, particularly when discussing the emotional needs of teachers. However, it should be noted that phenomenography is not concerned with individual differences between participants. Instead it aims to find similarities and differences in experiences across



the collective group. It is unclear whether having a greater number of male teachers within the research sample would have produced different findings.

As a teacher working in a special school, I have current, personal knowledge of the phenomenon in question. Whilst this could be seen as a limitation within phenomenographic research, particularly in relation to my own assumptions which could potentially bias my interpretations and interview approach (Ashworth & Lucas, 1998; 2000; Stenfors-Hayes et al., 2013), it can also be seen as a strength. Consciously deciding to share my 'insider' experiences at the outset of the interviews helped to build trust and rapport (Booth & Booth, 1994) and also helped to focus the participants on the essence of the phenomenon (Ashworth & Lucas, 2000). Many teachers, when talking about support systems, wanted to speak to someone who was far enough removed from their school and their situation, but still had that shared understanding. In my opinion, having that shared understanding with my participants, helped them to open up about their experiences without feeling that they were burdening me. Having this conscious awareness of my own insights, experiences and views, helped me to bracket prior assumptions throughout the interview and data analysis phase. Using phrases within the interviews such as 'are you saying...' or 'do you mean...' helped me to clarify what the participants were articulating.

Semi-structured interviews were utilised as the method of data collection in line with the phenomenographic approach. Whilst at the outset, face-to-face interviews were the aim, due to the geographical spread of participants it became apparent that interviewing face-to-face would not be feasible. Instead, online video technologies were used. This ensured that aspects of a face-to-face interview such as reading body language and recognising emotional distress remained in addition to bridging the geographical gap and providing greater flexibility (Deakin & Wakefield, 2014). Nonetheless, not conducting all of the interviews face-to-face meant that some differences may have existed within the interview approach. For example, some interviewees may have been conscious of being filmed and many of the interviews were interrupted either through loss of internet signal, pets or family members. These interruptions were not specific to the online interviews however. Two of the face-to-face interviews were also interrupted by building work. Ensuring that I referred back to my notes and asked further probing questions helped the participants to get back on track and rediscover meaning.

Finally, one of the main criticisms of the phenomenographic approach, particularly within doctoral studies, is that the data was collected and analysed by a sole researcher. Whilst the replicability and reliability of my research findings may be questioned (Marton, 1994), it can be argued that being a sole researcher has ensured consistency within the interview and coding process. Explicitly discussing my methodological decisions within this research report, in addition to the numerous illustrative quotations used within each category of description should help other researchers to recognise the different ways of experiencing the phenomenon (Marton, 1988). Other research has proved that it is possible to conduct phenomenographic research alone (Green, 2005; Jackson, 2009) and it is hoped that the present study also supports this.

### **10.8 Recommendations for Future Research**

This study adds to the existing research conducted to explore teachers' experiences of educating children with life-limiting conditions in mainstream schools (Durrant et al., 2014). However, this research is unique and original in that it focuses purely on the experiences of teachers who work with children with life-limiting conditions in special schools. Given the finding that SLT can provide a vital source of emotional support for teachers, it could be useful to conduct similar research with headteachers to examine their experiences and understanding of educating children with life-limiting conditions in their schools.

As school budgets are squeezed and the presence of school nurses in special schools decreases, undertaking research with support staff or education and healthcare assistants could provide an up-to-date picture of medical care in schools. These staff often work on a one-to-one basis with children who are medically complex. Understanding their emotional support and training needs might offer a further insight into what can be done to improve the wellbeing of staff as a whole. At the very least, an evaluation of the emotional support offered to teachers who teach children with life-limiting conditions should be considered with the aim of improving emotional wellbeing across the workforce.

## 10.9 Conclusion

The findings from this study suggest that teachers who work with children with life-limiting conditions in special schools experience many of the same challenges as teachers working with children with life-limiting conditions in mainstream schools (Durrant et al., 2014; Ekins et al. 2017). The difference however, is the numbers of children with life-limiting conditions now entering special schools (Carpenter, 2010a). As such, teachers within special schools are encountering large numbers of children, often in the same class, with life-limiting conditions requiring a range of medical interventions such as physiotherapy, tube feeding, suctioning and the administration of daily medication.

Teachers within special schools find themselves attending to medical emergencies such as prolonged tonic clonic seizures or a child who has stopped breathing on an almost regular basis. In addition, teachers within special schools are also experiencing the deaths of students more often than their mainstream counterparts. These issues therefore become a huge part of the teachers' educational biographies with a resulting impact on their emotional wellbeing. For those interviewed in this study, a medical emergency or student death were not just hypothetical situations, but ones that have been experienced on numerous occasions throughout their teaching careers. These situations cause intense emotions within those who experience them. Fear, grief, anger and shock were felt by all teachers when describing their experiences of teaching children with life-limiting conditions, observing their deterioration and experiencing their deaths.

Despite these intense feelings, emotional support was found to be lacking. Although professional support was provided for some of the teachers interviewed, it was often deemed insufficient due to constraints of staff cover and time. More informal methods of emotional support were found to be useful by some of the teachers interviewed however, a lack of understanding and awareness was considered to be a significant barrier to the efficiency of this support.

The teachers interviewed held a range of beliefs about what was best for children with life-limiting conditions. For teachers with a strong 'educator' identity, they were found to prioritise academic progress and focused their teaching on getting the most out of their students in order for them to progress. At the other end of the scale, some teachers prioritised a 'caring' approach and focused on providing

positive experiences for children nearing the end of life. Their main aims were to ensure that the children they taught were comfortable and happy whilst at school. In an attempt to combine both approaches some teachers accepted that on some days they could adopt the 'educator' identity whereas on others, the needs of the students meant they had to be more of a 'carer'. This approach enabled teachers to optimise learning opportunities when children were well and provide individual learning pathways that suited their unique and changing needs. Finally, a fourth group of teachers combined the two roles further in order to teach only things that would improve a child's quality of life. This ensured teachers kept their 'educator' identities without ever needing to fully turn it into a 'caring' one.

Overall, this study has found that working with children with life-limiting conditions in special schools is hugely challenging for teachers. They not only have to manage the more traditional and mainstream teaching challenges such as curriculum and assessment pressures, but also the challenge of dealing with regular medical emergencies as and when they occur within the classroom. Furthermore, these teachers are all too frequently experiencing the tragic death of a student, an event that instils a range of different emotions including shock and intense sadness. These challenges combined, have a significant and lasting impact on teachers' emotional wellbeing. School leaders need to recognise these challenges and ensure that appropriate and continuous emotional support is available in order to care for their staff effectively.

Teachers within special schools have access to a wide range of high-quality training that helps them to meet the medical needs of their children, however, their access to training regarding grief and bereavement is minimal. Schools need to consider their bereavement response and develop policies, procedures and training that can help all stakeholders navigate through the challenges of a student death. Those responsible for teacher training and professional development programmes should also carefully consider including grief and bereavement modules to begin to prepare teachers for what is an incredibly traumatic, but often frequent event.

Children with life-limiting conditions educated in special schools are often 'hidden' or 'unseen'. As teachers in this study have identified, there is little public awareness that these children exist let alone that they can and do die in childhood. This makes experiencing a student death even more challenging for teachers. Often the

emotions experienced by teachers when a student dies are overlooked or unacknowledged which makes obtaining emotional support that bit harder. By raising awareness of the experiences of teachers working with children with life-limiting conditions it is hoped that those who have lost a student are able to manage the aftermath of the death sensitively and provide the emotional support teachers need, exactly when they need it.

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## Appendix One – Sources of Support

### General Support Networks

- Education Support Partnership  
[www.educationsupportpartnership.org.uk](http://www.educationsupportpartnership.org.uk)  
Free Helpline: 08000 562 561  
Email: [support@edsupport.org.uk](mailto:support@edsupport.org.uk)
- Samaritans  
[www.samaritans.org](http://www.samaritans.org)  
Free Helpline: 116 123  
Email: [jo@samaritans.org](mailto:jo@samaritans.org)
- SupportLine  
[www.supportline.org.uk](http://www.supportline.org.uk)  
Helpline: 01708 765200  
Email: [info@supportline.org.uk](mailto:info@supportline.org.uk)

### Support for Teachers Teaching Children with Life-Limiting Conditions

- Together for Short Lives  
[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)  
Free Helpline: 0808 8088 100

### Bereavement Support for Teachers and Schools

- Childhood Bereavement Network  
[www.childhoodbereavementnetwork.org.uk](http://www.childhoodbereavementnetwork.org.uk)
- Cruse Bereavement Care: Help for Schools  
[www.cruse.org.uk/schools](http://www.cruse.org.uk/schools)  
Free Helpline: 0808 808 1677
- Grief Encounter  
[www.griefencounter.org.uk/professionals-schools/](http://www.griefencounter.org.uk/professionals-schools/)  
Helpline: 020 8371 8455  
Email: [professionals@griefencounter.org.uk](mailto:professionals@griefencounter.org.uk)
- Winston's Wish  
[www.winstonswish.org.uk](http://www.winstonswish.org.uk)  
Free Helpline: 08088 020 021  
Email: [info@winstonswish.org](mailto:info@winstonswish.org)
- Young Minds in Schools  
[www.youngminds.org.uk](http://www.youngminds.org.uk)

## Appendix Two – Participant Information Sheet



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### Participant Information Sheet

Title: How do teachers encounter, conceptualise and understand their experiences of working with children with life-limiting conditions in special schools?

You are invited to take part in a research study of the experiences of teachers who teach children with life-limiting conditions in special schools. Please read this form carefully and ask any questions you may have before agreeing to be in the study.

The study is conducted by Rachel Brunt as part of her Doctorate in Education studies at Durham University. This research project is supervised by Dimitra Kokotsaki ([dimitra.kokotsaki@cem.dur.ac.uk](mailto:dimitra.kokotsaki@cem.dur.ac.uk)) and Rosie Ridgway ([r.a.ridgway@durham.ac.uk](mailto:r.a.ridgway@durham.ac.uk)) from the School of Education at Durham University.

The purpose of this study is to explore the views and experiences of teachers who teach children with life-limiting conditions in special schools. A life-limiting condition can be defined as “conditions for which there is no reasonable hope of cure and from which children will die” (Fraser et al., 2012, p. 924). For the purpose of this research I also consider epilepsy to come under the above definition. I want to explore your pedagogical and day-to-day experiences of working with these students, the beliefs and values you hold about the pupils with whom you work and how all of this impacts on your actions and emotions as a teacher within your classroom.

If you agree to be in this study, you will be asked to talk with me at length about your experiences of teaching students with life-limiting conditions in a relaxed interview situation. The interview will be recorded via a Dictaphone to enable me to transcribe the interview for analysis. During the interview you may be asked about how specific students have impacted on your day-to-day working as well as your teaching career as a whole. If you have experienced the death of a student, you may be asked to talk about how this has impacted on your teaching. This subject nature is very sensitive and some of the things that you may wish to talk about could be distressing for you. It is important that you understand that you can stop the interview at any time if the nature of the interview becomes too upsetting or for any other reason, which you do not have to specify. You may wish to stop your participation in the research completely or re-convene at a later date. Either is fine. You are free to decide whether or not to participate. If you decide to participate, you are free to withdraw at any time without any negative consequences for you.

Your participation in this study will take approximately 40 minutes. There will be opportunities for a second interview at a later date in order for you to view the

initial interview transcript and to clarify anything or discuss themes further.

All responses you give, and interview data collected will be kept confidential. The records of this study will be kept secure and private. All files containing any information you give will be password protected. In any research report that may be published, no information will be included that will make it possible to identify you individually, the students that you may have spoken about or the school in which you work. There will be no way to connect your name to your responses at any time during or after the study.

If you have any questions, requests or concerns regarding this research, please contact me via email at [r.l.hall2@dur.ac.uk](mailto:r.l.hall2@dur.ac.uk) or by telephone at 07792150695.

This study has been reviewed and approved by the School of Education Ethics Sub-Committee at Durham University on 11<sup>th</sup> May 2015.

Rachel Brunt

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#### References

Fraser, L.K., Miller, M., Hain, R., Normal, P., Aldridge, J., McKinney, P.A., & Parslow, R.C. (2012). Rising national prevalence of life-limiting conditions in children in England. *Pediatrics*, *129*, (4), 923 – 929.

## Appendix Three – Participant Consent Form

### Declaration of Informed Consent

- I agree to participate in this study, the purpose of which is to explore the experiences and views of teachers who teach children with life-limiting conditions in special schools.
- I have read the participant information sheet and understand the information provided.
- I have been informed that the interview will be recorded via a Dictaphone to enable my interview to be transcribed by the researcher.
- I have been informed that I may decline to answer any questions or withdraw from the study without penalty of any kind.
- I have been informed that all of my responses will be kept confidential and secure, and that I will not be identified in any report or other publication resulting from this research.
- I have been informed that the investigator will answer any questions regarding the study and its procedures. Rachel Brunt, School of Education, Durham University can be contacted via email: [r.l.hall2@dur.ac.uk](mailto:r.l.hall2@dur.ac.uk) or telephone: 07792150695.
- I will be provided with a copy of this form for my records.

Any concerns about this study should be addressed to the Ethics Sub-Committee of the School of Education, Durham University via email (Sheena Smith, School of Education, Tel. (0191) 334 8403, E-mail: [Sheena.Smith@Durham.ac.uk](mailto:Sheena.Smith@Durham.ac.uk)).

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Date	Participant Name (please print)	Participant
Signature		

I certify that I have presented the above information to the participant and secured his or her consent.

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Date	Signature of Investigator
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## Appendix Four – Headteacher Information Sheet



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To Whom It May Concern,

My name is Rachel Brunt and I am currently undertaking my Doctoral Research as part of a Doctorate in Education at Durham University. I also teach full-time in a special school in Scunthorpe.

I am contacting you to let you know that a member of your staff has expressed an interest in being part of my doctoral research exploring the views and experiences of teachers who teach children with life-limiting conditions in special schools. The requirements of the study are for me to interview your staff member at length about the children they teach and their views and experiences.

As Headteacher I wanted to inform you that this was happening and also to allow you chance to read through the Participant Information Sheet (see below). It is not necessary to gain parental consent as children will not be named specifically throughout the interview and it was felt that as not all parents are aware or may not have fully accepted that their child has a life-limiting condition, it may do more harm than good. However, if you feel that parents in your school should be contacted about this interview, I do have parental information sheets and consent forms available. Please let me know if you would like these.

In line with ethical approaches, your school, staff member, or any of the children discussed will not be identifiable throughout my research report or any subsequent publications. I have received full ethical approval from Durham University.

Please let me know if it is ok for your staff member to go ahead with this research. Similarly, if you have any concerns or would like to discuss anything further then please get in touch.

Many Thanks,

Rachel Brunt

## Appendix Five – Participant Biographies

Participant Number	Previous Experience of SEND	Number of Years Teaching	Number of Years in Special Education	Phase Taught	Additional Responsibilities	Staff Support within Class	School Nurses On-Site	Number of Student Deaths Experienced	Additional Training	Interview Method
1	Yes, in extended family and through voluntary work	20 – 25	5 – 10	Secondary PMLD	None specified	4 teaching assistants and 3 education and healthcare assistants	2 school nurses and 2 healthcare assistants shared across 2 schools	2 in mainstream	None specified	Face-to-face
2	No	5 – 10	5 – 10	Primary PMLD	PMLD Lead	3 teaching assistants	2 healthcare assistants	2	None specified	Face-to-face
3	No	5 – 10	5 – 10	Primary PMLD	None specified	3 teaching assistants and 1 education and healthcare assistant	3 nurses and 1 healthcare assistant not always on-site at the same time	0	Grief and bereavement training	Face-to-face
4	Yes, immediate family	30+	30+	Primary PMLD	None specified	Education and healthcare assistants and teaching assistants	None	Many	None specified	Face-to-face

Participant Number	Previous Experience of SEND	Number of Years Teaching	Number of Years in Special Education	Phase Taught	Additional Responsibilities	Staff Support within Class	School Nurses On-Site	Number of Student Deaths Experienced	Additional Training	Interview Method
5	No	15 – 20	10 – 15	KS4 and Post 16 PMLD	None specified	Six teaching assistants	1 part-time nurse	Many	None specified	Skype
6	No	15 – 20	15 – 20	Secondary PMLD	Phase Leader	Teaching assistants and 1 education and healthcare assistant	A number of part-time nurses split over two sites. Always 1 nurse on-site	Many	None specified	Skype
7	No	30+	30+	Primary PMLD	Teacher for the Deaf	Teaching assistants	Team of nurses and healthcare assistants not always on-site at the same time	Many	SLD and Multi-Sensory Impairment	Skype
8	No	20 – 25	5 – 10	EYFS PMLD	Senior Leader	Teaching assistants	Team of nurses but not full-time on-site	2	Trained as a nurse before teaching	Telephone
9	Yes, immediate family	15 – 20	15 – 20	EYFS/ Primary PMLD	None specified	Teaching assistants and therapists	7 nurses on-site alongside a range of other medical services	Many	None specified	FaceTime

Participant Number	Previous Experience of SEND	Number of Years Teaching	Number of Years in Special Education	Phase Taught	Additional Responsibilities	Staff Support within Class	School Nurses On-Site	Number of Student Deaths Experienced	Additional Training	Interview Method
10	Yes, voluntary work	5 – 10	5 – 10	Primary PMLD	None specified	Teaching assistants and healthcare assistants for specific children	3 nurses and 2 healthcare assistants	Many	None specified	Skype
11	No	10 – 15	10 – 15	Primary Mixed Ability	None specified	Teaching assistants and education and healthcare assistants	None	5	None specified	FaceTime
12	Yes, as a teaching assistant	3 – 5	3 – 5	Primary PMLD	None specified	4 teaching assistants	1 full-time nurse	2	None specified	Skype
13	No	30+	20 – 25	KS5 PMLD	Sensory Needs Coordinator	Teaching assistant and therapists	7 nurses on-site alongside a range of other medical services	Many	Multi-Sensory Impairment	Telephone
14	Yes, parent used to care for child with PMLD	20 – 25	15 – 20	Primary PMLD	None specified	5 teaching assistants	2 part-time nurses but always 1 on-site	4	None specified	Skype

Participant Number	Previous Experience of SEND	Number of Years Teaching	Number of Years in Special Education	Phase Taught	Additional Responsibilities	Staff Support within Class	School Nurses On- Site	Number of Student Deaths Experienced	Additional Training	Interview Method
15	Yes, as a teaching assistant for over 20 years	5 – 10	5 – 10	KS5 PMLD	None specified	5 teaching assistants and 1-2 healthcare assistants for a specific child.	1 full-time nurse and some part-time nurses	Some	None specified	Skype
16	Yes, immediate family	15 – 20	15 – 20	Primary ASD PMLD	None specified	3 teaching assistants and healthcare assistants for specific children	2 full-time nurses and 1 part-time nurse split over two sites and six healthcare assistants	Many	None specified	Telephone
17	No	5 – 10	5 – 10	Primary PMLD	Complex Needs Lead	4 teaching assistants	2-3 full-time nurses and 2 full-time healthcare assistants	1	Research into sensory learning	FaceTime
18	Yes, as a teaching assistant	10 – 15	5 – 10	EYFS PMLD	None specified	1 higher level teaching assistant and four teaching assistants	5 nurses but they are shared by other schools and across a split site	1 from own class, others from within school	None specified	Telephone

## **Appendix Six – Participant Summaries**

I felt it important to give a brief summary of each participant and their teaching background as an introduction to the reader and in order to set the scene for this research. The previous teaching experience, children taught at the time of the interview, their staffing levels, nursing support and experience of student deaths are all outlined for each participant within the summaries below. It is hoped that this will give the reader an insight into the current picture of special education teaching as is presented in this current study. How the participants were recruited to the study is outlined in section 3.3.1. Due to the sole male participant and therefore the possibility of identifying his data from others, all participants have been given numbers and gender-neutral pronouns are used, in line with ethical considerations (see section 3.5). An overview of the characteristics of each participant can be viewed in tabular form in Appendix Five. Due to the wide range of terminology used within the interviews to describe support staff and healthcare assistants it has been necessary to use consistent language across all interviews. Therefore, within the summaries below the term ‘education and healthcare assistant’ has been used to describe teaching assistants who have additional healthcare responsibilities within the classroom but who remain employed within the education sector. The term ‘teaching assistants’ will be used to describe adults within the classroom who are employed to support the teacher, and the term ‘healthcare assistants’ will be used to describe staff employed by the NHS but who are not qualified or registered nurses. The role of healthcare assistants may be to support in schools either in a one-to-one role with specific children or working under registered nurses for the whole school.

### **Participant One**

Participant one trained as a secondary mainstream teacher and taught in inner city schools for more than fifteen years. They had experience of teaching children with SEND within mainstream as well as children with different ethnic backgrounds and first languages. Participant one had personal, family experience of SEND and completed voluntary work in this area whilst at university. They had taught in a special secondary school for the past five years, initially working in the school as a volunteer before progressing onto contractual employment. At the time of interview, participant one was teaching a class of eight students with many of them having life-limiting conditions. They were supported by seven staff, some of whom

had extra responsibilities within the classroom as education and healthcare assistants. The school shared two school nurses and two healthcare assistants with the primary special school in the area. Although participant one had not experienced the death of a student whilst working in special education, they had experienced the deaths of two students within a mainstream school who had been involved in road traffic accidents.

### **Participant Two**

Participant two trained as a primary school teacher and whilst completing their Post-Graduate Certificate in Education (PGCE), undertook a teaching placement in a special school with children with PMLD. They had taught in a special school for approximately five years since qualifying as a teacher and had additional responsibilities for PMLD within the school. At the time of interview participant two was teaching a class of seven children with PMLD and complex medical needs many of whom had life-limiting conditions. They were supported by three teaching assistants in class. The school was struggling to find a school nurse and as such they did not have nursing cover, instead they were supported by two healthcare assistants. Participant two had experienced the death of two students throughout their teaching career. One, whilst as a student teacher on placement and a second child from their class within their first two years of teaching.

### **Participant Three**

Participant three trained as a primary school teacher and began working in a special school as an NQT. They had been teaching for five years. The majority of their teaching experience involved children with PMLD and Severe Learning Difficulties (SLD). At the time of interview participant three was teaching a class of nine children, two of whom attended part-time. They were supported by three teaching assistants and an education and healthcare assistant. The school had a team of three nurses and one healthcare assistant though they were not all always on-site at the same time. Participant three had not experienced the death of a student but acknowledged the potential for a death to occur given the nature of their current class group.

### **Participant Four**

Participant four had been teaching for over thirty years with all of their teaching experience being in special schools. They had taught the full range of need from PMLD children to children with complex ASD but children with PMLD were their main interest. Participant four had a range of experience from different special schools throughout the country. At the time of interview participant four was teaching a class of children all of whom had life-limiting conditions. The school did not have a school nurse, instead participant four was supported with education and healthcare assistants in addition to teaching assistants within their class. Participant four had experienced the deaths of many children throughout their teaching career and discussed one student death in detail.

### **Participant Five**

Participant five had taught in special schools for thirteen years, teaching the full age range and level of need within that time. Although their current class did not have any children who would be classified as having a life-limiting condition, their class from the previous academic year included a number of children with life-limiting conditions. Within the class discussed throughout the interview, participant five was supported by six teaching assistants with some students allocated one-to-one staffing. The school was also supported by a part-time nurse. Participant five had experienced the deaths of a number of children throughout their teaching career but spoke about two children who they were particularly close to at the time of their deaths.

### **Participant Six**

Participant six was a phase leader in a school where over fifty percent of the children had life-limiting conditions. Some children had one-to-one education and healthcare assistants due to the severity of their medical need, whereas other children were supported more generally by teaching assistants within the class. The school had a number of part-time school nurses split over the two school sites meaning that there was usually always one on-site at all times. Within the three years that participant six had worked at the school there had been five student deaths, however they were not children that participant six knew well. Instead, participant six spoke about the death of a student from their previous school who they had had the most contact with.



### **Participant Seven**

Participant seven trained as an SLD teacher thirty years ago and had taught the full range of SEND across the country. They had a range of qualifications including as a trained teacher for the deaf. At the time of interview, participant seven taught part-time across two primary PMLD classes with a range of children with life-limiting conditions. Participant seven's school had a team of nurses and healthcare assistants from a local health centre available to support with medical needs, with the aim of having someone on-site at all times. Throughout their career, participant seven had had to plan for the possibility of children dying in their classroom and had experienced the deaths of many children. Within the previous three years, participant seven had experienced the deaths of three children whilst at their current school.

### **Participant Eight**

Participant eight trained as a secondary teacher and taught for 14 years in mainstream before entering special education. Before training as a teacher participant eight trained as a nurse. At the time of interview participant eight was a named teacher for an early-years, PMLD class in addition to their responsibilities as a senior leader. They were supported in class by three teaching assistants. One child had a healthcare assistant attend school with them due to the severity of their medical need. Participant eight also had access to a team of school nurses, however this access was due to decrease from full-time to part-time support. Participant eight had experienced the deaths of two children whilst at the school but had not taught them directly.

### **Participant Nine**

Participant nine worked in a specialist school for children with life-limiting conditions. They had personal experience of a child with SEND in their immediate family. Participant nine taught in a primary PMLD class supported by a team of teaching assistants. They also had physiotherapists and occupational therapists work in class alongside them. Participant nine's school had a large medical team with seven nurses on-site in addition to a range of other medical services such as physiotherapy, consultant led clinics and orthotics. Participant nine had experienced the deaths of many children throughout their teaching career.

### **Participant Ten**

Participant ten worked in a hospital for twenty years and had been teaching for approximately five years, always in special schools. They had worked with children with ASD but at the time of interview now worked with children with PMLD. Participant ten is supported by a team of teaching assistants but also healthcare assistants employed by the NHS for specific children with a greater severity of medical need. The school had a team of three school nurses and two healthcare assistants to support with medical needs. Participant ten had experienced the death of a number of children but spoke in detail about a child who had died in the week prior to interview.

### **Participant Eleven**

Participant eleven had been teaching in special schools for approximately ten years since qualifying as a teacher. They had taught across the age ranges in the schools that they had worked in with a range of level of need. At the time of interview participant eleven was teaching in a mixed ability class. Some children within their class were assigned a one-to-one teaching assistant and those with a greater severity of medical need might need an education and healthcare assistant, however participant eleven saw the staffing within her class as very much a team effort. Their school was looking into getting a school nurse however they did not have a school nurse at the time of the interview. Participant eleven had experienced the deaths of five children in the year prior to the interview however they had not directly taught any of the children who had died. This did not mean that participant eleven did not know the students however.

### **Participant Twelve**

Participant twelve had been teaching within special education for approximately three years since qualifying as a teacher. Within those three years they had taught a full range of need and at the time of interview had a class of six primary children with PMLD, all of whom had life-limiting conditions. Participant twelve was supported by four teaching assistants and one full-time school nurse, though they were uncertain of nursing cover for the coming year due to the school nurse needing to be absent for the long-term. Participant twelve had experienced the deaths of two children within her teaching career though not directly from their class.

### **Participant Thirteen**

Participant thirteen trained as a mainstream primary teacher over thirty years ago. They entered special education approximately twenty years ago teaching young children with ASD or sensory impairments. They had taught at their current school for nine years teaching a class of Post-16 students all with life-limiting conditions, PMLD and sensory needs. Participant thirteen was supported by a team of teaching assistants and therapists who worked in class. The school had seven nurses on-site and they also had access to a range of medical services such as consultant led clinics, physiotherapists and orthotics nearby. Participant thirteen had experienced the deaths of many children throughout their teaching career and had been at the death of one of their students. At the time of interview participant thirteen had experienced the death of a child within the previous week.

### **Participant Fourteen**

Participant fourteen had worked in special education for approximately nineteen years after becoming frustrated and disillusioned by primary mainstream education. At the time of interview participant fourteen had a class of eight primary aged children with PMLD, supported by five teaching assistants. The school had two part-time nurses and ensured that one nurse was on-site at all times due to the severity of medical need that some of the children presented with. Participant fourteen had experienced the deaths of four children from their class over the course of their teaching career, with the most recent death in the few months prior to the research interview.

### **Participant Fifteen**

Participant fifteen had worked with children with SEND for over twenty years as a teaching assistant before qualifying as a teacher and working in a special school. At the time of interview participant fifteen taught a class of six Key Stage 5 students all with PMLD and very complex medical needs. They were supported in class by five teaching assistants. One student required one to two healthcare assistants employed by the NHS, in order to meet their very severe and complex medical needs. Participant fifteen had not experienced the death of one of her students but had known of other students within the school who had died. They spoke about one child who had died in the year prior to the interview from the classroom next door.

### **Participant Sixteen**

Participant sixteen had worked in special education for approximately seventeen years, with their main area of interest being children with PMLD and complex medical needs due to their personal experience of SEND within their immediate family. At the time of interview participant sixteen was teaching a primary class of children with ASD but was moving back into the PMLD area in the coming year. Participant sixteen had a team of three teaching assistants to support their class of twelve students. Those children who had very complex medical needs were also supported on a one-to-one basis by healthcare assistants employed by the NHS. Participant sixteen had experienced countless deaths of children throughout their teaching career and discussed their general experiences of finding out that a student had died.

### **Participant Seventeen**

At the time of interview participant seventeen was teaching a class of early-years children with complex ASD. They spent most of the interview discussing their previous class of nine primary aged children with PMLD and complex medical needs. Participant seventeen was supported within that class by four teaching assistants. Due to the level of need in the school there were also two to three full-time nurses on-site and an additional two full-time healthcare assistants in order to support school staff. Participant seventeen had experienced the sudden death of one of the children from their class and discussed this experience at length.

### **Participant Eighteen**

Finally, participant eighteen had been teaching within mainstream for approximately ten years before moving into special education within the last five years. At the time of interview participant eighteen taught an early-years class of children with PMLD. For their class of nine children participant eighteen was supported by five teaching assistants. Within the school participant eighteen had access to five nurses though these were shared with other schools and across their own school's split site. There were occasions when there was no nursing cover on-site. Participant eighteen had experienced the deaths of some children within the school, one of whom was directly taught by the participant. It was this death that was focused on and discussed throughout the interview.

## Appendix Seven – Geographical Locations of Participants



## Appendix Eight – The Interview Guide

### Introductions

- Thanks for time
- Background and current role
- Restatement of research purpose and aims
- Restatement of definition of life-limiting conditions.
- Emphasis of ethics – confidentiality, withdrawal – if they need to have a break, further support available, what will happen.

### Interview

1. *Demographic Information*
2. *Please could you share your experiences of working with children with life-limiting conditions in school.*
  - a. Impact on knowledge, perceptions, awareness?
  - b. How did it make them feel?
  - c. How did they react (physically, emotionally, etc.)?
  - d. How has that impacted or affected their lives (professionally, personally – in the past, present and in the future)?
3. *Thinking about these experiences, how does working with a child with a life-limiting condition affect how your day-to-day teaching and experiences?*
  - a. What are their experiences?
  - b. Impact on pedagogical approaches
  - c. Relationships with parents
  - d. Relationships with other staff (teaching assistants, SLT, medical staff, etc.)
  - e. How did it make them feel?
  - f. How did they react (physically, emotionally)?
  - g. How has that impacted or affected their lives (professionally, personally – in the past, present and in the future)?
4. *Have you encountered any problems when trying to meet the needs of children with life-limiting conditions? If so, please could you explain?*
5. *Death of a Student – if experienced*
  - a. What are their experiences?
  - b. How did it make them feel?
  - c. How did they react?
  - d. Did they know what to say?
  - e. Did they refer parents/carers onto other people/other agencies?
  - f. What support is in place for teaching staff and for parents/carers?
  - g. Support systems in place – could they be improved? How?
  - h. Relationships with parents, other staff, students

- i. How has the experience affected the way that they think about teaching? if at all?
  - j. How has that impacted or affected their lives (professionally, personally – in the past, present and in the future)?
6. *What current practices, procedures, resources and people are helpful when you are trying to meet the needs of these children? Why? What makes them helpful?*
7. *What practices, procedures, resources would better help you to meet the needs of these children, if they were available? Why?*

### **Concluding Thoughts**

- Anything to add?
- Clarifications or changes to what has been said
- Further support available – share charity information
- Thanks for participation

## Appendix Nine – Ethical Approval



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11 May 2015

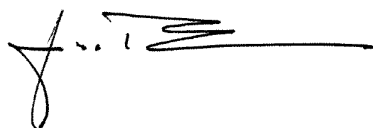
Rachel Brunt  
PGT student

*r.l.hall2@durham.ac.uk*

Dear Rachel

I am pleased to inform you that your application for ethical approval in respect of 'How do teachers encounter, conceptualise and understand their experiences of working with children with life-limiting conditions in special schools' has been approved by the School of Education Ethics Committee.

May we take this opportunity to wish you good luck with your research



Dr. J. Beckmann  
Chair of School of Education Ethics Committee

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