A theological consideration of ethical issues raised by human genetic manipulation, with particular reference to gene therapy

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Audrey Anne Elkington Abstract MA (research) Thesis, Autumn 1999.

"A theological consideration of ethical issues raised by human genetic manipulation, with particular reference to gene therapy."

Human genetic manipulation is considered in terms of genetic testing and screening, gene therapy and enhancement, and reproductive cloning. Deontological and utilitarian approaches to ethical decision-making prove less than satisfactory. An alternative approach, involving theological explorations into fundamental moral questions, is used.

Human beings are like other creatures in being; embodied, in limited control of their lives, and mortal. Humans are distinct from other creatures in reflecting the image of God. Responsibility in human life is considered in terms of stewardship and freedom. To be human is also to be an individual.

Theologies of progress suggest that working together with God towards our own salvation is our human calling and destiny. Theologies of realism recognise the failings of human beings and our inability to help ourselves. Moltmann's 'theology of anticipation' holds in a paradoxical whole human limitations and our ability to work with God towards anticipations of his coming kingdom.

A theological response to the limitations of medicine and health is explored through situations of disability and premature death. The Christian story, expressed in terms of tragedy and hope, provides a context in which to accept the limitations of genetic technologies and genetic health.

These theological explorations are applied in detail to the situations of genetic therapy and enhancement, in somatic and germ line cells. Suggestions are made regarding legislation.

The Christian story of tragedy and hope suggests a way of living which involves co-operation rather than competition with those who are genetically different. The Church can befriend and support those caught up in genetic tragedy, whilst celebrating our common hope.

"A theological consideration of ethical issues raised by human genetic manipulation, with particular reference to gene therapy."

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Contents

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Chapter 1: HUMAN GENETIC MANIPULATION - AN INTRODUCTION

1.1 Introduction

Less than fifty years after the elucidation of the molecular structure of DNA, scientists the world over are capable of manipulating this complex molecule and altering the genetic make-up of living things. A wide range of transgenic[1] organisms have been developed. Micro-organisms produce human growth hormone and insulin for medical uses. Tomato plants have fruit which does not overripen. Soya plants are resistant to herbicide and to attack by predators. Sheep produce human blood-clotting factors in their milk, and pigs are bred with a view to providing hearts for human transplants. Meanwhile human molecular genetics also advances. DNA profiling, or 'fingerprinting', is used to identify individuals, for forensic or other purposes. The 'Human Genome Project', originally considered far too ambitious, will have sequenced the entire human genome by 2001. Genes responsible for a variety of genetic diseases and predispositions have been identified, and DNA sequences patented and marketed. These advances are startling in themselves, and raise their own moral issues, but they only form the back-drop for the focus of this thesis.

'Human genetic manipulation', for the purpose of this thesis, is to include genetic screening and testing, gene therapy and enhancement, and human reproductive cloning.[2] These techniques described very briefly here, are covered in more detail later.[3] The identification of a number of genes known to cause disease enables groups of people to be screened, or individuals tested, for the presence of these genes, at a variety of stages of life. This technique is perhaps most significantly used in the testing of foetuses, together with the practice of 'therapeutic abortion' for those affected by serious genetic abnormalities. Small sequences of DNA can be added to people's cells in order to 'mend' defective genes causing disease; the early stages of clinical trials are already underway. Theoretically extra DNA could also produce 'enhancements' in the human body. Human reproductive cloning, the production of a

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1 See glossary for scientific and medical terms and abbreviations.

2 The term 'manipulation' is deliberately used rather than 'engineering' to avoid an over-simplistic, mechanistic view of human genetics. The main emphasis of the thesis is concerned with gene therapy and enhancement. Genetic screening and testing and human cloning are considered as they raise issues in common with those raised by the deliberate addition of genetic material to the human genome.

3 Ch.2.2.

baby from the genetic material of a single adult cell, is not currently legal but has been shown to be feasible in other mammals, primarily through 'Dolly' the sheep. The moral implications of these manipulations will be considered in the light of Christian theology. In this introductory chapter I consider the significance of such technology, in personal, cultural and ecclesial terms, and explore discussions of the moral issues which have taken place to date, before giving an outline of the whole thesis.

1.2 Human genetic manipulation - its significance

The significance of human genetic manipulation is considered in three areas. Firstly, I explain my interest in this subject. Secondly, I explore the cultural significance of these advances. It is not just scientists who will be affected by the advances of human genetics; it will affect all our lives. Finally, I describe the ways in which the Christian church is, and can be, involved.

i) Personal

As a schoolgirl I was fascinated by the account of Watson and Crick's elucidation of the structure of DNA.[4] This interest influenced my decision as an undergraduate to read biochemistry, with an emphasis on molecular genetics. Subsequent doctoral research involved developing a molecular tool to investigate the ways in which genes are 'turned on and off' in a particular bacterium.[5] The time I left practical science, to explore a vocation to Christian ministry, coincided with the publication of the Warnock Report.[6] This report was the result of investigations by a government-appointed committee into advances in artificial human reproduction. So began my interest in the ways in which human reproduction and genetics raise significant moral questions. These are moral questions which can affect many ordinary people, and yet which can be obscured by scientific, philosophical and theological language. As someone who could at least begin to understand both the science and the theology, I felt that perhaps I could enable other people to understand the moral issues raised. Even in the fifteen years since the Warnock Report things have changed greatly, and these changes have had cultural implications.

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4 James Watson, *The Double Helix.*

5 Audrey King. "*Streptomyces* gene fusions involving the *Eschericia coli* ß-galactosidase gene." (University of East Anglia, Ph.D. thesis, 1983).

6 *Report of the Committee of Inquiry into Human Fertilisation and Embryology*, 1984.

ii) Cultural

DNA and genes are no longer subject matter reserved for scientific papers. Pictures of DNA fragments separated in a gel, and the concept of evolution, have been used to advertise cars. Television, radio and popular newspapers report regularly on matters relating to genetic manipulation. Most recently this has concerned genetically modified (GM) foodstuffs, fuelled by Prince Charles' interest and involvement in the subject. Media reporting seems to swing wildly between two extremes. The horrors of "Frankenstein foods" and Hitler's eugenics programme, are found to vie with ideas that human beings now have the power to change the world. Scientists can be accused of 'playing God', or encouraged to become 'masters of the universe'.

The power of molecular genetics is indeed very great. The development of genetic technology has been likened to the harnessing of fire.[7] Parallels are also seen between the power of molecular genetics and that of nuclear energy.[8] To whom should this power be entrusted? The scientists, the government, the multi-national pharmaceutical companies, or even the consumers in the street? Unless people are aware of the power, the potential and the problems this technology raises, how can they voice opinions? Meanwhile things are moving very fast; twenty five years ago it was estimated that the information available in the field of genetics doubled every two years[9], now the only way people can keep up is through computers and the internet. The power of genetic technology is very great, and it can affect everyone.

Every human being is the result, at least in part, of the genetic material they inherited from their parents. Genetic technology can be used at, and impinge on, almost any stage of life; in the womb, post-natally, before marriage, before conception, whilst healthy, ill or dying. Knowledge of human genetics affects us all, and is beginning to change the way we think.

Human genetic technology is already influencing the way we think of ourselves, our children and other people. An announcement that a gene 'for' homosexuality has been found, encourages us to regard our life as being determined by our genetic material. The discovery of a genetic test for breast

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7 Jeremy Rifkin, *The Biotech Century; Harnessing the Gene and Remaking the World,* p.11.

8 *Ibid.* p.231, and Roger Shinn, *"Between Eden and Babel"*, in Ronald Cole-Turner (ed), *Human Cloning; Religious Responses,* p.106.

9 Joseph Fletcher, *The Ethics of Genetic Control; Ending the Reproductive Roulette,* p.xvii.

cancer, leads young women to undergo radical mastectomies rather than face the risk of developing cancer by the age of sixty. The ability to test for Down's syndrome in the foetuses of older mothers, leads to a dramatic reduction in the number of children born with this disease and assumptions concerning the nature of life worth living. A combination of IVF and genetic testing results in the implantation of an embryo with a pre-defined genetic make-up, and children can become regarded as consumer goods. Dolly the sheep reveals a new technology, and there is no shortage of people wishing to 're-create' a person through cloning. Each of these events influence our society which is already orientated towards individual achievement and recognition, consumer choice and satisfaction, and guaranteed, instant results. Subtly, human genetic technology is already influencing the way we think about ourselves. It can prompt questions about the meaning, purpose and value of life, and the significance of what it is to be human. For this reason, among others, the Christian churches have been involved in offering both insight and support.

iii) Ecclesial

The Christian faith has always claimed to understand something of what it is to be human, and of the meaning and value of human life. The Church has an important role to play in contributing to the debate about the morality of human genetic manipulation. Such involvement has already been made through contributions to government investigations. Anglican clergy serve on the Human Genetics Advisory Commission and the Human Fertilisation and Embryology Authority.[10] A working party of British Roman Catholic Bishops produced a report on human genetic intervention.[11] The Church of Scotland has been particularly active in this area; publishing a booklet and organising a day conference on Human Genetics, and publishing a web-site in the light of the 'Dolly-event'.[12] It will be important for the Church to maintain this contribution as technologies develop and increase, and if legislation relating to gene therapy or human cloning is formulated. The Church can play a prophetic role in challenging the

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10 Revd Dr John Polkinghorne serves on the HGAC and chairs the Cloning Working Group. The Rt Revd Dr Michael Nazir-Ali serves on the HFEA.

11 *Genetic Intervention on Human Subjects.* The Report of a Working Party of the Catholic Bishops' Joint Committee on Bioethical Issues.

12 William Storrar and Iain Torrance (eds), *Human Genetics; A Christian Perspective,* 1995.
"Bio-ethics for the New Millennium" conference at Aberdeen, January 1999.
"Looking back a year AD (After Dolly) - where are we now?" http://dspace.dial.pipex.com/srtscot/clonyear.htm

assumptions society makes about what it is to be human and about the significance and value of human life.

The Church has another role to play, not at the institutional level, but at the parochial level. The assumptions, beliefs and values of society, which are influenced by, and reflected within, genetic technologies, can also be influenced by the life and witness of a local body of Christians.[13]

But how are Christians to know when to encourage this technology and when to stand against it? What ethical framework can be used in approaching these issues? In what way will Christian comment be any different to that from secular society? There are a number of ways to approach the moral questions raised by human genetic manipulation. I discuss two 'classic' examples and suggest an alternative.

1.3 Approaches to the moral debate

In the early 1970s an awareness grew that advances in medical treatments were resulting in the perpetuation of genetic defects in the population, and meanwhile the possibilities of human genetic manipulation were beginning to be explored. In the light of these events, Paul Ramsey and Joseph Fletcher wrote what have become 'classic' works on the morality of human 'genetic engineering'.[14] Their approaches are very different. As a deontologist, Ramsey's views depend on principles which he sees as being valid no matter what the consequences. As in effect a utilitarian, Fletcher makes his decisions in the light of the consequences of an action. These two approaches are still applied to genetic technology today.

i) A matter of principles

Ramsey saw two principles as being relevant to any consideration of human genetic manipulation. Firstly; the unitive and procreative goods of human sexuality should not, in principle, be separated.[15] Secondly, no human being should be exposed to experimental medicine without consent.[16]

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13 Ch.7.

14 Paul Ramsey, *Fabricated Man; The Ethics of Genetic Control.*
Joseph Fletcher, *The Ethics of Genetic Control; Ending the Reproductive Roulette.*
There are also a number of secular approaches. A good summary of these is found in John Wyatt, *Matters of Life and Death; Today's healthcare dilemmas in the light of Christian faith,* pp.36ff.

15 *Fabricated Man,* p.32.

The human sexual act is seen by Ramsey as both an act of love, and a procreative act, in as much as each act tends towards these natural ends but does not necessarily achieve them.[17] He derives this principle, not from empirical observation, but from Scripture. By contrast with those who would refer to a creation-based argument and Genesis 2.23f., Ramsey uses the New Testament as the basis for this principle, referring to John 1 and Ephesians 5.[18] Just as God's great love led to his great creative acts, so in the same way human love leads to procreation.[19] To separate, in principle, the two goods of human sexuality would be to refuse to recognise the image of God's creation in our own procreation.[20]

Ramsey's second principle, concerning human medical experimentation, is based on the understanding that although God gave humankind dominion over all the animals at creation, no divine command, or even permission, allows one person to exercise the same sort of dominion over another.[21] To conduct any sort of medical experiment on a human being without their consent would be to reduce them to the level of an object, rather than a person. Any reproductive technique which, in being developed, would necessitate experiments which could result in deformed babies (who could never give consent to such experiments) is seen as morally wrong. These techniques in themselves may be perfectly ethical, but their development would be unethical because of the possible harm caused to a resultant zygote, foetus, or baby. This objection is based on an additional premise, that personhood begins at fertilization.[22]

Ramsey's principles seem very clear, and yet his application of them could appear arbitrary. In particular, this is seen as he considers which actions would result in an 'in principle' separation of the goods of sexuality. On the one hand, to deny oneself the option of parenthood for genetic reasons would not be seen as separating these two goods. This could be likened to the denial of sexual relations in

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16 *Fabricated Man*, p.87. This principle is covered in more detail in Ramsey, *The Patient as a Person; Explorations in Medical Ethics*.

17 *Ibid.* p.87.

18 *Ibid.* p.37.

19 *Ibid.* p.38.

20 *Ibid.* p.39.

21 *Ibid.* p.87.

22 *Ibid.* p.11f.

celibates, which can be "to the glory of God."[23] Continence, using three contraceptives at once, or sterilization, are all legitimate ways in which such birth control can be achieved without, apparently, separating the goods of sexuality.[24] Ramsey even suggests that the action of two carriers of the same genetic disease who set about having their own children "can only be called genetic imprudence..... [which] is gravely immoral".[25] By contrast, his objections to cloning human beings (maintaining a cloned population would necessitate avoiding sexual procreation), and to the use of AID (in which different men would be involved in providing the procreative and unitive goods), are based on the understanding that these actions would involve a separation of these two goods.[26] What yardstick has been used in order to deduce whether or not an action causes a separation of the two goods of human sexuality?

More recently other theologians have used the concept of immutable principles in their moral decision-making concerning human genetic manipulation. Oliver O'Donovan distinguishes between humans begetting children and making them, suggesting that the latter process is morally wrong as it would involve the separation of the two goods of human sexuality.[27] Waters writes of a "normative ordering of procreation" in which children "grow out of an enlarging relationship to which they in turn contribute in establishing a family".[28] As reproductive cloning would break the principle of this normative ordering he sees it as being morally wrong.

ii) A consequential approach

In direct contrast with Ramsey, Fletcher makes utilitarian judgements according to the assumed consequences of any action. He believes this is a more rational approach. Principles are regarded as "[b]land *a priori* assertions of opinion we cannot either verify or falsify".[29] He accuses those who make reference to principles of having opted out of the decision-making process.[30] In Fletcher's 'situation ethics', the best action or policy to adopt is determined through measuring the human need it serves, or

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23 *Fabricated Man*, p.59.

24 *Ibid.* p.120.

25 *Fabricated Man*, p.57.

26 *Ibid.* p.107 and p.133.

27 *Begotten or Made?*, pp.1, 75.

28 Brent Waters, *"One Flesh? Cloning, Procreation, and the Family"* in Cole-Turner (ed), *Human Cloning*, p.83.

29 *The Ethics of Genetic Control*, p.88.

the human well-being it brings about; health and happiness are what count.[31] This may sound an admirable ethical policy, but it does have its problems.

Firstly, the ethical conclusions one arrives at are very much dependent on the range of consequences considered. For example, Fletcher rejects the principle that a foetus should be regarded as a person, and therefore the consequences of any action from the point of view of the well-being of the foetus need not be considered.[32] He is therefore able to conclude that "pregnancy when wanted is a healthy process, *pregnancy when not wanted is a disease* - in fact, a venereal disease"; and that "[i]f the State is morally justified in repelling an unwelcome invader, why should not a woman do so when burdened or invaded by an unwelcome pregnancy".[33] Here it is only the woman who is pregnant for whom consequences have been taken into account. By contrast, when considering a situation in which a child with a "birth defect" may be born; it seems that the consequences of such a birth should be sought well beyond the mother, as far as society at large.[34] Fletcher cites the cost of caring for a retarded person during their lifetime, and suggests this money could be better spent on "normal but disadvantaged" children.[35] How does one decide how widely the consequences need to be considered, and who qualifies to be included in each 'situation'?

The second difficulty lies in one's ability to predict accurately the results of particular actions. Ramsey makes this criticism. He describes a situation in which it is assumed that increasing the population's intelligence would be beneficial. However, unless the number of altruists in the population were also increased, this would not necessarily be so. The result could be a breed of highly intelligent criminals. It may even be that the implications of genetic manipulation are so complex that the consequences can never be predicted: "[o]nly God knows.... enough to hold the future in His hands."[36] Consequences are also difficult to predict because we do not have total control over the situations we

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30 *The Ethics of Genetic Control,* p.119.

31 *Ibid.* p.31 and p.169.

32 *The Ethics of Genetic Control,* pp.132-142.

33 *Ibid.* p.142 and p.157, his emphasis.

34 *Ibid.* p151f.

35 *Ibid.* p.160.

36 *Fabricated Man,* p.130.

consider. Research scientists and medical practitioners may intend great good through the use of gene therapy, but they are not in total control of the consequences of such manipulation.

Thirdly, for all Fletcher's disparaging views of those who have principles, it is obvious that he uses principles too. How else would he be able to decide which consequence was better than another? His principle is that the highest good is that of human well-being; health and happiness.[37] Another principle which Fletcher uses states that foetuses need not be regarded as human persons. Holding this principle can seem to be as "*a priori*" and "pre-judiced" as Ramsey's principle of personhood beginning at fertilisation.

Finally, if moral decisions are to be made according to the criterion of 'human well-being', how is this quality to be measured? Fletcher suggests it can be assessed through a person's: "health, survival, growth, joy, social interest, self-realisation, and so on.".[38] But will this always be the case? Can it be assumed that anything which contributes to my ultimate well-being will always fill me with joy? And can such self-centredness and selfishness truly be the sum total of morality? An action which has consequences which may be bad for individuals or communities may still be the right thing to do.

For all the pit-falls of the utilitarian, consequentialist ethic, it is still very popular today. John Harris, the English philosopher, is a strong advocate of human genetic manipulation on the ground that it can be used to avoid needless suffering. (In parallel with Fletcher, Harris does not include foetuses in his consequential calculus).[39] Also from a utilitarian viewpoint, Jeremy Rifkin interestingly comes to a different conclusion. He has lobbied in America for caution in all fields of genetic manipulation for some time. He believes that the consequences of using such technology may not be as rosy as Harris imagines.[40] This surely illustrates the difficulties of accurately predicting consequences.

Neither the principled, nor the consequential approach seem an ideal way to approach the moral issues raised by human genetic manipulation. An alternative approach is needed.

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37 *The Ethics of Genetic Control*, p.120.

38 *Ibid.* p.31.

39 See Ch.3.7 (iii), below.

40 *The Biotech Century.*

iii) An alternative approach

It is not easy to find clear-cut rules from within the Christian faith which would make simple any decision-making about human genetic manipulation. Nor is it necessarily right, nor easy, to determine which particular manipulations would create the most happiness in the most people. An alternative approach, whilst making no claims that it is the sole legitimate Christian approach, can provide a broader overview, and insight from a range of theological perspectives. The approach involves three separate steps. First, the relevant genetic techniques are considered, and the main moral questions they raise identified. Second, a range of theology is explored for useful insights which shed light on these questions. Finally, the theological insights are drawn together and applied to a particular technology. This forms the basic outline of the thesis, but first, some explanation is given concerning the choice of theological perspectives used.

An exploration of the significance of the *imago Dei* necessitates an examination of the disagreement between Karl Barth and Emil Brunner.[41] A small number of theologians are deliberately sought for their view than humankind is not only in a position to, but called to, be active in changing its future.[42] As a balance and check, more 'realistic' theologies are also explored.[43] Ecofeminist theology is a very specific and radical form of theology, which has its own failings. It does, however, provide challenging material in terms of its emphases on responsibility not domination, co-operation not competition, embodiment, and an understanding of death.[44] Stanley Hauerwas provides not only his distinctive narrative approach to theology, but also much insight into health, medicine and suffering.[45] Frances Young gives a challenging theological insight into the contribution of disabled people in

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41 *Natural Theology: Comprising 'Nature and Grace' by Professor Dr. Emil Brunner and the reply 'No!' by Dr. Karl Barth.*

42 Theodosius Dobzhansky, *Heredity and the Nature of Man* and *The Biology of Ultimate Concern.*
Karl Rahner, *Theological Investigations* Vol.9, Ch.14, *"The Problem of Genetic Engineering"* and Vol.21, Ch.1, *"Profane History and Salvation History"*.
The ecofeminist theologians (note 44).

43 Reinhold Niebuhr, *Faith and History: A Comparison of Christian and Modern Views of History.*
Oliver O'Donovan, *Resurrection and Moral Order: An Outline for Evangelical Ethics.*

44 Sallie McFague, *The Body of God,* and *Super, Natural Christians: How we should Love Nature.*
Rosemary Radford Ruether, *Gaia and God: An Ecofeminist Theology of Earth Healing,* and *Sexism and God-Talk: Towards a Feminist Theology.*

45 Stanley Hauerwas, *Naming the Silences: God, Medicine and the Problem of Suffering, Suffering Presence* and *Truthfulness and Tragedy.*

communities.[46] Perhaps the most helpful and influential theologian is Jürgen Moltmann. Not only does he explore theology in the light of recent scientific and ecological advances, and in the light of his experience with handicapped people, but his eschatological work provides a theological approach between the extremes of 'Progress' and 'Realism'.[47] This exploration is certainly not exhaustive, but it takes a wide enough sample to gain a breadth of theological insight which can be usefully applied to the moral issues of human genetic manipulation.

1.4 Thesis outline

In Chapter 2 I describe the techniques of genetic testing and screening, gene therapy and reproductive cloning. I categorise the moral issues which they raise in terms of issues relating to human nature, eugenics and health. In the following three chapters I make a theological exploration of these areas. Chapter 3 considers what it is to be human; in relation with God, with ourselves and with the rest of creation. Chapter 4 explores theological responses to humankind being able to alter its own future. Chapter 5 seeks theological insight into the interrelated areas of medicine, health, and wholeness. In Chapter 6 I draw together these theological explorations and apply them to the specific situation of gene therapy and enhancement, making suggestions concerning legislation in this area. The final chapter forms a post-script for the Christian church, considering roles which the church can play for all those affected by human genetic manipulation.

46 Frances Young, *Face to Face; A narrative essay in the theology of suffering.*

47 Jürgen Moltmann, *God in Creation: An Ecological Doctrine of Creation, The Future of Creation* and *The Power of the Powerless.*

Chapter 2: GENETIC MANIPULATION - A MORAL PERSPECTIVE

2.1 Introduction

In this chapter I describe the main genetic technologies which could be applied to human beings, and the uses to which they could be put. These technologies are: genetic testing and screening, gene therapy, and cloning. In addition, the moral issues which these technologies raise will be identified. The areas of morality considered are those concerning human nature, eugenic implications and health issues. First, I describe the context of the development of human genetic technologies.

In the last hundred years huge advances have been made in the prevention and treatment of infectious diseases in the Western world. A great increase in standards of hygiene and nutrition, combined with the growth in our understanding of the ways in which micro-organisms infect and affect us, and the development of vaccinations and drugs (particularly antibiotics) to counter such infection, have together reduced the incidence of infectious disease. As a result we are now far more aware of those diseases caused, not by infectious agents, but as a result of genetic changes.

In Britain about one child in thirty is born with a genetic problem of some kind. Over a third of registered blind people are blind for genetic reasons, and more than half of all cases of severe mental handicap have an inherited cause.[1] About four thousand diseases are now known which are caused by a disruption to a single gene.[2] Those most well known include: Duchenne muscular dystrophy, haemophilia, cystic fibrosis, sickle-cell disease, Tay Sachs and Huntington's disease. The frequency of each particular inherited disease is relatively rare, but there are many of them and their effects can be devastating.[3] Other diseases appear to be caused by the effect of more than one gene combined with environmental factors.[4] In these cases the presence of a certain mutation will only ever indicate a

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1 Steve Jones, *The Language of Genes*, pp.284f.

2 J. Robert Nelson, *On the New Frontiers of Genetics and Religion*, p.41.

3 See Glossary.

4 For example coronary heart disease, diabetes and certain cancers.

person's predisposition to a disease. There are no standard cures for inherited diseases; there is only the possibility of the relief of symptoms or (in a few cases) preventing the symptoms from developing.[5]

Alongside our increasing awareness of diseases with a genetic cause, there has been an increase in our knowledge of the make-up of the human genome, and the location and nature of disease-causing genes. The "Human Genome Project" is a multi-national, multi-billion dollar venture aiming to establish the sequence of the entire human genome by the early years of the next millennium. This will involve 'reading' and recording over 3 billion units of genetic information, enough material to fill 12 copies of Encyclopaedia Britannica. Within these 3 billion units of genetic information there are approximately one hundred thousand genes, the information for which only accounts for 3-5% of the total information stored in the human genome. The function of the remaining 95% of DNA is still a mystery. One of the fruits of the Human Genome Project has been a steady growth in the identification of disease-causing genes, and the nature of their mutations. This information can help in establishing the cause of, and therefore methods of treatment for, these inherited diseases. Another use of such information is in testing or screening for the presence of disease-causing mutations in the genomes of individuals or groups of individuals.

Genetic manipulation in bacteria, yeast, and latterly plants and animals, has led the way to the development of techniques which will make possible the manipulation of the human genome. Early clinical trials for the treatment of simple genetic diseases in humans, through the addition of particular DNA sequences, are already underway. It is also theoretically possible to use genetic manipulation to 'improve' the human genome, and to make changes which will be passed on through subsequent generations. 'Dolly' the sheep has also revealed the feasibility of another means of genetic manipulation in humans, in that it may now be possible to produce a baby which will be a genetically-identical clone of an adult person.

Genetic testing and screening, gene therapy and cloning are now described in more detail, and their potential applications for human beings.

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[5] Ranging from the careful diet for phenylketonuria sufferers and insulin injections for diabetics (very effective) to physiotherapy (limited effect) or heart-lung transplants (risky, limited availability) for cystic fibrosis patients. For many genetic diseases (over 80%) there is no treatment at all, including Huntington's and Tay Sachs diseases.

2.2 Genetic manipulation - techniques

i) Genetic testing and screening[6]

It is now a quite simple procedure to identify those people who are suffering from, will suffer from, or are carrying recessive genes for, a number of inherited diseases.[7] DNA can be extracted and analysed from just a small number of cells, such as those released by a mouth-wash, extracted through amniocentesis or chorionic villus sampling, or even a single cell removed from an embryo *in vitro*. There are a number of reasons why one might want to test a particular individual, or screen a particular group.

a) Genetic testing

PRESYMPTOMATIC TESTING

This involves testing for the presence of a particular gene before it begins to have any obvious effect on a person. Not all inherited diseases show their effects from birth. Boys who have Duchenne muscular dystrophy seem normal until the age of about 6 years, and those who have Huntington's disease only begin to show symptoms in early middle-age. Genetic testing can allow a person to determine whether they are likely to suffer from an inherited disease well before any symptoms are obvious. As many genetic diseases remain untreatable, the value of such information has been questioned. However, it can help people to plan for the future, for example in the case of those at risk of Huntington's disease who are planning to have children. It is interesting to note that although a test for the Huntington's disease gene has been available since 1987, only a few hundred of the many thousands of people known to be at risk have chosen to be tested.[8]

TESTING CARRIERS

Huntington's disease is a condition which is inherited dominantly, i.e. only one copy of a defective gene is necessary for the disease to be manifest. Other conditions are inherited in a recessive manner. Recessive inheritance requires both copies of a gene to be defective before the genetic disease will manifest itself. Those people who have only one copy of a mutant gene, and are not affected by the

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6 The ethical issues raised by this technology are considered only in as much as they overlap with those raised by gene therapy. For a detailed ethical consideration of genetic testing and screening, see: British Medical Association, *Human Genetics: Choice and Responsibility.*

7 These include; cystic fibrosis, Duchenne muscular dystrophy, Huntington's disease, Tay Sachs, sickle cell disease and some forms of inherited breast cancer (Rifkin, *The Biotech Century,* p.27).

8 Jones, *The Language of the Genes,* p.295.

disease, are called 'carriers' because they can pass this mutant gene on to their descendants. Cystic fibrosis is inherited in a recessive manner. If two people from families known to suffer from cystic fibrosis (but themselves healthy people) were exploring the possibility of starting a family, they may well want to discover whether either or both of them were carriers.

FOETAL TESTING

A combination of chorionic villus sampling and DNA analysis can now allow foetuses to be tested for a number of inherited conditions (embryos *in vitro* can also be tested). These include not only single-gene mutations, but also chromosomal abnormalities. Tests of this sort are offered to those thought to be at particular risk (because of information from family histories, or the mother's age). The difficulty with foetal testing currently is that so few inherited diseases can be successfully treated, even if identified before birth. The only 'treatment' which can be offered today is that of a 'therapeutic abortion'.

b) Genetic screening

Screening populations for particular conditions is already an important medical tool. Pregnant women are routinely screened for their rhesus blood group, and adult women are regularly screened for the presence of cervical cancer. One particular genetic condition has been screened for in this country since 1973. Phenylketonuria (PKU) is a disease which prevents people from metabolising a certain chemical found in everyday food. A build-up of derivative chemicals in the body causes brain damage leading to severe mental handicap. All babies in this country are screened for PKU at birth; those found to be suffering from it can be fed a particular diet which prevents brain damage occurring.[9]

PKU is one of the few genetic conditions which has a successful treatment. Many genetic diseases for which it would now be possible to screen large numbers of people (detecting both sufferers and carriers) have no treatment. Would the knowledge gained from screening programmes be valuable or destructive? Both are possibilities, as is illustrated by examples of genetic screening already conducted in the United States.

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9 This screen has been available for so long because it depends on detecting high levels of a certain chemical in the baby's blood, rather than a mutation in the PKU gene.

Sickle cell disease is a recessively inherited abnormality of red blood cells which is particularly prevalent in certain ethnic groups, especially those of African origins.[10] The symptoms of the disease include: pain throughout the body, swelling of hands and feet, and damage to eyes, lungs, hips and shoulders (all due to misshapen red blood cells clogging blood vessels). In the 1970s many US states conducted screening programmes for sickle cell disease; black people were required by law to submit to such testing. The screening was handled very badly, due mainly to insufficient (comprehensible) information being given to those screened. The whole process was seen as a means to racial discrimination. Many carriers mistakenly thought they had the disease, and became stigmatised and discriminated against in terms of employment, insurance and marriage.[11]

By contrast, a positive example of the use of genetic screening can be seen in the case of Tay Sachs disease. This is also a recessively inherited disease which is mainly observed in a particular ethnic grouping. Those suffering from Tay Sachs are by and large Jews who have their ancestral roots in Eastern Europe. Tay Sachs is a severe example of inherited disease. Mental and physical deterioration occurs in early infancy, bringing death in early childhood. In this situation, the request for genetic counselling came from within the Jewish community itself. Combining the screening programme with very good counselling and public education, resulted in the incidence of Tay Sachs being reduced by 90%.[12] About 25,000 Ashkenazic Jews are tested annually.

As the information regarding the human genome grows, and the number of genetic tests available to us increases, more genetic conditions will be open to screening programmes. The biologist Steve Jones questions the value of gleaning such information as most people carry mutations of some description, and there is little which we can do with the knowledge.[13] This situation may become significantly different if the technology of gene therapy comes to provide an effective cure for genetic disease.

10 This is probably because carriers have some protection against malarial infection.

11 Tom Wilkie, *Perilous Knowledge; The Human Genome Project and its Implications,* pp.99ff.

12 *Ibid*, p.113.

13 *The Language of Genes*, p.288.

ii) Gene therapy

The (currently) incurable nature of genetic disease has been mentioned. The alleviation of symptoms can be achieved in some situations, but a cure will only ever be effected by changes to the genetic make-up of sufferers. Altering somatic cells will not transmit genetic changes to subsequent offspring. Germ line therapy would produce a change which would be inherited. Using similar techniques to those of gene therapy, it would also be possible to add improvements to the human genome.

a) Somatic cell therapy

Clinical trials are already underway in this country exploring the use of gene therapy to cure monogenic diseases such as cystic fibrosis and SCIDS.[14]

Severe combined immunodeficiency syndrome (SCIDS) is a disease caused by a defect in both copies of the gene which carries the information needed to make an enzyme known as ADA[15]. ADA is a vital ingredient needed by cells of the immune system in order to fight infection. Infants suffering from SCIDS seldom live very long; even the common cold can be fatal to them. Mercifully it is a very rare disease, occurring in approximately 1 in 250,000 births worldwide.[16] Attempts have been made to increase the life-span of SCIDS children by avoiding infectious organisms (the child lives in a sterile 'bubble') or by boosting the immune system (through bone marrow transplants and, more recently, injections of artificial ADA). In September 1990 a four-year-old girl in the United States made medical history by receiving revolutionary gene therapy treatment. Some of the child's bone marrow cells had been removed from her body, a 'good' ADA gene added to them, and the cells reintroduced into her body. The girl is still alive, and is able to attend school. A number of other children have since been treated in the same way. The precise efficacy of the gene therapy in this situation is not known, as the child also receives regular injections of ADA enzyme.[17]

Cystic fibrosis affects about 1 in 2,000 babies born in Caucasian populations.[18] The disease is caused by the loss of a single protein from a certain type of cell in the lung and digestive system, causing

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14 William Clark, *The New Healers*, p.122-133 give details of other trials.

15 Adenosine deaminase.

16 Wilkie, *Perilous Knowledge*, p.17.

17 Jones, *The Language of the Genes*, p.293.

18 Nuffield Council on Bioethics, *Genetic Screening - Ethical Issues*, p.108.

problems in digestion and a sticky mucus to accumulate in the lungs. Children suffering from cystic fibrosis are prone to chest infections, the only treatment currently available is antibiotics and regular physiotherapy. The average life expectancy of those suffering from cystic fibrosis is about 30 years. A more drastic (and more risky) form of treatment is that of a heart-lung transplant which, if it takes, is considerably more effective. Attempts have been made to use gene therapy to cure this disease. It was originally thought that a simple nasal spray would be sufficient, but there are difficulties in delivering sufficient DNA into the cells which need it. Scientists assume that it is simply a matter of time before the practical details are sorted out, and gene therapy can be used on a routine basis.[19]

For some monogenic diseases, it is not the absence of a 'good' gene, but the presence of a 'defective' gene which causes the problems. This appears to be the case in Huntington's disease.[20] Huntington's disease could not be cured simply by the insertion of effective copies of the HD gene into cells of the central nervous system. A cure could only be achieved by the removal of the 'defective' copies of the gene from all such cells. This would be a far more complicated, if at all possible, matter.[21]

Another area in which the use of gene therapy is being explored is in the treatment of cancers. Cancer is not a simple monogenic disease like cystic fibrosis or SCIDS. Most cancers are caused by a combination of a number of genetic and environmental factors. Nevertheless, attempts are being made to treat cancer by the addition of genetic material, generally this extra DNA causes the cancer cells to 'commit suicide'.[22] The theory of gene therapy for cancer treatment may not be as simple as that for monogenic diseases, but its use may be far greater because of the higher incidence of cancer. In 1997 over half the 204 gene trials approved in the US were for the treatment of cancers.[23]

Gene therapy in somatic cells has already been developed as far as clinical trials because it has no effect on the inheritance of future generations. This very fact may cause a higher incidence of genetic disease in a given population. If the girl from America who first received gene therapy survives to child-

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19 Clark, *The New Healers*, p.133.

20 *Ibid*, p.216.

21 The possibility is being explored in the case of sickle cell disease, blood cells being far more accessible. The defective gene is not so much removed as inactivated. (Lee Silver, *Remaking Eden; Cloning and beyond in a Brave New World*, p.232).

22 Clark, *The New Healers*, pp.134-160.

23 "In sickness and in health", in *New Scientist*, 25.10.97., pp.20f.

bearing age, she will pass on to her children the same defective gene which caused her to suffer from SCIDS in the first place. It has been suggested that somatic gene therapy is no real cure because it simply serves to increase the number of disease-causing genes in the population. An alternative form of gene therapy, that which would alter a person's reproductive cells and so would be passed on to subsequent generations, is also theoretically possible.

b) Germ line therapy

It may be possible to alter the genetic make-up of an embryo *in vitro*, or a foetus *in utero*, so that a disease-causing mutation is repaired not only for the baby which develops, but also for all her descendants.[24] At the moment there is a complete moratorium on such treatments in this and many other countries. But the reasons behind the ban appear to be more practical than moral. The Clothier Committee was set up by the Department of Health to look into ethical issues raised by the possibility of gene therapy. In 1992 its Report recommended a ban on any genetic modification of embryos that could be passed on to future generations because of "insufficient knowledge to evaluate the risks to future generations".[25] Future experiments on animals, and human cells in culture, may convince us of the safety of germ line therapy. It is therefore important to consider if, and under what circumstances, it would be right to use this technique.

c) Genetic enhancement

The more we discover about the human genome and its functioning, the more it becomes likely that we will become able to change human characteristics as well as simply repair dysfunctional genes. Individuals already spend considerable amounts of time, energy and money attempting to influence their physical, mental and emotional state. Not surprisingly the possibility of using genetic manipulation as a means to the same ends has been considered. The concept appeals to a significant proportion of people

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24 This has been achieved in animals - hence the sheep with special milk and the pigs designed as organ donors, amongst many others. The feasibility of germ line therapy has recently been questioned due to the difficulty of achieving 'pure lines' of manipulated individuals. (Storrar and Torrance (eds), *Human Genetics*, p.17). The concept of germ line therapy will still be considered in this thesis, because of the possibility of unintentional (albeit partial) manipulation of germ cells, and also because the feasibility of this technique may well change in the future.

25 *The Clothier Report*, 5.1, 5.2, 7.2.

today; Rifkin cites a Harris poll taken in 1992 in which 43% of Americans "would approve using gene therapy [*sic*] to improve babies' physical characteristics".[26]

The genetic factors involved in facial features, body form, intellectual ability and general fitness are likely to be far too complex, as well as having a range of environmental influences, to be able to be readily influenced by genetic manipulation. However, there are other characteristics which may be more easily changed. It may be possible to increase our natural resistance to infectious disease by adding to, or altering, the genes involved in the immune system. Genes involved in the ageing process may soon be located. Delaying the functioning of these genes, or removing them from the human genome, may have a significant effect on the human life-span. Genes could be added to the genome which would offer protection against pollution or cancer-causing agents. It may be possible to manipulate genes involved in brain activity to reduce our need for sleep, or increase memory capacity. It would appear that the general public would be in favour of the use of genetic enhancements, however, the Clothier Committee recommended that gene therapy should not be used to change normal human characteristics.[27]

iii) Cloning

The cloning of human beings has been considered a theoretical possibility for some time. Science fiction novels like *Brave New World* and *The Boys from Brazil* have cloned people central to the plot.[28] Almost thirty years ago serious theological and ethical consideration was being given to the possibility of human clones.[29] Nevertheless, the announcement in 1997 of the birth of 'Dolly', a sheep cloned from a cell from an adult sheep, captured the imagination of the world's press. The threat of clones of Hitler jockeyed for position with the promise of clones of Claudia Schiffer. No-one appeared interested in the potential of this technique for the cloning of transgenic sheep which would secrete human proteins in their milk (the motivation behind the research). Far more exciting was the possibility of cloning human beings!

The governments of powerful nations were immediately requested to make comment and draft legislation. The Human Genetics Advisory Commission and Human Fertilisation & Embryology

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26 *The Biotech Century*, p.143.

27 *The Clothier Report*, 4.22, 7.5. See also BMA, *Human Genetics*, p.198.

28 Written by Aldous Huxley and Ira Levine.

Authority in the UK published a consultation document in January 1998 seeking public opinion on the matter.[30] It was seen that cloning could be used for a number of reasons: to 'replace' a dead child, in order to obtain an organ donor for a sibling, by an individual hoping to 'cheat' death, by lesbian or infertile couples wanting children genetically their own.[31]

The subsequent report, issued in December 1998, pointed out that the Human Fertilisation and Embryology Act 1990 already forbids human reproductive cloning using the technique used to produce Dolly.[32] Having been influenced greatly by the results of the consultation, the report supported a complete ban on human reproductive cloning, but recommended that changes to the 1990 HFE Act should be made to allow 'therapeutic cloning'.[33] Indicating the extent to which the report's conclusions were influenced by public opinion, it was also recommended that "the issues are re-examined again in, say, five years time, in the light of developments and public attitudes towards them in the interim".[34]

Recent experiments in animal cloning suggest that it may be a while before the techniques of mammalian cloning will be sufficiently safe for use with human beings.[35] If the technology does become sufficiently developed, and if public opinion were to change as a result, would this mean that human reproductive cloning would be a morally appropriate thing to do? Or are there any moral implications which need to be considered irrespective of 'public opinion'?

Having described the techniques of genetic testing and screening, gene therapy, and cloning, consideration is now given to the moral issues they raise. These issues can be grouped into three main

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29 Ramsey, *Fabricated Man*, p.62ff, (1970). Fletcher, *The Ethics of Gentic Control*, p.154f (1974).

30 *Cloning Issues in Reproduction, Science and Medicine - A Consultation Document.*

31 *Ibid.* 8.3, 8.5.

32 *Cloning Issues in Reproduction, Science and Medicine - A Report*, 3.4. Reproductive cloning (that used to bring about the birth of a cloned baby) was distinguished from 'therapeutic cloning' (which could be used to provide cultured cells for the treatment of serious disease), 5.1.

33 *Ibid*, 4.4 and 9.3. Therapuetic cloning will not be considered further in this thesis. It raises distinct ethical issues not to be covered here.

34 *Ibid*, 9.7.

35 A very small proportion of embryos having received a nuclear transfer actually develop into a viable foetus (*Cloning Issues in Reproduction, Science and Medicine - A Consultation Document*, 2.2), there may also be complications relating to aging ("Worn away" in *New Scientist*, 29.5.99., p.12).

areas. They relate to our understanding of what it is to be human, to the concept of eugenics, and to our understanding of health.

2.3 Genetic manipulation - moral issues

Some of the ethical issues raised by genetic manipulation are practical, relating to the implementation of the techniques. These issues include those of safety, financial matters and the use of genetic knowledge. In terms of safety; the insertion of new fragments of DNA into a genome happens at random, and can destroy important sequences. This could have implications for the health of the gene therapy patient, or for future generations if the effect is not felt immediately. One of the ways in which DNA is introduced into chromosomes is through the use of viruses. These viruses will have been altered so that they do not cause disease, but there is the possibility of them being able to become active again. Some human genes which are regarded as 'defective' may actually be vitally important in certain situations; removing these genes through gene therapy could be detrimental in the long-term (as in the case of the sickle cell gene affording resistance to malaria). Safety issues relating to cloning have already been mentioned.[36] In financial terms; sequences of DNA and transgenic animals have been patented. Genetic technology is incredibly expensive; gene therapy may therefore become an issue of the use of limited resources in the National Health Service.[37] In terms of genetic knowledge; despite the amazing genetic technology available, 100% accuracy can never be guaranteed in tests for disease-causing genes, new or rare mutations can slip through the net of the test. What is the value of such knowledge if there is still no treatment for such diseases, or if one is found to be a carrier of a relatively rare disorder? Who should have access to genetic information: other family members, potential marriage partners, insurance companies, employers? Practical questions such as these will be considered only when they impinge on the deeper, more fundamental moral issues raised.

Some very basic moral questions are raised by genetic testing, gene therapy and human cloning. These are the questions I intend to address, they include: What does it mean to be human? Is it right to alter the course of human evolution? What do we mean by 'health'? and What are we aiming at through our use of medicine and genetic technologies?

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36 Previous footnote.

37 See Ch.3.7 (ii), below.

i) Issues of human nature

a) Determined or free?

The Human Genome Project and associated genetic research is providing a new dimension of insight into human nature. Walter Gilbert, one of the pioneers of DNA sequencing, has suggested that when we have read the entire human genome, then we will know what it is to be human.[38] The assumption behind this statement is that human beings are the sum of their genes. In the light of acquiring so much genetic information about ourselves, we could be reduced to believing that we 'are' the 3 billion letters which make up our genome. A person could be defined by the mutations she carries. We may come to have an increasingly deterministic attitude towards ourselves. Already suggestions have been made that genes 'for' schizophrenia, alcoholism, homosexuality, criminality and manic depression have been found.[39] But are human beings simply robots, made and functioning according to the instructions in their genomes? It is really true that we have no control, that we are unable to influence the way our lives work out, that we are simply machines set to run a pre-determined course? Can we blame everything on our genes, or is there a way in which we are actually responsible for our own lives? What does it mean to be human?

b) A question of worth

Human life has been considered to be unique, even morally superior to animal life.[40] This is due in no small part to the traditional Christian understanding of the early chapters of the book of Genesis. The value of human life is called into question in two ways by recent genetic advances: by comparing human and animal genomes, and through the testing of foetuses for genetic abnormalities.

As our genetic knowledge of humans and a huge variety of other creatures grows, it becomes increasingly obvious that humans share much of their genetic make-up with animals, plants and even bacteria. The DNA of human beings and chimpanzees differ only by about 1.6%.[41] This is especially startling as there is a 2.6% difference between the genomes of the almost indistinguishable willow warbler and chiff chaff. Where then is the unique value, the moral worth, of the human being to be

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38 Wilkie, *Perilous Knowledge*, p.182.

39 John Kilner, Rebecca Pentz and Frank Young (eds), *Genetic Ethics; Do the Ends Justify the Means?*, p.78 and 84.

40 Wilkie, *Perilous Knowledge*, p.176.

41 Jones, *The Language of the Genes*, p.129. See also "The greatest apes" in *New Scientist*, 15.5.99, pp.26-30.

found? Some animal rights campaigners regard any understanding of humans having unique value as being 'speciesist', on a par with sexist, racist and ageist views.[42] Is there any reason for unique value being afforded to human beings? At what stages in life is this value to be found?

It is now possible to test human foetuses for a number of genetic anomalies. As most genetic diseases have no effective form of treatment, there is little that can be done on receiving a positive test result. 'Therapeutic abortions' are offered as a means of avoiding a life of suffering. This action implies there are human lives which are not worth living, and/or a foetus does not afford the same moral value as a baby.

The question of the value of human life lies at the heart of the issues raised by much of the genetic technology available to us now. It is the question which Wilkie sees as being of crucial importance.

> This then may be the final challenge posed by the Human Genome Project: to redefine our sense of our moral worth and to find a way of asserting, in the face of all the technical details of the genetics, that human life is greater than the DNA from which it sprang, that human beings retain a moral value which is irreducible and which transcends the sequence of 3 billion base pairs within the human genome.[43]

What does it mean to be human?

c) Masters of the universe?

The powerful and creative genetic technology available to humans can lead to delusions of grandeur. It may appear anything is possible, that we can design and make any form of life, that we can be 'masters of the universe'. If only we had sufficient knowledge, and could develop the necessary technologies, then we would be able to do anything, we could design the world the way we want it to be. This attitude is commonly seen as springing from the Enlightenment, and in particular the work of

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42 Richard Ryder, *Animal Revolution: Changing Attitudes towards Speciesism,* cited in Andrew Linzey, *Animal Theology,* p.196.

43 *Perilous Knowledge,* p.191.

Francis Bacon.[44] The value of knowledge, and the use to which it can be put, was seen by Bacon in terms of humanity needing to overcome the limitations and 'ruin' which nature brought upon them; "Nature may be - and must be - mastered".[45] Taking this way of thinking, we see genetic disease as the 'ruin' thrust upon us by nature. We could fight this, applying the genetic knowledge we have gained, and perhaps bring about a human population free of genetic disease. Our genetic limitations are seen as restrictions forced upon us by nature; these too could be fought using enhancement and cloning techniques. We could overcome disease, and the limits of our genetic make-up. We could become 'masters of the universe'.[46]

Is the Baconian way of thinking valid and realistic? Is it true that nature is 'out to get us', that we need to fight against its forces? Is it true that if only we knew enough we could apply our knowledge to overcome the limitations and the 'ruin' of this life? Can we become masters of the universe? What does it mean to be human?

ii) Eugenic issues

Any attempts to use genetic manipulation to fight disease or to escape our limitations will have eugenic implications. An awareness is needed of the significance of eugenics, and the ways in which it is already affecting our lives. There is no doubt that humans have already altered the course of their own evolution by indirect means. For instance, Jones suggests the invention of the bicycle was "the most important event in recent human evolution"![47] But to what extent would it ever be right for us to take an active role in directing our evolution?

a) A historical perspective

The term eugenics (from the Greek *eugenes,* meaning well-born) was first coined in 1883 by Francis Galton (a cousin of Charles Darwin).[48] His assumption was that; "What Nature does blindly and

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44 Allen Verhey, *"Playing God"*, in Kilner, Pentz and Young (eds), *Genetic Ethics,* p.62f. Also Gerald McKenny, *To Relieve the Human Condition; Bioethics, Technology, and the Body,* p.2-5.

45 Allen Verhey, *"Playing God"*, in Kilner, Pentz and Young (eds), *Genetic Ethics,* p.63.

46 It is a scenario very much like this which Silver envisages in *Remaking Eden.*

47 *The Language of the Genes,* p.315. Bicycles increase our rate of outbreeding.

48 For more detail see; Enzo Russo and David Cove, *Genetic Engineering; Dreams and Nightmares,* p.166-176.

ruthlessly, man may do providently, quickly and kindly".[49] This could be achieved through positive eugenics (the planned reproduction of the fit) and through negative eugenics (the prevention of reproduction of the unfit). Eugenics became remarkably popular and influential in countries including Britain and America during the first half of this century.

An experiment in positive eugenics begun a century ago warns that the outcome may not always be that expected. Elizabeth Nietzsche (sister to Friedrich) selected a group of people whom she saw as ideal specimens on the grounds of the 'German purity of their blood'. They were sent to a remote part of Paraguay in order to found 'New Germany', a new superior race. A century later their descendants, far from being a 'master race', are poor, in-bred and diseased.[50]

Meanwhile, it has been negative eugenics which has been practiced the most. At the time when Hitler was sterilising the mentally ill, America, Denmark, Finland, Sweden, Norway and two provinces in Canada were doing the same. (In America, many state sterilisation laws called for the sterilisation of criminals, the feeble-minded, inebriates, the blind, and the deformed, as well as the mentally ill.) Not unnaturally, the attractions of eugenics paled in the light of Hitler's overt 'Racial Hygiene' programme during the Second World War, but it cannot be said that the influence of the movement has been totally lost. Rifkin warns that "America's eugenics past is a sobering reminder that 'it can happen here'."[51] To some extent it already is.

b) The present reality

Attempts at positive eugenics are being made today. In California there is a sperm-bank known as the 'Repository for Germinal Choice' which contains sperm samples donated by Nobel Prize winners and members of Mensa. This sperm is available, presumably at a suitably high price, to those women wishing to give birth to 'genetically superior' babies.[52] Admittedly this process may not have much eugenic effect, as we have seen through Elizabeth Nietzsche's experiment, but it does show that people are in favour of the principle.

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49 Cited in Jones, *The Language of the Genes*, p.282.

50 Jones, *The Language of the Genes*, p.282.

51 *The Biotech Century*, p.117.

52 Andrew Kimbrell, *The Human Body Shop; The Engineering and Marketing of Life*, p.77.

The effect of negative eugenics is certainly being felt in the present. People can now be tested to see if they are carriers for a recessive disease, or can have their foetuses tested to see if they will suffer from a disease, and can make their reproductive choices in the light of such knowledge. This applies especially for those diseases which are prevalent in particular ethnic (or other) groupings. Testing and genetic counselling, and testing combined with the use of 'therapeutic abortions', has already significantly reduced the incidence of Tay Sachs disease among Ashkenazi Jews, and of thalassaemia among people from Cyprus.[53] Testing older pregnant mothers in Denmark has led to a five-fold decrease in the number of children born with Down's syndrome.[54] These incidences do not arise out of any desire to alter the genetic make-up of a population, they are all choices made by individuals concerning their own offspring. Nevertheless they are having a eugenic effect.[55] How may this effect be felt in the future?

c) Whither the future?

Attempts at positive eugenics through the breeding of the 'fit' with the 'fit' have been shown to be limited in their success. More accurate, and presumably more successful, positive eugenics could be achieved through the use of germ line gene therapy and cloning. Gene therapy and genetic enhancement which bring about changes to the genetic make-up of germ line cells will influence future generations. For this influence to be felt in all subsequent offspring, it will be necessary for the 'engineered' to breed with others 'engineered' in the same way. Otherwise the genetic alteration will be diluted throughout the general population, and its effects lost. One way to ensure a particular genetic combination could be passed on to future generations would be through the process of cloning.

Current practice and future possibilities raise the question over whether it is right for humankind to make a deliberate attempt to alter their future. Do we have the capacity to engineer ourselves a better future? Would it be right for us to attempt to do so? Is 'eugenics' still a dirty word to be associated with Hitler, or does it offer us hope?

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53 See above 2.2 (i) b and Wilkie, *Perilous Knowledge*, p.100.

54 Jones, *The Language of the Genes*, p.286.

55 It has been suggested that this is simply restoring the process of natural selection which used to operate before modern medicine provided the means to keep alive those with genetic abnormalities (Peter Singer and Deane Wells, *The Reproduction Revolution; New Ways of Making Babies*, p.172).

iii) Health issues

The third area to be considered has already been touched on, through the issue of human value and the implications of therapeutic abortions, that is the area of health and 'normality'. Genetic medicine is already a distinct field in its own right. Molecular tests and genetic counselling are available to those in need. The more we learn about the nature of genetic diseases, the more we are able to find strategies for combatting them; such strategies could include gene therapy. Both 'therapeutic' cloning and reproductive cloning could have medical uses, especially in the field of organ or tissue transplantation. Genetic technology raises moral questions concerning health and medicine; questions concerning the role of medicine and the nature of health.

a) Christianity and Medicine

In the light of Christian belief, it is not surprising that there has always been a central tension, almost a necessary paradox, in the Church's approach to medicine. On the one hand there is a recognition of God's providence. In this context, purpose is seen in illness acting as a spur to repentance, or being a means by which faith is tested and strengthened. This view is captured magnificently in 'The Order for Visitation of the Sick' found from the *Book of Common Prayer.*[56] Today such verbose language may not be used, but the belief that God uses illness or disability to bring people back to himself, or to strengthen faith, remains.[57]

On the other hand, there have always been Christians involved in the medical profession. Healing is seen as an effect and a sign of God's mercy.[58] A scriptural (if Apocryphal) justification for doctors is found in Ecclesiasticus Ch.38.[59] Caring for and treating those who are ill is an extension of Christ's healing ministry, and a response to the commandment to love our neighbour as ourselves. Our present physical bodies may not be of eternal significance, but this does not mean to say that the state of them is irrelevant. In the light of this tension, what is it that we should expect of medicine?

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56 As pointed out by Stephen Pattinson in *Alive and Kicking: Towards a Practical Theology of Illness and Healing,* p.46.

57 Michael Beates *"God's Sovereignty and Genetic Anomalies"* in Kilner, Pentz and Young (eds), *Genetic Ethics* p.52-54. McKenny, *To Relieve the Human Condition,* p.221f.

58 Paul Tournier, from *"A Doctor's Casebook in the Light of the Bible"* quoted in Stephen Lammers and Allen Verhey (eds), *On Moral Medicine: Theological Perspectives in Medical Ethics,* p.21.

59 Karl Barth, from *"Church Dogmatics III/4"* quoted in Lammers and Verhey (eds), *On Moral Medicine,* p.8.

b) Advances in medical technology

The question concerning the role of medicine has been highlighted in recent years by a rapid and widespread growth in medical technologies. An expectation has developed that medicine can, and should, treat anything.[60] Evidence of this expectation is seen in the five-fold increase in the per capita cost of running the Nation Health Service between 1960 and 1994 (inflation having been accounted for).[61] How are these technologies best to be used? Is it our moral duty to use them at any and every opportunity? If gene therapy becomes standard treatment, will it be the duty of doctors to use it in all cases of genetic abnormality or difference? As germ line gene therapy would be more effective in removing genetic abnormalities from a population, would this be regarded as morally preferable? If health advantages could be given to people by adding new genes, would this be a good use of a medical technology? Should cloning be used to produce lines of very healthy people?

c). Expectations of 'health'

The question of the role of medicine begs the question of our understanding of the nature of health. What is it that medicine is aiming to achieve? One could say; 'healthy people', but then how would 'health' be defined? In 1948 the World Health Organisation defined it as: "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity".[62] There is value in regarding health not simply as the absence of disease, but the understanding of 'complete' well-being has perhaps contributed to health becoming something of an idol in today's Western culture. Glossy magazines, advertisements, television and films all promote an image of health involving beautiful, fit bodies. Health clubs, fitness regimes, plastic surgery, even ordinary foodstuffs are promoted as being sources of 'health', and pander to this idolisation.

Medical treatments can even contribute to this tendency as is seen in the case of human growth hormone in America.[63] Normal growth in children is dependent upon, amongst other factors, the presence of human growth hormone (hGH). There are some children who are born without the ability to

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60 Wyatt, *Matters of Life and Death,* p.32.

61 *Ibid,* p.35.

62 From the preamble to the constitution of the WHO, quoted in Lammers and Verhey (eds), *On Moral Medicine,* p.157.

63 From Donal O'Mathuna, *"The Case of Human Growth Hormone"* in Kilner, Pentz and Young (eds), *Genetic Ethics,* pp.203-217, Rifkin, *The Biotech Century,* pp.140-142, and Wilkie, *Perilous Knowledge,* pp.135-138.

make this hormone, who without any therapeutic treatment will develop into dwarves (having not only very short stature, but also complications with their internal organs). The treatment for such a situation is injections of hGH, originally extracted from human pituitary glands, and latterly produced by genetically modified bacteria. In the 1980s, two American drug companies were awarded patents for the genetically modified form of hGH. Partly through marketing strategies, and partly through parental pressure, demand for hGH has expanded to 'normal' children who are shorter than average for their age. These children do produce hGH, but due to other factors (genetic or environmental, or both) are significantly shorter than normal. The drug companies have redefined 'normal shortness' as an illness, arguing that the bottom 3% in height of any age group are in need of hGH treatment. These children are being given expensive, weekly injections, even though there is no real indication that they make a significant difference to their height. This example indicates the extent to which parents may desire genetic enhancement for their children simply because they fall below average in some particular characteristic, implying that a healthy life has to be an average or normal life.

Similarly, using the WHO definition, the parental desire for a 'healthy' baby can effectively become that for a 'perfect' baby. The influence of this way of thinking is already being felt through our ability to diagnose and abort those babies we would rather not bring to birth. The most common response to a serious genetic pre-natal diagnosis is abortion.[64] Yet a 'serious genetic illness' may not be the only situation leading to such a decision. In Russia, apparently pregnancies have been terminated because the foetus carries genes causing a predisposition to diabetes.[65] A genetic predisposition to excess weight, was considered by 40% of Americans surveyed as sufficient reason to abort a foetus.[66] What is health? To what ends should we be using medical technologies?

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64 Liz Hepburn, *"Genetic Counselling"* in Maureen Junker-Kenny and Lisa Sowle Cahill (eds), *The Ethics of Genetic Engineering*, p.35.

65 Jones, *The Language of the Genes*, p.286.

66 Eberhard Schockenhoff, *"First Sheep, then Human Beings?"* in Junker-Kenny and Cahill (eds), *The Ethics of Genetic Engineering*, p.88.

Human genetic manipulation raises moral questions concerning; being human, eugenic practices, and health and medicine. In the following three chapters I explore theological themes which will help to answer these questions. I turn first to the question of what it is to be human.

Chapter 3: ON BEING HUMAN

3.1 Introduction

The possibilities, and practice, of using molecular genetic technologies, as described in the previous chapter, have raised a number of questions relating to the moral significance of human life. Who are we? Are we no more than machines run on the software of our genetic inheritance? What is our worth? Are we the pinnacle of the evolutionary process, or no more significant than any other form of life? What is our purpose? Should we exploit to its fullest, or decide never to use, the awesome technology at our fingertips? A theological understanding of what it is to be human may help to address these fundamental moral questions. In this chapter I explore what it is to be human in terms of: our continuity with, and yet difference from, other animals, our responsibility within creation, and the variations within the human race. Finally, reference will be made to the implications such theological understandings have for the field of human genetic manipulation.

3.2 On being in continuity with other animals

The discovery that all living creatures share the same genetic material (DNA), which uses the same genetic code to give instructions for the making of proteins, points towards a common origin of all life on earth. Recent advances in cosmology and particle physics similarly point towards a common origin of all matter. There is no reason why these discoveries should conflict with the Christian doctrine of creation. Eco-feminist theology is an example of ways in which recent advances in scientific understanding have been incorporated into Christian thinking.[1]

The common origins of all animals, including humans, are also seen in the common molecular basis to the whole of our lives. Humans are remarkably similar to other animals, not only in the way genetic information is stored and processed, but also in the way in which food is digested, bodies are built up and grown, off-spring are conceived, and ultimately our bodies die. This brings us to a common biological and theological observation about all animals; that they are limited creatures. Human beings

[1] Alternative approaches can be seen in the works of John Polkinghorne, for example *Science and Christian Belief; Theological Reflections of a Bottom-Up Thinker,* and Keith Ward, *God, Faith & the New Millennium; Christian Belief in an Age of Science.*

are just like any other animal in being embodied, in being limited, and in being mortal. Human beings, for all their skills, abilities and intellect, are still creatures.

i) Embodied

One of the main emphases of feminist theology is the importance of bodies and a recognition of embodiment.[2] Humans are far more than mere spiritual or intellectual beings; we are also physical, we are embodied. In the past religious or philosophical thought has regarded the human soul or mind as of greater importance, greater significance and greater influence than the human body. Feminist theologians criticise traditional Christian theology for tending to be 'otherworldly' and emphasising the salvation of the individual soul, rather than recognising that the Christian hope involves a hope for the whole of creation.[3] The Christian faith seen in its fullness bears witness to the importance of our embodiment; this is seen in God's work of creation bringing about bodies, in Jesus Christ's taking on our flesh, and in the resurrection promise of transfigured bodies.[4]

The reality and significance of human embodiment needs to be taken into consideration in discussions concerning the morality of genetic manipulation. Moltmann writes of embodiment being the "end of all God's works".[5] Thus the Christian life is not about trying to find a gnostic escape from our bodies, but about living life in all its fullness within our bodies.[6] It is natural that there are limitations to our bodies. These limitations need to be recognised and honoured. A body can inform a soul/mind as much as vice versa, we need to learn to listen to our bodies.[7] In addition, the state of our physical existence does matter. We cannot spiritualize away our illnesses, our disabilities, our suffering; they are real, they do matter.[8] It is important that genetic diseases are treated seriously. They may be rare but their effects on people can be devastating.

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2 Margaret Farley, "*Feminist Theology and Bioethics*" in Ann Loades (ed.), *Feminist Theology; A Reader* pp243ff., McFague, *The Body of God,* Elisabeth Moltmann-Wendel, *I am My Body.*

3 McFague, *The Body of God,* p.102 and p.109.

4 Moltmann, *God in Creation,* p.245f.

5 *Ibid.* pp.244-275.

6 Compare Ch.4.3 and Ch.5.3.

7 Moltmann-Wendel, *I am My Body,* p.3, Moltmann, *God in Creation,* p.260.

8 McFague, *The Body of God,* p.18.

The fact that we are bodies necessitates limitations in our lives. Two of these limitations are explored below.

ii) On being in limited control

The huge strides in human intellectual achievements and technical abilities over the last two hundred years can lead to a mistaken belief that we are in total control. As a society and as individuals we think we are in control of our environment, of other creatures and of ourselves.

For Reinhold Niebuhr, it was the horrific events of the two world wars which provided conclusive evidence that for all our advances, humans are still limited creatures.[9] He saw that a level of control over nature may have been achieved (although this in itself is limited: witness the devastation still wrought in the world through earthquakes, tornadoes, bush fires, drought and flood) but humans still had little control over their own nature. Humanity's advances in knowledge, and apparent conquest of nature, had not seen a parallel development in the wisdom, and ability, necessary for the conquest of human nature. Nor was it simply a case that social wisdom was not keeping apace with technical advances. Humans are creatures with creative ability, but they are not creators who are in total control, either of themselves, of other people, or of that which they create. [10] Niebuhr suggests that it is a significant part of the recalcitrance of the human heart that rather than recognise our limitations, and live with care in the light of them, we have the tendency to attempt to defy our limitations and to live without our Lord and Creator. This is what it is to sin.[11]

Niebuhr also suggests that our creaturely limitations are shown in natural distinguishing features of humanity which (he thought) no amount of technology could erase: sexual, ethnic, and linguistic differentiation.[12] Confirming his observations about our tendency to fight our natural limitations, a significant amount of effort and technology over the last 50 years has been applied to overcoming the first two of these 'distinguishing features'. It is highly likely that genetic technology also will be used in attempts to overcome sexual and ethnic differentiation. The gender of embryos *in vitro* and foetuses *in*

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9 *Faith and History; A Comparison of Christian and Modern Views of History.* Niebuhr's theology has been described as 'Christian Realism'.

10 *Ibid.* p.70 and p.83.

11 *Ibid.* p.121.

12 *Ibid.* p.75f.

utero can easily be established, and although not legal in this country, selective implantation or abortion could take place. Genetic manipulation of individuals could take place in order to alter their apparent ethnic origins. These possibilities raise questions regarding the significance of our individual physiological structure. Does the physiology with which we are born (e.g. our gender or our physiological ethnicity) have an absolute claim on us, or could it be changed in some circumstances? Are such limitations God-given and not to be fought, or can they be surmounted through individual choice?

Writing towards the end of the twentieth century, many human advances and human failings later, Oliver O'Donovan recognises the same limitations in human life. He describes humanity's 'fallen state' in similar terms to those of Niebuhr, recognising our refusal to adopt the role given to us by God, and our resultant confused moral knowledge:

> man has refused the role assigned him by his Creator. Knowledge will therefore be inescapably compromised by the problem of fallenness, the defacement of the image of God, and by the fallen creature's incapacity to set himself right with good will and determination.[13]

Writing around the same time, many feminist theologians find such traditional language offensive. They regard the dichotomy of good and evil as part of the 'error of patriarchalism'. Especially as the 'evil' side of humanity is often regarded as 'female'.[14] The only way in which nature can be thought of as fallen is in the way that it has been marred and distorted by human misdevelopment (rather than it being evil in itself).[15] Neither McFague nor Radford Ruether ever refer to humanity as fallen, yet they still recognise that human beings are capable of, indeed are prone to commit, sin. For Radford Ruether, to sin is to create, and preserve socially, dysfunctional or distorted relationships, leading to victimization and tyranny. Such relationships can be with the earth, with our ecological community, and with each other[16], with one's own body, with those who are different from oneself, with nature, and with God/ess.[17] In a similar way, McFague sees sin "as it always has been understood in the Jewish and Christian

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13 *Resurrection and Moral Order; An Outline for Evangelical Ethics*, p. 81f.

14 Radford Ruether, *Sexism and God-Talk* p.160.

15 *Ibid.* p.91.

16 *Ibid.* p.88.

traditions, living a lie".[18] 'Living a lie' entails refusing to see or to accept where we fit in the common creation story, a refusal "to accept our proper limits so that other individuals of our species as well as other species can also have needed space".[19] In contrast to more traditional Christian theology, McFague sees sin only as a dysfunctional relationship with God in as much as, using the model of the world as God's body, to sin against any other body is to sin against God.[20] In their recognition of human sin, albeit using slightly different language, the ecofeminists also recognise that humans are not in total control, they recognise our tendency to misuse power, to victimise and tyrannise. (Both theologians do, paradoxically, seem to imply that human beings could ultimately overcome this tendency.)[21]

Each theologian sees sin as being a tendency to try to overcome the natural, proper limits of human life. It is important to recognise two different human limitations which are being discussed here. As humans, we are in limited control of our own behaviour, we have 'recalcitrant' hearts - this is expressed theologically in terms of our sinful nature. As humans, we are also limited in our bodily nature; in what we can do, what we look like, the way our bodies work. These limitations are not the result of the 'ruin' of nature which must be mastered[22], but rather they are the result of the creative work of God. These natural, proper limits are given to the human race for our own benefit, it is within the confines of these limitations that we function best.[23] In considering genetic technologies, it is important to attempt to establish what our 'proper' limits are; those limits which it would be totally inappropriate, sinful, to try to defy. Having established these limits, and recognising human failings, it would seem necessary to draw up suitable legislation (even across international boundaries if possible) to guard against those who would seek to defy these limits.

iii) On being mortal

One of the most obvious examples of our creaturely limitations, is that of mortality. No matter how much control we may have over disease, health or lifestyle, we cannot avoid death. It is an

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17 *Sexism and God-Talk,* p.161.

18 *The Body of God,* p.110.

19 *Ibid.* p.113.

20 *Ibid.* p.114.

21 See Ch.4.2, below.

22 See Ch.2.3 (i) c, above.

unavoidable fact of human life. And yet, of all our creaturely limitations, it is death which humans attempt the most to defy, in particular through our use of medicine. Hauerwas observes that there is little on which society as a whole can agree today, "but almost everyone agrees that death is a very unfortunate aspect of the human condition which should be avoided at all costs".[24]

Within feminist theology, the attempt of the individual to escape mortality, is seen as part of the patriarchal mind-set. Any Christian concept of apocalypticism, including the final resurrection and eternal life, is seen as based on the fantasy of escape from mortality.[25] By contrast, the ecofeminist view of death recognises that it is a natural part of life, part of the interrelatedness and interdependence of all life. What is seen as being of importance is the life of the whole universe rather than the life of the individual. Christian redemption is understood as; "the fulness of life within these finite limits."[26] For Radford Ruether, human life is only 'everlasting' in the sense that when we cease to exist as an individual the matter of which we are composed is recycled, giving rise to new forms of life within the world.[27] A similar sentiment is expressed by McFague using the 'body of God' model for the universe.[28] I do not agree with this particular view. The ecofeminists argue that we are more than our sequence of DNA[29], so surely I am more than the atoms which make up my body. Just because after my death the chemical constituents of my embodiment will be recycled within the earth, does not imply that I will continue to exist. Each day of my physical life atoms from my body are being lost and replaced, and yet 'I' still exist as an identifiable individual. In their approach towards death, as in their approach to redemption, these feminist theologians are not prepared to see God doing a totally new thing. However, I do believe that we can learn from their insistence that death is a natural process, and not something which is to be regarded as failure; it is a 'proper limit'. The current fear of death is leading geneticists to search for ageing genes in order to delay the process, perhaps even hoping to achieve immortality. The ecofeminist perspective on death as a natural process could challenge this trend.

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23 Wyatt, *Matters of Life and Death*, p.50 and p.62.

24 *Naming the Silences*, p.99.

25 Radford Ruether, *Gaia & God*, p.83.

26 *Ibid*, p.139.

27 *Sexism and God-Talk*, p.257.

28 *The Body of God*, p.176.

29 McFague, *Super, Natural Christians*, p.77.

There is much about the limitations of human life which remind us of our continuity with other animals, yet at the same time it is almost universally recognised that human beings are also distinct from other animals. It will be important to establish the moral significance of this distinction.

3.3 On being different from other animals: the imago Dei

Speaking biologically the difference between human beings and other animals can be expressed in terms of our intelligence, our use of language and abstract concepts, or our capacity for self-consciousness.[30] Speaking theologically the difference is often expressed in terms of human beings having been created in the image of God, the *imago Dei*.[31] Human beings' uniqueness in having been created thus was confirmed and fulfilled through the incarnation. Jesus Christ, God become a human being, was the perfect example of what it is to be human, what it is to bear the *imago Dei*. In this section I explore the meaning of this term, and its significance in relation to human genetic technologies.

i) Substantial and relational theories

In a very useful historical survey of the theories concerning the *imago Dei*, Ramsey suggests there are basically two types of theory: the substantial and the relational.[32] According to the former, the image of God is to be found "*within* the *substantial form* of human nature". It is something which is essential to the make-up of human beings; one of the faculties or capacities which distinguishes humans from all other animals. Various suggestions have been made as to the particular faculty or capacity involved, either something physical (the size of the brain, the upright stance, or the prehensile thumb), or some inner capacity (reason, conscience or free-will). This 'substantial' or 'structural' understanding of the image of God uses an analogy with plastic or pictorial arts, such as sculpture or painting. Just as these art forms use a model which has the "form" or image of that which is to be fashioned; so in the same way it is seen that something about human beings is modelled in the image of God.[33]

Ramsey sees a significant difficulty in the substantial theories in that they tend to blur the distinction between humans and God. The theories imply; "Man is, no doubt, smaller than God, but

30 McFague, *The Body of God*, p.60 and p.122.

31 Genesis 1.26f.

32 Paul Ramsey, *Basic Christian Ethics*, pp.250ff.

33 *Ibid.* p.254.

quintessentially they are the same".[34] Yet Ramsey sees Genesis 7.22-23 as saying that humans are made of the same substance as other living creatures, not of the same substance as God. This distinction is not nit-picking, it has obvious ethical implications. To consider oneself of the same substance as God, one could be led to act as one's "own God in microcosm".[35]

Whereas the substantial theory uses the analogy of a model, the relational theory uses that of a mirror reflecting an image. This view suggests there is nothing within the make-up of humans which constitutes the image of God. Only when humans form responsive relationships with God, then the image of God is reflected in their lives and their actions. It is not so much that humans are made in God's image, or even that they bear God's image - but rather that through relationship with God they reflect or live within his image. This view does not deny that human beings have a number of unique capacities, but recognises that in themselves these capacities do not reflect God's image; "nothing about man *not presently involved in response to God* can be called God's image."[36]

ii) The *imago Dei*, Barth versus Brunner.[37]

In recent history perhaps the most famous clash between theologians holding differing theories regarding the image of God, was that between Emil Brunner and Karl Barth. While Barth held a purely relational view, Brunner proposed a view in which the image of God contained both substantial and relational elements.

EMIL BRUNNER

In *Natural Theology* Brunner argues that the image of God is found in humans in two different ways; he uses the terms 'formal' and 'material'.[38] The 'formal' aspect of God's image involves something structural, that which makes them different from/superior to all other creatures - the *humanum*. Scriptural support for this view is thought to be found in Genesis 1.26 and Psalm 8. Brunner sees the

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34 *Basic Christian Ethics*, p.252.

35 *Ibid*, p.254.

36 *Ibid*. p.255, my italics.

37 The clash can be seen in all its glory in *Natural Theology*, which was first published in 1934. The theological wranglings continued in the later works of these men; in particular in Brunner's *Man in Revolt* and Barth's *Church Dogmatics*.

formal image in humanity's 'capacity for words' and 'responsibility' (or 'subjectivity'). These characteristics (and therefore the formal image of God) are retained by humans despite their rebellion against God, despite their sinful behaviour, despite the 'fall'.

By contrast, the 'material' aspect of the image, which is to be found within a person's relationship with God, is understood to be totally destroyed by the 'fall'. It is the formal image of God in a person, retained despite sin, which Brunner sees as being the 'point of contact for the divine grace of redemption'.[39] When, through his grace, a person's relationship with God is restored; then the material image of God in her is also restored.[40]

KARL BARTH

By contrast, Barth sees it is as essential that the image of God in humankind is purely relational. He maintains there is nothing inherent in what it is to be human (as against a snowflake or the sea) which involves bearing God's image - but rather, the image is revealed only through acknowledging and serving God.[41] Anything structural or substantial would imply that salvation is not purely a gift of God's grace. This image is totally destroyed by sin. Rather than reflecting God's image, a rebellious person reflects either their own will, or the will of an idol.[42] (Even though the image of God is totally destroyed through a person's sin, Barth nevertheless recognises that there is still something unique about human nature; "even as a sinner man is man and not a tortoise"[43], but this uniqueness in no way reflects the image of God). When through the grace of God, a person enters into a relationship of trust and obedience with God - then the (material) image is reflected in their life. This is not a damaged or destroyed image being repaired, it involves a totally new creation; a death followed by new life.[44] There is an eschatological, a 'now but not yet', element to this. Each individual Christian is 'being transformed into his likeness', it is

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38 In his later works, *The Divine Imperative* (Macmillan, 1937), and *Man in Revolt* (trans. Olive Wyon, Lutterworth Press, 1939), Brunner abandoned these particular terms - but he still appears to have held much the same understanding of God's image in humans.

39 *Natural Theology*, p.31.

40 *Ibid.* p.34.

41 Ramsey's paraphrase of Barth's view, *Basic Christian Ethics*, p.258.

42 *Ibid.* p.278.

43 *Natural Theology*, p.79.

44 *Ibid.* p.74 see also pp 92-94.

an on-going process as each continues to subject her/himself to God, to receive his grace and the power of his Spirit.[45]

Barth argues against Brunner's concept of the *Imago* on two grounds. Firstly, he questions whether the 'formal' image is purely formal, or whether there has to be an element of the material to it, because a 'point of contact' for God's grace seems to imply a relational aspect. If a person can see something of God in creation, or history, or their conscience, the material (relational) aspect of God's image cannot be completely lost. This is Barth's major criticism of Brunner's theory.[46] Secondly, and more practically, Barth is concerned with the implications for those human beings without the 'capacity for words' and 'responsibility'. The implication of Brunner's concept would seem to be that they are not made in the image of God. Barth was particularly concerned about new-born children and the mentally handicapped: "Are they not children of Adam? Has not Christ died for them?"[47] A third objection is made by Ramsey, who questions whether our supernatural relationship with God can be completely destroyed without other aspects of human nature also being affected.[48] Recent advances in the understanding of human life have come to see that each individual is an interrelated whole, body, mind and soul. The reality of this is borne out by our own experience - our sinful nature does affect our rational nature, our free will, and our moral judgements. This leads Ramsey to conclude: "If the unity of human personality be taken seriously, then the only way to avoid a notion of 'total' sinfulness is to have no notion of sin at all."[49]

iii) Further explorations of the relational image.

There is a strong Christological element in the relational view of the image of God. Jesus Christ is seen as the image of the invisible God, as he alone has lived in perfect relationship with the heavenly Father.[50] Jesus effectively recreates the image in which humankind was originally made, and it is he who provides that 'point of contact' through which God's grace may reach humanity.

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45 2Cor.3.18, also Col.3.10 and 1Cor.15.49.

46 *Natural Theology,* pp.120f.

47 *Ibid.* p.89

48 *Basic Christian Ethics,* p.282.

49 *Ibid.* p.284.

50 Col.1.15, also 2Cor.4.4 and Heb.1.3.

Ramsey observes that to be in good relationship with God, inevitably implies being in good relationship with one's neighbour, this is seen in Jesus' life.[51] This theme is followed more deeply, and expanded on, by Geoffrey Brown with reference to Barth's *Church Dogmatics*.[52]

Brown suggests that Barth's doctrine of the image of God is concerned not only with man's relationship with God - but also with relationships within the Trinitarian godhead, and relationships between human beings. As we come to understand something of the relationships within the godhead, so we learn something of what it means to live within God's image with other human beings. The internal relations of the godhead - Father, Son and Holy Spirit - reveal a freedom of God to be himself, reflecting an equality of power, authority and glory. So human relationships within the image of God will reflect a similar freedom for self-determination, and affirmation of the equality of persons. The Christological emphasis of Barth's doctrine; seeing Jesus Christ as the true human being, the One through whom we too may come to live within God's image - informs our understanding in a similar way. Jesus Christ revealed the true image of God through his relationship of love and service with his Father, and his relationships of love and service with other human beings.[53] Finally, recognising that it is through the grace of God alone that we exist and that we reflect God's image, serves as a theological basis for the solidarity of, and need for mutual respect between, fellow human beings.

iv) The image of God and genetic manipulation

SUBSTANTIAL THEORIES

Any substantial view of the image of God is misleading in suggesting that a human being is 'of the same substance' as God. As current genetic technology and understanding is advancing so rapidly, and with such power, it is not exactly surprising that we may be lulled into thinking we <u>are</u> like God. And yet human beings are <u>not</u> of the same substance as God, but rather of the same substance as all other living creatures - totally reliant on the grace of God for our existence and the fulness of our life.

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51 *Basic Christian Ethics*, p.259

52 "*Clones, Chimeras, and the Image of God: Lessons from Barthian Bioethics*", in John Kilner, Nigel M. S. Cameron and David Schiedermayer (eds), *Bioethics and the Future of Medicine*, pp.238-249.

53 *Ibid.* p.242.

The most significant difficulty arising from a substantial concept of the image of God, when relating it to ethical issues of genetic manipulation, concerns the status of those human beings who would be judged not to bear God's image. If the image of God is to be found in the human ability to walk upright, what does this say about the crippled? If the image is to be found in a person's responsibility and capacity for words, what does this say about the unborn child, the mentally defective, the senile, the comatosed? Are these people to be regarded as beyond the pale of humanness? In deciding on the capacities which result in a person bearing God's image; we decide for ourselves which people we choose to regard as 'human beings'.

RELATIONAL THEORIES

Those who hold to the relational view of the image of God object to the exclusiveness of any substantial view; the image of God is nothing to do with what a person may have achieved or has the potential to achieve, but rather to do with what God has given. It is through God's grace that someone exists, and through his grace that, in a relationship with God, they can reflect his image. The substantial view is rejected because it denies the image of God in certain human beings. If it is important, however, in terms of moral decision-making, to know who reflects God's image, then the relational view is no more helpful. On the one hand, the relational view is clear in specifying that it is only through a relationship with God that one can reflect his image. But on the other hand, it is certainly not the role of any person to pass judgement on the status of his neighbour's relationship with God. Some who hold this relational view seem to err on the side of universalism[54]; others leave the problem to God, referring to his election, his decision, his calling.[55] The concept of human beings reflecting God's image through relationship, is therefore of no help to ethical decision-making if one attempts to discern those who may or may not be reflecting his image. This doctrine may be of greater help through an exploration of the implications a relationship with God has on one's relationship with one's neighbours.

To be in relationship with God inevitably means to be in relationship with one's neighbour. This truth can be seen within the prototype of the Trinity, in the life of the 'one true human being', Jesus

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54 Brown, *"Clones, Chimeras, and the Image of God"* in Kline, Cameron and Schiedermayer (eds), *Bioethics and the Future of Medicine,* p.243.

55 Joan O'Donovan, *"Man in the Image of God; The Disagreement between Barth and Brunner Reconsidered"* in *Scottish Jounral of Theology* (39), p.456f.

Christ, and within the teaching of Scripture. To be a recipient of God's grace in one's own life, will result in the desire to share that grace with others. Those who seek to truly reflect the image of God in their lives, will need also to pay attention to their relationships with other people.

Ramsey provides some very helpful insights in this area through a consideration of Human Rights.[56] He suggests that from a Christian viewpoint 'rights' are not exactly the best place to start. Christian ethics require a shift of emphasis from 'rights' to 'duties', and this means; "When a man stands most in the image of God..... he is least concerned about his own value".[57] To reflect the image of God is to be in a relationship of love and service with God which naturally spills out into a relationship of love and service with one's neighbour. This implies that value is found not in the person bearing God's image, but in the person loved by the one bearing God's image.

> Infinite value is placed upon the neighbour's personality, value is created and realized there, whenever, in the service of God, a person forgets his own claims and becomes in some measure a Christ to his neighbour. To be in the image of God means to do the work of love in valuing one's neighbour.[58]

In other words, reflecting God's image by living in a relationship with God inevitably brings with it responsibility; responsibility to live in good relationship with one's neighbour, one's environment, and oneself.

3.4 On being responsible

The responsibility of human beings reflecting God's image to offer love and service to their neighbours has already been touched upon. This section looks at our responsibilities towards the whole of the created order, and also towards ourselves.

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56 *Basic Christian Ethics*, pp.351-366.

57 *Ibid.* pp.353f.

58 *Ibid.* pp.354f.

i) Human stewardship

The Biblical creation story speaks not only of God making human beings in his image, but also of God giving them responsibility for the world in which they live.[59] In the past the commands to 'subdue', 'have dominion over', and 'be master over' the world have tended to be misinterpreted as 'dominate' or even 'exploit'. Nature has been regarded as existing as a resource for humans to use, to manipulate, to control.[60] In recent years this imbalance has begun to be redressed, not least as a result of ecofeminist theology.[61]

McFague and Radford Ruether see a parallel between the domination of women by men, and the domination of nature by human beings.[62] An ecological understanding of the world highlights the interdependence of all life, but the unique human ability of self-consciousness gives us a responsible role. Right relations are to be found in responsibility, not in domination. The rest of creation exists for humans to live responsibly alongside, not for humans to use as it wishes.[63]

McFague sees that recent advances in science have resulted in a decentre-ing and recentre-ing in our understanding of the place of humanity within the whole created order. We have been decentred in as much as humans are no longer regarded as the point and goal of evolutionary history, but we have been recentred by rediscovering our responsibility as stewards of life.[64] Somewhat ironically, having been determined to play down the position of humanity in creation, McFague recognises our role as stewards of the earth as being very significant, giving us; "a far higher status than being little lower than the angels, subjects of a divine king, or even the goal of evolutionary history".[65]

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59 Gen.1.26-28.

60 Lynn White Jr. maintains that Western Christianity "bears a huge burden of guilt" for our current ecological crisis through a wrong understanding of Gen.1.28 (*"The Historical Roots of our Ecological Crisis"* in *Science*, 155, 1967, pp.1203-1207). This may be an overstatement, other factors (economic and social) will have contributed to this attitude. Cultures with other religious backgrounds have been equally ecologically unsound.

61 It is this branch of theology which will be considered here. A more responsible attitude towards creation is also to be found in more recent mainstream theology, for example Jürgen Moltmann, *The Future of Creation*, pp128f. and *God in Creation*, p.139; Oliver O'Donovan, *Resurrection and Moral Order*, p.52.

62 *Sexism and God-Talk*, pp.82ff. and *Super, Natural Christians*, pp.150f.

63 Radford Ruether, *Sexism and God-Talk*, pp.87f.

64 *The Body of God*, p.197.

65 *Ibid.* p.201.

In the past the living world has been so dominated, oppressed and misused that McFague suggests we regard it as the "new poor", taking special care of it as Christians do the oppressed, the outcast, the vulnerable.[66] This does not mean that we cannot use the living world in any way. The ecological discovery of the interdependence of all living things would contradict such a suggestion, but our use must be tempered with respect.[67] McFague helpfully distinguishes between looking at creation with an arrogant eye, and looking at it with a loving eye.[68] An arrogant (patriarchal) eye looks at everything in terms of being either 'for me' or 'against me'. This simplification of reality is made in order to control, to see creation in terms of what it can do for me or ways in which it can be used by me, it treats the other as object. By contrast, a loving eye acknowledges and respects the other as subject. It is prepared to acknowledge the integrity and the interests of the other, as well as the complexity, mystery and difference of the other. Treating nature as a subject rather than an object does not mean that we cannot use it at all: "we will, of course, use earth others, as we use human others, but we will do so remembering that they are subjects".[69] McFague is realistic in recognising that nature is more than "butterflies and redwood trees", that our relationship with nature cannot be all "love and harmony", because within nature there are also "killer bees, poison ivy, cancer cells and the AIDS virus".[70] In considering the role of science, McFague acknowledges that scientific knowledge need not be exploitative, it is important to learn about the living world in order to exercise proper responsibility towards it.[71] She does, however, regard molecular biology as being the most extreme example of the drive to reduce nature to object. Its reductionist views regard organisms simply in terms of their DNA rather than as complex interactive, interdependent living beings. "A tree is not just its DNA any more than we are."[72] These insights are helpful, but more work is obviously needed in terms of what they mean practically. How does one respect and yet use nature, use and yet not dominate, care and yet kill? What does this mean when intending to grow maize which is resistant to a herbicide, to clone transgenic sheep producing a drug in their milk, to sell tomatoes containing a gene from a fish, when faced with the

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66 *The Body of God*, p.165

67 *Ibid.* pp.166f.

68 *Super, Natural Christians*, pp.32ff.

69 *Ibid.* p.111, see also p.151.

70 *Ibid.* p.152.

71 *Ibid*, p.76 and p.154.

tragic effects of genetic disease in a new-born baby, or hoping to destroy cancer cells through gene therapy? At least in part, this will involve recognising that the great variety of living things only survive through a highly complex network of interrelationships and interdependencies.[73] As a result, all attempts to alter the genetic makeup of any creatures, bug, plant, animal or human, will need to take into consideration this finely tuned ecological network.

McFague's criticism of the reductionism of molecular biology leads into another area of human responsibility, namely human freedom.

ii) Human freedom

One of the classic Christian doctrines is that of human freedom. Whilst believing in the sovereignty of God, at the same time human beings are understood to have genuine responsibility and freedom in their lives. Augustine of Hippo upheld the reality of this truth in his theological battle with the fatalistic beliefs of Manichaeism (also recognising a bias towards evil within our free will, in response to the Pelagian heresy).[74]

Recently this Christian belief has been denied through a tendency towards genetic determinism. Newspaper headlines and radio bulletins convincingly inform us of the discovery of genes 'for' a variety of mental conditions and personality characteristics.[75] Scientists at the forefront of human genetic studies can be as much to blame as newspaper headline-writers for this attitude. James Watson (co-discoverer of the double-helix, and heavily involved in the Human Genome Project) is reported as having said, "We used to think our fate was in our stars. Now we know, in large measure, our fate is in our genes."[76] There are even examples of genetics being used as a defence in a murder trial, and being sought to solve the problem of homelessness![77]

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72 *Super, Natural Christians,* p.77

73 McFague, *The Body of God* p.46.

74 Gerald Bonner, *St Augustine of Hippo: Life and Controversies.*

75 See Ch.2.3 (i) a, above.

76 Rifkin, *The Biotech Century,* p.154.

77 Kilner, Pentz and Young (eds), *Genetic Ethics,* p.80 and p235.

Christian theology claims individuals have freedom and responsibility. A proper understanding of human genetics supports this view. There are very few situations in which it can be said: I have gene 'X' therefore I will exhibit 'x' in my life. The action of the vast majority of genes must be seen in a broad context; in combination with the effects of a number of other genes and environmental factors, and in the context of the development of the whole human body.[78] With a humorous touch, Polkinghorne asserts that a clone of Adolf Hitler would be just as likely to grow up to be an industrious house-painter as to be a dictator; "[t]here is no simple genetic determinism of who we shall be".[79]

If there is no simple genetic determinism, then humanity needs to be responsible. Responsibility is a virtue, not a status; it is something which needs to be worked at. We need to be responsible, not only for our own actions, but also for the environment in which we live. Many diseases come about as the result of subtle interactions between genetic predispositions and environmental triggers. There is no point in trying to eradicate the genetic predispositions (through selective abortion, genetic therapy or selective breeding) if one is not also prepared to eradicate the environmental triggers (e.g. by taking exercise, eating fruit and vegetables, not smoking). We need to be responsible.

3.5 On being individual

A wide range of difference and variety is to be found within the human race. These differences have seldom been celebrated or enjoyed, more often they are feared and sought to be removed. People have been discriminated against as a result of their race, their creed, their gender, their class and their disability. Recently things have begun to change. Consider those people who suffer from disabilities. It is now illegal in this country for an employer to discriminate against someone because of their disability. The political correctness movement, which began in America, has changed much of our terminology. There have been 'disability rights' campaigns, and people have even claimed the 'right to abnormality'.[80] Ironically, at the same time there is a striving for perfection in human lives. Women are being offered, or are asking for, abortions because their babies are thought to be carrying a genetic abnormality which is seen as unacceptable. The screening of IVF embryos can ensure a certain quality of embryo to be

78 Elving Anderson, *"Resisting Reductionism by Restoring the Context"*, in Kilner, Pentz and Young (eds), *Genetic Ethics*, pp.84-92.

79 *"Cloning and the Moral Imperative"* in Cole-Turner (ed), *Human Cloning*, p.37.

implanted. The possibility of genetic enhancement leads us ever further up the path towards striving for perfection. An exploration of human variability will be made by considering the issues of standards and labels, and a Christian approach to difference.

i) Standards

Many of the possibilities opened up through genetic technology have raised questions about standards and expectations in human life. At the highest extreme is the attitude that we are striving for perfection. Many adults would be realistic, and recognise that they cannot be perfect, and yet they will expect exactly this standard of any baby they have. Genetic manipulation has played a large part in generating this expectation, and appears to take little account of the natural limitations and variations in human life.

> What makes the new language of molecular biology so subtly chilling is that it risks creating an unattainable new archetype, a flawless, errorless, perfect being to which to aspire - a new man and woman, like us, but without the warts and wrinkles, vulnerabilities and frailties, that have defined our essence from the very beginning of our existence.[81]

Or perhaps there are those who would simply say that they want their baby to be 'normal', but what exactly does this term mean? Statistically speaking 'normal' will refer to something in the range of 'average'. There are always, by definition, samples which fall above or below the average. Seldom do people mind if their children are above average in any quality, but what of those who fall below average? The marketing of hGH injections has led to the bottom 3% of any height range being regarded as 'abnormal' and in need of such injections.[82] This illustrates a reluctance to accept the normal range of variability within a particular quality. If it should become possible to screen foetuses for qualities such as height, weight, beauty, intelligence, sporting prowess, artistic ability, would we want to screen out the foetuses found in the bottom 3% of each category? More relevant is the question of how existing people in the bottom 3% of any of these categories are being treated. Do we ignore them, reject them, leave

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80 Liz Hepburn, "*Genetic Counselling*" in Junker-Kenny and Cahill (eds), *The Ethics of Genetic Engineering*, p.39.

81 Rifkin, *The Biotech Century*, p.147.

82 See Ch.2.3 (iii) c, above.

them on the scrap heap, simply because they are not normal? Moltmann recognises that "the demand to be normal can be tyrannical unless we understand that the normal condition of our being together is that we are all different".[83]

If neither the standard of 'perfect' nor 'normal' is satisfactory, then perhaps the most appropriate and most helpful standard to use for all people is that of 'individual'. This recognises that people will be different from one another, but makes no judgement about any person being more worth-while, more valuable, more significant than another. It is irrelevant to note that a short person could be a very talented artist, a deaf person compose beautiful music, or a severely disabled person be a brilliant physicist, this simply perpetuates success-oriented value judgements of people. What matters is that every individual has been given a past, a present and a future through the grace of God, and has the potential to reflect the image of the God to whom they owe their being.

One of the ways in which 'different' people have been disadvantaged or discriminated against is in the labels used to define them.

ii) Labels

The terminology which we use to describe people with any sort of 'difference' is a reflection of, and self-perpetuates, the attitude of society towards such people. In his introductory chapter in *Suffering Presence,* Hauerwas himself struggles with terminology with respect to the 'retarded'.[84] The same difficulty is inevitably to be found in terms of genetic illness or handicap. Medical journals, popular scientific books and daily newspapers all refer to genes as being 'bad' or 'defective', 'diseased' or 'abnormal', 'dysfunctional' or 'unhealthy'.[85] The people who carry such genes could easily take (or be given) these labels for themselves, and be treated very differently as a result. When in the 1980s 'Political Correctness' became the vogue, especially in the United States, labels such as 'differently abled' and 'visually challenged' took the place of 'lame' and 'blind'.[86] But these labels did not

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83 *The Power of the Powerless*, pp.213f.

84 *Suffering Presence*, p.16. See also p.161 which recognises terms are often reflections of social values.

85 Although it is interesting to note that Francis Collins takes the effort to use the term 'misspelled'. (*"The Human Genome Project"*, in Kilner, Pentz and Young (eds), *Genetic Ethics*, p.95-103).

86 Between 1982 and 1998 Jean Vanier moves from referring to the 'mentally handicapped' to those with 'intellectual disabilities', *The Challenge of L'Arche* and *Becoming Human.*

necessarily mean that those unable to walk or to see were treated any more positively. Labels in themselves will not change the way in which people are treated. What needs to be changed is attitudes, practices and institutions.[87] One of the ways in which such changes may begin to take place is by individuals striking up personal relationships with other individuals seen to be 'different'. This can be seen in the experience of Moltmann and Young[88], and is the basis of projects such as those in Ireland which bring together Catholic and Protestant children.

From her personal experience of bringing up her severely handicapped son, Young believes it is still important to be realistic about handicap. She finds the term 'learning disabilities' "a bit incongruous when dealing with someone so profoundly handicapped as Arthur", and it has to be recognised that until people's attitudes are changed, whatever term is used will, in the end, become derogatory.[89] Similarly, she is uncomfortable with those policies which insist that there is no difference between the handicapped and other people, this can be both hurtful and dangerous.[90]

Having recognised that all human beings are individuals, and that the labels we use to describe people can be unhelpful, I explore a distinctive Christian approach to genetic difference.

iii) A Christian approach to difference

The availability of genetic tests for an increasing number of inherited diseases has opened up the possibility for parents of prenatal testing and subsequent 'therapeutic abortion'. The pressure on parents to produce the 'perfect baby' is increasing; it may even be seen to be self-imposed competitive pressure ('We want our baby to be better than the Jones's). As fewer children are born with any sort of disability, what is society's attitude towards such children going to become? Will parents be discriminated against for 'choosing' to have a disabled child? Will they be denied financial help towards their child's care because they chose not to abort it? A similar situation could be arrived at through the ability to test for genetic disease years before any symptoms can be seen. Discrimination by employers, insurance

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87 In this context it is interesting to note that the BMA distinguishes between a disability and a handicap. A disability is a reduction in the ability to perform certain activities caused by disease, disorder or injury. A handicap is a social disadvantage resulting from an impairment or disability which limits or prevents the fulfilment of a normal social role. (*Human Genetics*, p.17f.).

88 See Ch.5.4 (i) a, below.

89 *Face to Face*, Preface p.vii. and p.176.

90 *Ibid.* p.173 and p.175.

companies, even social groupings is possible. Could the attitude of society lead to the annihilation of those who are of different ability or health through (passive or active) eugenics?

A common thread to be found in all feminist theology, is an attack on the 'patriarchal, male-orientated mind-set of domination', against any who are different to oneself. Such domination is seen as a dysfunctional, sinful relationship. Feminist theology calls for a new mode of relationship, a relationship which recognises value while affirming variety and particularity, a relationship of mutuality which allows us to affirm different ways of being, a relationship which celebrates difference.[91]

An attitude which is generally seen by feminists to appear along-side patriarchal domination, is the attitude of competition. If someone/thing is different from me, then it is either a case of defeating it or being defeated by it.[92] It is this attitude which has led to the subjugation of women, to racial discrimination, to the Nazi programme to eliminate Jews, gypsies, homosexuals, and the mentally retarded, and to the more recent horrors of 'ethnic cleansing'. Ecofeminist theologians recognise that ecological studies have taught us that absolute competition is not a 'Good Thing'. There is great value in difference, and there is a profound interrelatedness and interdependence of all living things.[93]

Difference and variety are vital aspects of human existence, they are to be affirmed and enjoyed. Difference in others should engender responsibility and co-operation rather than domination and competition.

3.6 On human genetic manipulation

The theological understanding of what it is to be human has a number of implications relating directly to human genetic manipulation. These are discussed under four main sub-headings; those relating to the beginnings of human life, human embodiment, limitations and responsibility.

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91 Radford Ruether, *Sexism and God-Talk,* p.20, and McFague, *Super, Natural Christians*, p.28.

92 Radford Ruether, *Sexism and God-Talk,* p.179. This is also recognised by Moltmann, *The Future of Creation,* p.100.

93 Radford Ruether, *Gaia & God* p.56.

i) On the beginning of human life

The dependence of genetic technologies on artificial reproductive techniques has been alluded to in a number of ways. IVF is necessary for the screening of embryos before implantation, would be necessary if ever genetic manipulations were to be conducted on embryos, and has been the basis from which (animal) cloning has developed. The achievement of one's genetic end can depend on the rejection of 'defective' foetuses and embryos, and on experiments being conducted on embryos to develop new techniques. At the moment the only ways in which potential parents can ensure their children are free of a given genetic disease, is via IVF and selective implantation, or via natural conception and 'therapeutic abortion' after screening. All of these situations call into question the moral status afforded to the human embryo and foetus. A brief consideration of this matter is given below.

The discussion concerning the moral worth of the human foetus is not a new one. Two extreme positions can be identified, and a whole range between. At the 'liberal' extreme one can find the philosopher John Harris and the feminist theologian Marjorie Maguire, neither of whom would regard the human foetus as having any moral status of its own. Harris takes a purely rational, utilitarian approach to the issue. He defines a person as "a creature capable of valuing its own existence", and argues that only persons are of moral value, on the grounds that only in depriving a person of their life would something of value be taken away.[94] Humans (of whatever age) who are incapable of valuing their own existence are not considered to be persons, they cannot be wronged by depriving them of their life (because, by definition, they do not value it) but can be wronged by causing them needless suffering. Working from these principles, Harris believes it is far better to abort a human foetus with a genetic disorder, than to allow it to be born and experience needless suffering. It is highly significant that Harris' definition has implications not only for the beginning of human life, but also for its duration. At any point in one's life a human could become a 'non-person' through injury, or disease, or decay (if one's capacity to value one's life were destroyed). As soon as the human was no longer capable of valuing their life, then no harm would be done by depriving them of that life. This concept assumes that humans have no inherent value, only that which is 'self-imposed'. It also has implications for those who are suicidal, lacking in self-confidence and grief-stricken through bereavement. Are these people non-persons too, even if only

94 John Harris, *Clones, Genes and Immortality; Ethics and the Genetic Revolution*, p.87.

temporarily? More significantly, Harris never says how can one ever tell if someone values their own life. On what practical basis will this viewpoint be lived out?

Maguire takes an entirely different approach. She argues that moral status should be given to a human foetus only if the woman carrying it chooses to afford it status, by entering into a relationship of covenant love with it. Thus it is proposed that personhood begins when the mother accepts the pregnancy, and never begins if the mother does not "consent" to the pregnancy.[95] In this way any pre-implantation embryos, and any unwanted foetuses (including those rejected due to genetic 'imperfections') are seen as non-persons. Junker-Kenny points out the irony of Maguire, as a feminist, using an argument based on a "feudal relationship .... [having] one-sided power to elect" and denying any concept of mutuality normally seen in feminist theology.[96] Equally ironic is Maguire's failure, as a Christian theologian, to recognise the value which is given each human being through the relationship of covenant love they have with God.

Often it is our having been made in God's image, which is understood to confer moral value on human beings.[97] An alternative understanding is that reflecting God's image does not confer value on us, it rather confers infinite value on those whom we love.[98] This idea could be thought to tie in with Maguire's concept that a foetus only becomes a person when its mother enters into a relationship of covenant love with it. However, it is important to remember that God's love is unconditional. If we who reflect his image are to love as he loves, then we will recognise the infinite value in all those we come across and love, whatever their age, their health, their handicap.

At the opposite end of the spectrum to Harris and Maguire are those who would afford absolute moral status to the human fertilized egg (and therefore embryo and foetus). This 'conservative' position (which includes that of the Roman Catholic Church) is usually based on the argument that a 'radically

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95 Junker-Kenny, *"The Moral Status of the Embryo"* in Junker-Kenny and Cahill, *The Ethics of Genetic Engineering*, p.45.

96 *Ibid.* p.46.

97 Nigel M de S Cameron, *The New Medicine*, p.172.

98 See 3.3, above.

new beginning' has taken place when one particular sperm fertilises one particular egg.[99] There are some difficulties with this viewpoint; the embryo will develop into nothing unless it implants in a womb, not all the cells of an 8-cell embryo actually develop into the foetus (some become the placenta), and twinning can occur (giving rise to two individual people) at any stage before implantation. Affording absolute moral status from the point of fertilisation will have considerable implications for the use of much genetic technology.

The Warnock Report illustrates one example of an 'in-between' view on the status of the human embryo. When considering the possibility of experimenting on human embryos, the committee were unable to make a decision about the actual status of the embryo. The Report recommended that experimentation could occur up to 14 days after fertilisation.[100] This was not totally arbitrary. The neural streak of a developing embryo only begins to develop after this time-span, and such a restriction ensured that no pain could be experienced by the embryo.

Space prohibits further consideration concerning the moral status of the human embryo and foetus. A brief outline of different view-points, and their implications, have been given. Taking the issue no further will not prevent the exploration of other moral issues raised by genetic technologies.

ii) On being embodied members of creation

Feminist theologians have called to our attention the importance of embodiment. Humans are not just souls or spirits who have inhabited a body for a time. We do not <u>have</u> bodies, we <u>are</u> bodies. Our embodiment necessitates taking our afflictions seriously; they are not just temporary trials before our souls are set free. Feminist theology reminds us that suffering in this world is very real and that it matters. Yet at the same time it is not the perfection of our bodies, nor freedom from our body's limitations, for which we should be striving. McKenny suggests that it is our vain attempts to escape 'fate or fortune' that have impoverished our moral lives, and that what we need is to rediscover the "moral significance of the body". Sadly he is neither clear enough nor (by his own admission)

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99 Junker-Kenny, *"The Moral Status of the Embryo"* in Junker-Kenny and Cahill, *The Ethics of Genetic Engineering*. p.48.

100 *The Warnock Report*, 11.20.

"sufficiently fine-tuned" regarding this moral significance to be able to make specific suggestions regarding the implications this understanding may have.[101]

One of the realities of our embodiment is that we are complex organic beings, not just living machines. We cannot be considered to be simply the product of our own genetic make-up. We are more than the sum of our genes. We must be wary of any reductionist attitudes springing up as a result of the increase in our knowledge and understanding of the human genome. This will have implications regarding our attitudes towards people whose genes make them different from others.[102] It also means that we need to take responsibility for our environment, our own health and welfare, and not simply blame our genes.[103] We must explore ways of changing our environment, as well as exploring ways of changing our genes. If people with gene K find it difficult to walk up steep steps, is it easier to remove gene K from the population or to lower our public steps? The discovery that gene J makes people less susceptible to a particular pollutant, should not allow companies to restrict employment to those with gene J and be lax with their attitude towards safety. It is our responsibility to use chemicals safely, rather than exploit people who appear to have a natural resistance to them.

iii) On being limited members of creation

One of the realities of our embodied state is that our lives are limited; this is our natural state. We are not of the same substance as God, but rather of the same substance as other living things. The reality of our mortality has been noted, as has our tendency to try to fight this limit. In the light of this recognition we need to be wary. Research will continue to take place into the process of ageing, but what will we do with the results of this research? There is the possibility that cloning will be used by people in an attempt to 'defeat death' (irrespective of the reality that even a clone will never 'be' a continuation or repetition of that person). Legislation may help protect against some of these attempts at 'immortality' (at least in those countries applying it) - but perhaps what is needed more is a change of perspective, a recognition that our 'three score years and ten' need not be prolonged indefinitely. Other limits to

101 *To Relieve the Human Condition*, p.226.

102 See Ch.3.5, above.

103 See Ch.3.4 (ii), above.

humanity need to be considered too, two are explored here. The former a 'natural' limit, and the latter a 'practical' limit.

Naturally, it is a 'given' that parents are totally unaware of, and incapable of controlling, the genetic make-up of their offspring. A child may be male; with his father's hair-line, mother's eyes and sense of humour and grandfather's predisposition to heart-disease. Or she may be a daughter; with her mother's colouring, her father's chin and singing voice, and long legs despite the short stature of both parents. There are so many variables, and so many possible combinations that the natural process of conception and child-birth could never predict nor control the outcome. The look, the nature, the talents of any child are a surprise, a recognition that new life is a gift. However, genetic technology is giving us ways of designing and controlling the make-up of our offspring. Embryos generated through IVF can be screened, and those that are wanted selectively implanted. Foetuses can be screened, and 'therapeutic abortion' used to prevent the birth of unwanted genotypes. Genetic manipulation could be used to 'design' a child with a particular genetic make-up, or total control achieved through cloning. The more we move towards the design or selection of our children, the more we will turn them into consumer goods, and the more we will treat them as such.[104] Would our 'natural limit' imply that we should have nothing to do with any genetic foreknowledge of our children? To maintain the understanding of 'gift', should our attitude be; 'you'll get what you're given, and like it'? What then of those potential parents who are both carriers for a serious, recessive disease, like Tay Sachs? What of the couple, one of whom carries a dominant gene like Huntington's disease? Are the only options open those of abstaining from having their own children, or taking the chance? Is it right, in any situation, to be in control of the genetic make-up of one's offspring? Part of the answer to these questions will depend on our understanding of the beginnings of human life, and the responsibility we have towards embryos and foetuses. If it is seen as appropriate to overcome our natural limitations in the instances described above, when would it become inappropriate? This impinges on our understanding of human health and wholeness.[105]

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104 Tom Shakespeare, *"Eugenics? Slipping down the slope"*, in *Splice*.

105 See Ch.5.3, below.

The second limitation to be considered is the limitedness of our health resources. Genetic medicine and reproductive technologies are expensive. Any consideration of the use of these technologies has implications for the availability of other treatments (unless they are restricted to private medicine, and therefore only available to those who can pay, an issue of justice from a different angle[106]). The sociologist Tom Shakespeare argues that the huge amounts of money used in genetic research and medicine will only benefit individuals, and that this money could be far more effectively spent on "social change, preventative medicine, and better welfare services".[107] We are responsible, as stewards of our natural, limited resources, to ensure that our use of these resources best reflect the justice and the mercy of God. Shakespeare's words make us realise that there are alternative approaches; it will be important not to be blinded by the brilliance of genetic technologies.

iv) On being responsible members of creation

Ecofeminist theologians highlight the way in which the huge variety of life on earth exists within complex networks of interdependence. All living creatures are dependent on others for their survival. The balance between these networks is finely tuned. If one species were totally wiped out, or if one species came to dominate to the exclusion of others, the whole ecological balance could be thrown out of kilter. If humans are to act as responsible stewards of God's creation, then it will be important that we do nothing to threaten this fine balance. McFague points to the value of science (ecology and biology in particular) to help understand the ways in which living things interact and interdepend.[108] Considerations of ecological balance have been used to argue against releasing transgenic crops into the environment in Britain. This fine balance of interdependence and interaction must also be considered within single living bodies.

Adding new genetic material to any creature could upset their metabolic or developmental balance. Clinical trials in human beings for gene therapy (in somatic cells) are already taking place. Taking responsible action in these situations will involve giving consideration to the complex interactions which take place within the human body. So complex are these interactions, we can never be sure that

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106 Maxwell Mehlman and Jeffrey Botkin consider the situation in the United States. They conclude that the only fair system for the allocation of genetic resources would be that of a 'lottery'. (*Access to the Genome*, p.125).

107 *"Eugenics? Slipping down the slope"*, in *Splice*.

108 *Super, Natural Christians*, p.154.

molecular biologists have all the answers. Some genes can only ever be 'turned on' by the action of the product of another gene, which in turn is dependent on the product of another gene. Sometimes more than one molecule is needed to act to 'switch on' a gene. Other molecules switch on one gene while turning off another. Meanwhile some enzymes (which catalyse reactions in the body) are also turned on or off by other enzymes. Complex patterns of interactions, including 'cascades', mean that the presence of a single enzyme can have a huge effect on the body's metabolism. The molecular interactions in a single body are as finely balanced as ecological interactions between a number of bodies. We must alter them only with caution.

Similarly, there may be hidden or unexpected effects caused by removing a certain disease-causing gene from a population. It has been discovered that those who are carriers for the blood disorder sickle-cell disease are resistant to malaria, and that carriers of cystic fibrosis may have some resistance to cholera. Removing all the copies of a certain disease-causing gene from the population may actually be harmful under certain conditions. The effect of doing so may not be felt for a number of generations. Harris suggests this is a risk worth taking; the advantage given to us genetically can be gained by other means.[109] Others suggests a more cautious approach.[110]

A responsible stewardship of genetic manipulation will involve taking small steps at a time, ensuring sufficient, appropriate, *in vitro* and animal trials are taken, and always being aware that perhaps we do not know everything. This will be particularly necessary if ever germ line manipulation is considered.

Human beings are part of the created order, they are also unique within that order. Our uniqueness brings with it responsibility, responsibility to our Creator, responsibility for ourselves and our world. We are responsible to use our genetic skills and knowledge wisely. Could it also be that God intends us to use this technology to further his purpose? Is the Creator asking us to work with him, as co-

109 *Clones, Genes and Immortality,* p.200.

110 Singer and Wells, *The Reproduction Revolution,* p.184.

creators, through our ability to manipulate DNA? This is the question the following chapter seeks to address.

Chapter 4: ON THE FUTURE OF BEING HUMAN

4.1 Introduction

Human beings are unique creatures in this world. Only humans (in being self-aware and self-determining) are capable of planning, predicting and even controlling their own future. We are beginning to understand how inheritance works at the level of the molecule. We have the ability to test embryos and foetuses for a growing number of genetic traits, and can choose those we wish to allow develop into a baby. We are exploring the possibility of altering a person's genetic make-up, for either therapeutic or enhancement purposes. It may even be possible to produce genetically identical clones of individuals in the future. We are now in the position of being able to direct the course of our own evolution. In this context language is often used which implies genetic manipulation will be the source of human salvation or redemption: "the quest for Paradise Restored through human technology", "the eugenicist vision represents our human attempt to define ourselves and our destiny ..... become masters of our own destiny ... define ... improve... customize .... replicate ... redeem ourselves through our genetically enhanced and clonally produced progeny".[1] Is directing our own evolution something we want to do, something we ought to do? Can genetic manipulation be the source of human 'salvation'?

Utilitarian conclusions depend on the predicted consequences. Harris considers it our moral responsibility to use this technology in order to improve the human condition.[2] The biologist Steve Jones believes that any changes we make to our genetic future will have less impact than some of the evolutionary changes which happen without our realising it.[3] Others refer to the horrors of Huxley's *Brave New World*[4], or fear inequalities, injustices and discrimination far worse than at present.[5]

What theological framework can we use to view the concept of humankind taking control of their own future? The image of God could become totally lost as humans choose to create themselves in their own image. Or we could simply be living out our God-given destiny, taking our stewardship

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1 Henk Jochemsen, *Reducing People to Genetics* in Kilner, Pentz & Young (eds), *Genetic Ethics* p.81.
Albert Mohler, *The Brave New World of Cloning* in Cole-Turner (ed.), *Human Cloning*, p.99.
Also Lee M Silver, *Remaking Eden*.

2 *Clones, Genes, and Immortality*, pp.203f.

3 *The Language of the Genes*, p.298.

4 Russo and Cove, *Genetic Engineering: Dreams and Nightmares*, p.160..

responsibilities seriously, working together with God towards his ultimate plan. In this chapter I explore theological approaches to the idea of humankind moulding their own future. Theologies of progress (represented by Karl Rahner, Theodosius Dobzhansky and ecofeminist theologians) regard it as humankind's responsibility to work together with God towards the fulfillment of his will. Theologies of realism (represented by Reinhold Niebuhr and Oliver O'Donovan) recognise the reality of human failings and limitations, leaving us totally dependent on God's grace for our redemption. Finally, Jürgen Moltmann's 'theology of anticipation' is explored; a theology which holds together both realism and progress in a paradoxical whole, and offers a possible Christian approach to our new-found abilities.

4.2 Theologies of Progress

From a secular, utilitarian view-point, Fletcher regards it as our human responsibility to use genetic technologies as much as we are able. It is a moral imperative that we take responsibility for our own genetic inheritance, we are no longer able to 'blame God': "[t]his is the direction of the biological revolution - that we turn more and more from creatures into creators".[6] How should this view be considered from a Christian standpoint? Could it be that what God expects of, even calls human beings to, is to turn more from 'creatures into creators'? There are some who would believe this to be the case, that to grow, to progress, to improve the lot of humanity, is to work together with God in his ultimate aim for his children.

i) Karl Rahner

When considering the genetic manipulation of human beings in abstract terms, Rahner advocates the practice wholeheartedly. He sees it as the fulfillment of our freedom and responsibility.

> [M]an is characteristically the being who has been handed over to himself, consigned to his own free responsibility. In this sense he *must* 'manipulate' himself. Freedom is the

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5 Rifkin, *The Biotech Century*, p.3.

6 *The Ethics of Genetic Control*, p.200.

inevitable *necessity* of self-determination, by which man.... *makes himself* what and who he wants to be.[7]

In the past this 'manipulation' has taken place at the level of the individual, in terms of the moral-transcendent plane of convictions and conscience - but now man is able to manipulate himself through technology. Rahner twice states that he can see nothing immoral in the abstract concept of genetic manipulation.[8]

In considering concrete examples, however, Rahner becomes much more conservative. Applying examples to Catholic principles of Natural Theology, he concludes that in practice genetic manipulation would be a violation of that which is sacred. The principle of the sanctity of all life would prohibit experiments involving foetuses or embryos produced through IVF.[9] The possibility of AID, which Rahner initially sees fit to consider, is later seen as inappropriate as it involves the separation of the goods of human sexuality.[10] Rahner also sees that it is important for humans to accept the gift of life, as a gift which is not totally within our control.[11] He concludes, despite his original enthusiasm, with a negative reaction to human genetic manipulation.[12]

On a separate occasion, Rahner recognises that humans will never be able to engineer their own salvation; "Christians expect their fulfillment only from God whom they cannot create."[13] Other Christians, however, do believe that humans could have their fate in their own hands.

ii) Theodosius Dobzhansky

Dobzhansky is an evolutionary biologist, writing from the point of view of a scientist rather than a theologian, but having been influenced considerably by the work of Teilhard de Chardin.[14]

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7 *Theological Investigations,* Vol.9, Ch.14, *"The Problem of Genetic Manipulation"*, p.227f. Rahner's emphasis.

8 *Theological Investigations,* Vol.9, p.229 & p.233

9 *Ibid,* p.236.

10 *Ibid,* p.237 and p.246

11 *Ibid,* p.245.

12 *Ibid,* p.251.

13 *Theological Investigations,* Vol.21, Ch.1, *"Profane History and Salvation History"*, p.13.

14 *The Biology of Ultimate Concern,* Ch.6, *"The Teilhardian Synthesis"* (referring especially to *The Phenomenon of Man).*

In *The Biology of Ultimate Concern* Dobzhansky's aim is to develop a *Weltanschauung* which includes the understanding of the world gained from evolutionary biology.[15] Scientifically, it has become obvious that the world is not fixed, finished or unchangeable; but engaged in evolutionary flow and development.[16] Theologically, Dobzhansky relates this to Romans 8.19-22.[17] Humankind is still in the process of evolving, which is of significance both biologically and theologically.

Dobzhansky discusses three levels of evolution which have already taken place: cosmic (inorganic material, the universe, the stars), biological (organic, living things), and human (conscious, self-aware creatures).[18] Transformation points occurred when evolution moved from cosmic to biological (with the origin of life), and from biological to human (with the origin of human beings). These radical transformation points Dobzhansky refers to as 'transcendent'.[19] He then goes on to suggest that a third transcendent event will occur (cf. Teilhard's 'megasynthesis')[20], when humankind (through love) evolves into creatures capable of living harmoniously, finding unity in diversity (cf. Teilhard's Omega point).[21]

Dobzhansky goes on to propose that humankind is in a position to contribute to this evolutionary process, to: "be its protagonist, and eventually its pilot".[22] This concept he also attributes to Teilhard.[23] Dobzhansky does not explore the practical implications of this theme in *The Biology of Ultimate Concern.* One wonders what genetic changes he thought would be needed in order to aid the evolutionary process culminating in humans being able to live together in perfect harmony. Two years

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15 p.5.

16 *The Biology of Ultimate Concern,* p.7 and p.110, see also *Heredity and the Nature of Man* p.139.

17 *The Biology of Ultimate Concern,* p.8.

18 *Ibid,* p40ff.

19 *Ibid,* p.50

20 *Ibid,* p.116

21 *Ibid,* p.134.

22 *Ibid,* p.7, see also *Heredity and the Nature of Man,* p.140 and p.165.

23 *The Biology of Ultimate Concern,* p.137. I question Dobzhansky's interpretation of Teilhard. In *The Phenomenon of Man,* Teilhard does suggest humans will soon be able to "control the mechanism of organic heredity" and talks of "seizing the tiller of the world" (p.275). There is very little other reference in his work to humanity controlling its own evolution by genetic means. In *Christianity and Evolution* Christ is seen as the force behind, and the goal of, evolution (p.180).

earlier however, he had published his initial thoughts concerning genetic manipulation in *Heredity and the Nature of Man.*[24]

In recognising that advances had been made in some forms of treatment for genetically based diseases, Dobzhansky points out that sufferers are now able to procreate and so perpetuate the disease-causing genes. His chilling observation is; "[i]t is a depressing thought that we are helping the ailing, the lame, and the deformed only to make our descendants more ailing, more lame, and more deformed."[25] He therefore suggests that it is our human responsibility to replace 'automatic, blind, purposeless' Natural Selection with "the sound core of eugenics, the applied science of human betterment".[26] The optimistic view is that humankind can choose to direct their evolution towards those purposes believed to represent the "will of the Creator".[27] However, it is highly significant to note that the 'Racial Hygiene' programme of the Nazi era began for a very similar reason.[28] This observation calls into question our ability to know, and to work towards, the "will of the Creator". This is discussed below.[29]

iii) Ecofeminist theologies

In line with current scientific understandings, the ecofeminists regard our universe as unfinished, dynamic, still in process. God is seen as a continuing creator.[30] Human beings are not seen as the 'crown and goal' of creation, but our consciousness and technical abilities mean that we have the knowledge and the power to destroy, or to help, the process of ongoing creation. This is a position of profound responsibility and of critical importance.[31]

In ecofeminist theology, salvation is understood in very physical, embodied terms (both individual and global), and is concerned with the restoration of right relationships.[32] McFague criticises

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24 Especially Ch.6 "*Whither Mankind*".

25 *Heredity and the Nature of Man,* p.159. Also Ramsey and Fletcher, Ch.1.3.

26 *Heredity and the Nature of Man,* p.161.

27 *Ibid,* p.163.

28 Arthur Dyck, "*Eugenics in Historical and Ethical Perspective*" in Kilner, Pentz and Young (eds), *Genetic Ethics,* p.26.

29 Ch.4.3.

30 *The Body of God,* p.105

31 *Ibid,* p.108.

32 McFague, *The Body of God,* p.18 and p.23. Radford Ruether, *Sexism and God-Talk,* p.215f.

Christianity for its 'otherworldliness', and its emphasis on the salvation of the individual.[33] Salvation, the continuing creation of the world, is suggested as being in our hands, it depends on human action as the "self-conscious, reflexive part" of creation.[34] This continuing creation, this evolution, would however appear to be cultural or moral rather than genetic.[35] Radford Ruether sees embracing the Jubilee tradition of the Old Testament to be fundamental to this process.[36] Both theologians draw up very practical strategies for working towards a redeemed world, strategies which include; city planning, nature writing, phasing out fossil fuels and human population control.[37]

As the salvation of the world would appear to be in our own hands, it is not surprising that the ecofeminist theologians see Jesus Christ as little more than a 'good example' to us. For Radford Ruether the example of Jesus is but one example among many. We experience glimpses of the fullness of redeemed humanity within history in the lives of those whose own authenticity discloses the meaning of true personhood. It is through the example of Jesus, especially in his relationships with women, that we learn what it means to be liberated from hierarchical relationships.[38] McFague speaks of the 'Christic paradigm', a paradigm of God's immanence, which shows that the direction of creation is "toward inclusive love for all, especially the oppressed, the outcast, the vulnerable."[39] It is significant to note that this calling to solidarity with all creatures, especially the vulnerable and needy, could never have been envisioned by our common creation story or evolutionary science.[40]

Ecofeminist theology has begun with the experience of women, and with the insights gained from ecological and scientific studies. As such it covers its 'ecofeminist' credentials, but there is an extent to which it sometimes seems an exaggeration to call it 'theology'. The role of God in creating the complex, fruitful, interrelated and interdependent world in which we live, and in being the source of its

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33 *The Body of God,* p.102 and p.109.

34 *The Body of God ,* p.105 and p.124.

35 McFague, *The Body of God,* p.80. Radford Ruether, *Sexism and God-Talk,* p.89 and p.113.

36 *Sexism and God-Talk,* p.255, *Gaia and God,* pp.211ff.

37 McFague, *Super, Natural Christians,* Chapters 6 & 7. Radford Ruether, *Gaia and God,* Chapter 10.

38 *Sexism and God-Talk,* p.114 and p.136f.

39 *The Body of God,* p.160.

40 *Ibid,* p.198.

life-giving energy, is acknowledged.[41] However, further than this the ecofeminists seem reluctant to go. God is powerless to do anything about the suffering of creation other than 'suffer with'. Jesus Christ becomes the 'Christic paradigm' whose death on the cross was but a supreme example of suffering with. Admittedly this theology is realistic about the presence of suffering within our world. But where is the hope of such theology? There is no purpose or direction to evolution, nor any way in which humans can be helped in their responsible role within creation. It seems simply that we have to pull ourselves up by our own bootlaces, something which we patently have been unable to do throughout history. The resurrection stories only instill a vague belief and hope "that diminishment and death are not the last word".[42] There is no sight here of any concept of God breaking into history and doing a 'new thing'. In stripping Christianity of its 'paternalistic, monarchical' view of God, ecofeminism seems also to have stripped Christianity of its hope. Christianity has always had a very strong theology of hope, more than simple wishful thinking.[43] Despite these critical comments, ecofeminist theology does have useful contributions to make to the debate concerning the ethics of genetic technology, in particular concerning human beings' responsible role within creation, embodiment and health, and attitudes towards difference.[44]

Each of these theologies of progress has a major problem, an over-optimistic belief in humanity's ability to help itself. There is no recognition of the limitations of human existence. Rahner does recognise natural limits to human life, for example the unity of the relational and procreative goods of marriage, but says nothing of the human tendency to misuse power. Ironically, Dobzhansky illustrates the way in which human knowledge and ability can be used to the detriment, as easily as to the benefit, of others. Ecofeminists (by their own bias) highlight the emptiness of a hope based only on ourselves. In any consideration of the future of humanity, or of our ability to help ourselves, there also needs to be a realistic understanding of human failings.

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41 *The Body of God*, p.151ff.

42 McFague, *The Body of God*, p.191.

43 See sections 3 and 4, below.

44 See Chs.3.4, 3.2, 5.3, and 3.5.

4.3 Theologies of Realism

Theologies of realism are based on the understanding that human beings are limited; flawed, broken, fallen. On our own we are unable to help ourselves. The views of Niebuhr and O'Donovan on this matter have already been addressed.[45] It is on the basis of such understanding that their beliefs about salvation and our future hope are founded.

i) Reinhold Niebuhr

Niebuhr sees the two World Wars as having destroyed the unfounded optimism of the nineteenth century. This optimism was based on the illusion that growth or progress could fulfill the meaning of life and redeem it of its ills and errors, an illusion which assumed an exaggerated understanding of the degree of human freedom and power, and made the mistake of identifying freedom with virtue.[46] Niebuhr saw humankind as unable to help itself , only 'divine mercy' could provide a solution.[47]

It is through the "self-disclosure of a divine love" that God is able to overcome the evil inclination to self-worship in the human heart, and to take the evil of history into and upon himself. Within history there is the possibility of the renewal of life and the destruction of evil "whenever men and nations see themselves as they truly are under a divine judgement, which is as merciful as it is terrible".[48] Niebuhr recognises that the salvation of humankind, or the world, is not complete. There are still 'moral ambiguities' in history. The innocent still suffer, those who are evil still triumph, the 'justice' which is meted out in this life is not complete. Only when history is fulfilled will ultimate justice be done, through the final judgement and general resurrection. This will be brought about only through the divine mercy, not by human achievement.[49] The concept of the final judgement is very important for Niebuhr, for it is when justice will be seen to be done in a way never possible within the ambiguities of

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45 See Ch.3.2 (ii), below.

46 *Faith and History; A Comparison of Christian and Modern Views of History,* p.69.

47 *Ibid,* p.126.

48 *Ibid,* p.125.

49 *Ibid,* p.213.

history.[50] The general resurrection is the fulfillment of the individual 'renewals' possible within history. These events form the fulfillment and the end of history, they cannot be found within history itself.[51]

Nevertheless, Niebuhr regards it as important that a defeatist attitude is not taken up towards the possibility of renewal taking place within society, within history.[52] It is the responsibility of the Christian to strive to allow the love of God to affect and influence society, whilst at the same time recognising that ultimately this work is something which we cannot achieve, and will not be achieved within history as we know it.[53]

ii) Oliver O'Donovan

It is not natural to link O'Donovan's theology with that of Niebuhr, but both men are realistic about the failings of humankind. For all our apparent progress, O'Donovan believes we contribute nothing towards the salvation of our world.[54] The fulfillment of history will not be generated from within history - this is what the Reformers sought to safeguard with their *sola gratia, solo Christo* slogans. It is not just that God is at work within history, but he is also working 'from outside', doing something new. This means that the fulfillment of creation is in no way dictated by the nature of creation. Its destined end is not immanently present in the beginning or in its history.

Where O'Donovan departs from Niebuhr, is in saying that God's salvation, brought about through Jesus Christ, will involve the whole of creation rather than just humankind. Niebuhr sees ultimate salvation taking place outside history, involving the final judgement and resurrection of human beings. This could be seen as a 'gnostic' hope of escaping the limits of our bodies. By contrast, O'Donovan talks of the redemption *of* creation, rather than redemption *from* creation, which he sees affirmed by God in the resurrection of Jesus from the dead.[55]

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50 *Faith and History,* p.232.

51 *Ibid,* p.235.

52 *Ibid,* p.200.

53 *Ibid,* p.213.

54 *Resurrection and Moral Order,* Ch.3 *"Eschatology and History".*

55 *Resurrection and Moral Order,* p.14. The concept of redemption *from* creation he refers to as 'gnostic' hope. Also, N.T.Wright, *New Heavens, New Earth; The Biblical Picture of Christian Hope.*

In contrast to those advocating theologies of progress, O'Donovan sees the created world as being "complete, whole and satisfying" at the end of God's six days of creative activity.[56] The world was seen as being "good", it needed no further improvement, and it contained within it natural teleological and generic ordering which gives coherence and totality to it.[57] The completeness of creation does not, however mean that God is no longer at work in the world (contrast ecofeminist thought); God's work in the "providential government and redemption of history" is as yet incomplete.[58] The ordering of creation remains important to O'Donovan when thinking of the fulfilment of creation. The God who rules the world is the same as the God who made it, and so the outcome of history will affirm rather than deny the order of its making.[59] The place of humankind within the created order, the place which has been rejected by us all, has however been fulfilled in and through Jesus Christ. It is he who lived in perfect obedience to the Creator, he who reflected his glorious image, he who lived as beneficent ruler over the rest of creation, he who defeated death and gloriously sits at the Father's side.[60] In Christ we see the order of the world to come, "the vindication and perfect manifestation of the created order which was always there but never fully expressed".[61]

In parallel with Jesus Christ's resurrection and ascension, O'Donovan suggests that the final redemption will involve both restoration and transformation. Humankind will be restored as ruler of the ordered creation that God has made. However, this will not be a matter of "returning to the Garden of Eden", or restoring the *status quo ante* - but rather it will be a going on, to that place towards which creation had always been directed.[62] The vision of humankind's eschatological hope can be seen in the risen and ascended Christ. However, the eschatological hope for the whole of creation is hidden from us. It cannot be guessed by extrapolating past history; it cannot be the work of philosophy. If we are to know anything of the ultimate future for creation, it will be a disclosure of prophecy.[63]

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56 *Begotten or Made*, p.12, *Resurrection and Moral Order*, p.60..

57 *Resurrection and Moral Order*, p.31f.

58 *Ibid*, p.62.

59 *Ibid*, p.44.

60 *Resurrection and Moral Order*, p.54.

61 *Ibid*, p.53.

62 *Ibid*, p.55.

63 *Ibid*, p.83.

Humanity can contribute nothing to the fulfillment of the created order, nor can we predict its nature, but we do have a responsibility to live morally in the meantime.[64] The concept of ultimate redemption being both a restoration and a transformation influences O'Donovan in his moral thinking: we need to respect the natural structures of life in the world, while looking forward to their transformation.[65] This is something we cannot strive for, nor achieve, on our own - but only through our participation in the life of Christ.[66]

Both Niebuhr and O'Donovan stress humankind's inability to help itself. Technology, knowledge and skill may advance, but only the love and mercy of God is able to bring hope for the future. Until that ultimate future is realised, it is our responsibility to live morally within the present age. Niebuhr's understanding of our ultimate hope (not involving this physical world) leads him to suggest that the meaning of living morally involves striving for minor 'renewals' and justice in human terms, which are but foretastes of the final judgement and resurrection. A more biblically-based, understanding of ultimate hope involving the whole created order, leads to a fuller picture of our moral obligations within current history.

O'Donovan suggests our moral values should be informed by the natural order of creation, but also by the Christian hope of its ultimate transformation. The nature of this transformation cannot be predicted, but will only be revealed through prophecy, and achieved through our life in Christ. O'Donovan's work leaves me unsatisfied in two respects when applying his moral framework to the issues arising through genetic manipulation. Firstly, whilst he shows well the importance of being realistic about human failings, there can be the implication that human advances can do no good within the predicaments of this world. The implication would seem to be that genetic technology has nothing to offer humanity. Secondly, how should O'Donovan's moral framework be applied in the field of genetic manipulation? Is the 'natural order' of creation to be seen within the species boundaries of living

64 *Resurrection and Moral Order*, p.76.

65 *Ibid*, p.58

66 *Ibid*, p.85.

things?[67] Would it therefore be immoral to transfer a gene from a plant into a human being? How does one apply both the natural order of this world and the, unpredictable, order of the world to come in ethical situations?[68]

A theological approach which seems to be able to combine both the optimism of progress, and the realism of human failings, within the context of today's technical advances, thus enabling a greater ethical understanding, is that of Jürgen Moltmann. I shall refer to his ideas as a 'theology of anticipation'.

4.4 A Theology of Anticipation

i) Creation - open

Together with those who propose a theology of progress, Moltmann recognises the world to be still in the process of evolving. Creation is not complete, it is open.[69] Creation was not finished at the end of the sixth day only to be spoilt by humankind, it has not yet reached its end. This concept has come from both an understanding of recent scientific thinking about open systems[70], and from recent biblical exegesis[71]. Creation is open, it is equally open to disaster and to salvation. This is seen in the account of creation, in that the chaotic forces of the night and the sea were only given boundaries, rather than totally destroyed.[72] God's creative activity is thus not seen as a single event resulting in the 6-day creation of the world, but rather as a continuous process. Within this continuous process God acts in the initial creation,

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67 He suggests that there is a natural 'generic' ordering within created life, an ordering which has not just been imposed by the ordered mind of human beings. (*Resurrection and Moral Order*, pp.36f.).

68 See also 4.5 iii, below.

69 *The Future of Creation*, Ch.8 *"Creation as an Open System"*.

70 The universe is no longer thought of as a static closed system at equilibrium, but rather as an open system with an unrepeatable history. The mechanistic views of Newtonian science have been absorbed into the dynamistic views of Einstein. Real systems are too complex for all the necessary variables to be taken into account in order to make mechanistic predictions concerning their behaviour. The flapping of a butterfly's wings can make huge differences to weather patterns on the opposite side of the world. Predictions can only be made according to the laws of probability. This means that the future is not completely inherent in the present, rather it includes randomness and unpredictability. *God in Creation*, p.199ff.

71 *Bara*, the unique word for the divine creation, is found used in the bible in the context of God's work of liberation and salvation within history far more often than in the context of the initial creation of the world. "So it is theologically inadequate if we restrict the divine creative activity to the beginning". (*God in Creation*, p.208, also *The Future of Creation*, p.121).

72 *The Future of Creation*, p.120.

within history, and in the End-time.[73] All of these actions are creative: "*creatio originalis - creatio continua - creatio nova*".[74]

ii) Humanity - limited

Together with Niebuhr and O'Donovan, Moltmann is realistic about human failings. He regards 'being truly human' as a matter of relationships; relationships with God, with other humans and with the rest of creation.[75] All people fall short of this ideal in all three areas of relationship. In breaking off one's relationship with God, the open system of human life becomes closed. Instead of experiencing the open, creative, fruitful relationship of love with God, rebellious humans become petrified as a closed system, experiencing deadly self-isolation. This is sin and slavery.[76] Human relationships are so often destroyed through fear, fear which turns to aggression.[77] Moltmann recognises that progress, development, and increasing freedom, are not going to solve all humankind's problems.[78]

Progress cannot change human nature. Moltmann also recognises that progress can be one-sided, and not beneficial to all. What has been progress for one, has tended to be exploitation for another (whether human or nature).[79] This can be due to a deliberate misuse of power, or even the result of not being able to predict or control the outcome of a particular advance.[80]

iii) Humanity - co-creators?

Having recognised these human limitations, Moltmann still suggests that the development of the human race <u>is</u> in our hands:

> Today, the direct continuation of the evolution that led to the origin of the human species on earth lies in the hands of human beings themselves. They can either destroy

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73 *God in Creation*, p.55, *The Future of Creation*, p.119.

74 *God in Creation*, p.208.

75 Compare Ch.3.3.

76 *God in Creation*, p.210f. and *The Future of Creation*, p.122.

77 *The Future of Creation*, p.100.

78 *Ibid*, p.53, also p.122f.

79 *God in Creation*, p.138.

80 *The Future of Creation*, p.135.

this stage of evolution, or they can organize themselves into a higher form of common living than before, and advance evolution further.[81]

In contrast to ecofeminist thought, Moltmann sees humanity's ability to be involved in its own evolution as entirely dependent on the prevenient work of God. People close themselves off from God (in their rebellion), but God is never closed to them. They break off communication with God, but God does not break off his communication with them. Thus the future of humanity is always kept open, no matter how closed or self-isolated we may be, there is always the possibility for conversion and new direction.[82] God's work of salvation liberates people from the slavery of their closed system, he brings about a divine opening of that which is closed and dead.[83] Through God's salvation the Christian is liberated "from fear for hope, from self-seeking for love, and from the enslavement of evil for resistance to evil".[84] This liberation can be experienced in history (contrast Niebuhr) but is only a foretaste of the liberation which is to come.[85]

iv) Future - new creation

O'Donovan speaks of the redemption of creation involving both restoration and transformation. Moltmann's understanding is very similar, even if not immediately obviously so. Salvation involves not just restoration (of the original good creation, of the broken fellowship with God, of man's disintegrated identity, of the peace of creation), but it also involves new beginnings. In redemption there is the beginning of a new creation, something new which has never been before is called into life.[86] God created the cosmos as an open system. The goal of the history of creation is not a return to its original condition, but the revelation of the glory of God.[87] This consummation will be a new creation (as seen through the prophetic theology of the Old Testament[88], and the teaching concerning the resurrection and

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81 *God in Creation*, p.196. It was perhaps this statement that led to some misunderstanding that Moltmann was proposing a salvific evolutionary process. Such a misunderstanding is clearly corrected in Moltmann's later book *The Way of Jesus Christ*. (Richard Bauckham, *The Theology of Jurgen Moltmann*, p.194).

82 *God in Creation*, p.210f.

83 *The Future of Creation*, p.122, *God in Creation*, p.211.

84 *The Future of Creation*, p.102.

85 *Ibid*, p.104.

86 *The Future of Creation*, p.149ff.

87 *God in Creation*, p.56 and p.207.

88 *Ibid*, p.209.

the Holy Spirit in the New Testament[89]), whilst at the same time must also be seen as the completion of the whole process of creation.[90] It will be the fulfillment of the promise implanted in creation from the beginning, and yet will surpass everything that can be told about creation within history.[91]

Moltmann distinguishes two understandings of 'future'. There is the future in the sense of that which will be from what already is; a prolongation of being. This is a future which can be predicted, and is the sense of the Latin word *futurum* (from which 'future' is derived). There is also future in the sense of the arrival or coming of something new, as in 'the coming year'. This future involves something which has not been present, still is not present yet, and cannot therefore be predicted even if it can be anticipated. This is the sense of the Latin word *adventus* (from which 'Advent' is derived).[92] Christian eschatology can only be anticipated, not predicted.[93] This anticipation has been given to us in Jesus Christ.[94]

v) Present - anticipation

For Moltmann the consummation of creation will not supplant history, it is already to be found within history in the form of anticipation.[95] Christians need not regard their ultimate future as being a matter indifferent to their present life, but nor can it be expected that we can bring about 'heaven on earth'.[96] Living in the 'now already' in the midst of 'not yet', the Christian should distinguish between the future which can be predicted and the future which is hoped for.[97]

The paradox of 'both now and not yet' is complemented by the paradox of 'solely God's work and also man's'. It is only through the creative acts of God that the new creation will come about. Only through his opening of closed systems, only through his suffering of love, only through the death of Jesus

89 *The Future of Creation*, p.123

90 *Ibid*, p.124.

91 *God in Creation*, p.207.

92 *The Future of Creation*, p.29f. and *God in Creation*, p132f.

93 *The Future of Creation*, p.55.

94 *Ibid*, p.53. Compare O'Donovan above.

95 *The Future of Creation*, p.16f.

96 *Ibid*, p.17 and p.47.

97 *Ibid*, p.55.

on the cross.[98] Moltmann also implies that liberation is both God's work for the ultimate future, and humankind's work in the present:

> Without faith's hope for the divine messianic future there is no hope in action which can stand its ground. Without hope in action faith's hope becomes ineffective and irresponsible.[99]

In a suggestion which turns on its head current attitudes towards success and achievement, Moltmann states that any expression of 'hope in action' will involve taking on the cross of Christ in our own lives. Such 'hope in action' is therefore not to be found in the great advances and developments of humankind, but in identifying with, representing, loving, the victims of society's progress.[100] The future of God is manifest in the crucified Christ, the anticipation of this future is therefore to be found in "representing those who have no future"; the hungry, the naked, the homeless, the unemployed, the imprisoned.[101]

Moltmann suggests that the foretaste of the liberation which is to come, can be experienced through humankind's striving for liberation. This liberation is seen to take place in five areas:

> " (i) In the struggle for economic justice against the exploitation of man.
>
> (ii) In the struggle for human dignity and human rights against the political oppression of man.
>
> (iii) In the struggle for human solidarity against the alienation of man from man.
>
> (iv) In the struggle for peace with nature against the industrial destruction of the environment.
>
> (v) In the struggle of hope against apathy in asserting the significance of the whole in personal life."[102]

98 *The Future of Creation*, p.52.

99 *Ibid*, p.113.

100 Compare the ecofeminist suggestions, observed to go against the grain of natural selection (section 2 (iii), this chapter).

101 *The Future of Creation*, p.54, also p.17 and p.57.

102 *Ibid*, p.110.

Each liberation is mutually interactive, true liberation must be pursued in all directions simultaneously. The list begins with economic liberation, but it finishes with the most important one which is religious liberation. Without the liberation from fear and apathy, any moves towards other liberations will only lead to oppression.

vi) God - openness personified?

The consummation of history has been described as the revelation of the glory of God. Creation was made an open system, by the God who redeems by opening up that which is closed; thus even this consummation, this fulfilment, must be open - in fact it must be "openness *par excellence*".[103] It will not be timeless eternity, but eternal time. Not the end of history, but the end of pre-history and the beginning of the eternal history of God, man and nature. Such openness will lead to perfect communication between God and man and nature; the universal "sympathy of all things".[104] This concept points towards a radical implication, which is that God can no longer be thought of in terms of 'The (static) Perfect Being', but rather as "the transcendent making-possible of all possible realities".[105]

The theologies of progress, realism and anticipation have been described, and their failings and useful insights discussed. The ways in which these theologies have implications for the use of genetic technologies will now be considered.

4.5 Implications for genetic manipulation

i) Realism

The salvific language which is used in connection with genetic engineering has already been referred to. As the possibilities and promises of manipulating our own genetic future are dangled seductively before us, we will do well to remember the theologies of realism. Niebuhr knew of the limitations of human beings. We do not have unlimited freedom and power, we do not have total control over our own nature, let alone the rest of the created world. Niebuhr describes sin as a corruption of

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103 *The Future of Creation*, p.126 and *God in Creation*, p.213.

104 *God in Creation*, p.213.

105 *The Future of Creation*, p.127 and *God in Creation*, p.214.

freedom leading to the recalcitrance of the human heart and 'moral ambiguities' in history. For O'Donovan, sin is the refusal of human beings to adopt the divinely ordained position given to them in creation, which leads to confused moral knowledge. Moltmann describes sin as the rebellion of human beings against God, which leads to the closing down of open systems, to deadly self-isolation and spoilt relations between other human beings and nature. Each theologian gives a different nuance to the reality that human beings refuse the sovereignty of God and suffer the consequences. All the technological expertise in the world cannot solve our problems, so long as we struggle with recalcitrant hearts, and with a confused moral knowledge, which continually result in the closing of open systems.

Without the grace of God, powerful techniques open up the possibilities of power for bad as well as power for good, whether through ignorance or our own deliberate fault. The last sixty years have highlighted ways in which the power of genetics could be misused. The experiences of the holocaust and more recently 'ethnic cleansing' in the former Yugoslavia and Rwanda, have illustrated this possibility only too vividly. Just as Jews and gypsies were taken to gas chambers by Nazis, Albanians driven from their homes by Serbs, and Tutsis slaughtered by Hutus, so the more sophisticated, more powerful, genetic technologies could be used to discriminate and eliminate more effectively. The limitations of humanity highlight the need for proper legislation in the use of genetic technologies.

ii) Unpredictable future

An additional problem with the concept that genetic manipulation could bring about our own salvation, is that the nature of our salvation cannot be predicted by the extrapolation of current history. Both Moltmann and O'Donovan agree that the ultimate fulfillment of creation will involve something totally new. If this is so, which scripture certainly seems to suggest, we cannot say: 'If only we could design a human being to be more tolerant, more loving, more intelligent, more artistic..... then the world's problems will be solved.' This is not something which we can predict or work out by extrapolation. Equally, no amount of genetic manipulation will ever produce the 'perfect human being'.[106] Only Jesus Christ can be described thus, that is, until the fulfillment of time when that which is anticipated in Christ can be our experience too. Nor does the genetic manipulation of humans (alone) fit in with the understanding that the fulfillment of history is to involve the whole of creation.

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106 See Ch.6.4 (ii), below.

iii) Anticipation in the present.

Moltmann and O'Donovan appear to have very differing views about creation and its fulfillment. I suspect they may be using different words to say the same thing. O'Donovan emphasises the complete nature of God's creative act. By contrast, Moltmann stresses the openness of creation. God's creative activity is continuous, working in the initial creation, within history, and in the End-time. Is this concept so very different from O'Donovan's, in which God is still working out his providential government and the redemption of history, even if his 'creative activity' is complete? Similarly, although O'Donovan speaks of the sabbath in terms of the celebration of the completeness and integrity of God's creation, he also describes it as a sign looking forward to the fulfillment of history when all creation will be able to "enter into that completeness".[107] It may be that the apparent differences between these theologians' views are a result of the different view-points against which they are arguing. Moltmann is coming from a Marxist background, and arguing against a 'pie in the sky when you die' attitude, and so stresses the creative work of God even within history. O'Donovan is more concerned about the false notion of salvation through evolutionary progress, and so stresses the transcendence of God.

O'Donovan and Moltmann may be saying very similar things about creation and its fulfillment, but their approaches to the moral implications of living within history are very different. For O'Donovan it is the ordering of creation which is paramount, both in its teleological and generic forms. God created the world as "ordered totality", and the outcome of history will affirm rather than deny this ordering, therefore such ordering should inform and direct our ethical decision-making. O'Donovan has never explicitly commented on this area (to my knowledge), but it would seem from his argument that the ordering of the species may be of greatest importance when considering genetic manipulation. As species (by definition) do not inter-breed, it would seem to go against the ordering of creation to transfer a gene from one species to another. But is the species part of God's 'ordering' of creation, or is it a convenient way for human beings to describe the natural world?[108] Some 'species' are separate simply due to their geographic location, and if brought together can inter-breed very successfully. As evolution continues even now, which pattern of species is God's 'creation ordering'?

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107 *Resurrection and Moral Order*, p.61.

108 Note this is a question concerning generic ordering - rather than the issue of human-imposed teleological ordering (*Resurrection and Moral Order*, p.52).

One concept of O'Donovan's which may be helpful in thinking about how to live morally in history, is his understanding that our salvation will not be from this world, but rather it will include the salvation of this world. This implies (as with ecofeminist embodiment) that our material being is important; it is not just our 'souls' that will be saved. In addition, it implies that our salvation will not be from the limitations of our physicality, but from the limitations of our fallenness.

Moltmann's emphasis is not so much about moral living until such time as history is fulfilled, but rather he is concerned with the anticipations of the eschaton which are possible within history. But how can we work towards such anticipations if the fulfillment of history cannot be predicted or extrapolated? How are we to know what is the desirable future, as against the predictable future? For Moltmann; "[t]he anticipation of the coming kingdom of God has taken place in history in the crucified Jesus of Nazareth."[109] Therefore our anticipations are found in our identification with the people whom Jesus called 'the least of his brethren'; not the progressive leaders, but their victims. This has radical implications for genetic technology. It implies that it is not through identifying ourselves with the famous scientists, the drug company directors, or the patent lawyers, that we can bring about an anticipation of God's kingdom. It will not be through our promotion of the wonders of this modern technology to change our world and ourselves. Rather anticipations of God's kingdom will be seen through our identification with the victims of genetic technology. So it will be:

- through our care for the disabled child who, despite the genetic testing results, was chosen by her parents to come to birth,
- through our defense of Third world countries whose genetic inheritance is being pirated through the patenting work of multi-national drug companies,
- through sharing the grief of the couple who choose not to have children because of their own genetic make-up,
- through our love for those who are marginalised because of their 'genetic handicaps',
- through our objections to Third world countries being used as testing sites for genetically manipulated material .....

.....it will be through actions such as these that we might bring about an anticipation of God's kingdom in our world. This is a concept which is very powerful and challenging. It may also seem rather

negative. It does not take into account the positive ways in which genetic technology could be used in the world. Alongside the concept of identification with the victims, I would therefore promote Moltmann's five areas of liberation.[110] These areas could serve as a useful framework against which to measure any proposed genetic technique. Recognising that it is not always possible to predict the implications of any advance, a useful yardstick would be to ask what implications a particular advance may have for economic justice, for human dignity, for human solidarity, for peace with nature, and for the significance of the whole in personal life.

Genetic manipulation will not be the solution to all our problems. This technology has, however, great power to solve some people's problems, even to bring about an anticipation of God's kingdom. It also has great power to create problems for many other people. In our use of this technology we must always be realistic about our human limitations, our human failings, our tendency to misuse power. The one true perfect human being is the one who laid down his power and became one with those who were downtrodden at the edge of society. It is his likeness, by the grace of God, that we must strive towards.

Moltmann's five areas of liberation do not appear to include liberation in embodied terms, for example liberation from the limitations of illness or disability. Is this an omission on Moltmann's part, or is such liberation not part of the Christian hope for this world (or even the world to come)? Many genetic technologies raise issues concerning the nature of health, the role of medicine, social attitudes towards illness and disability. These are discussed in the following chapter.

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109 *The Future of Creation*, p.53.

110 See section 4 (v), above.

Chapter 5: ON HUMAN HEALTH AND WHOLENESS

5.1 Introduction

Human beings cannot bring about their own salvation, nor the salvation of the world. Humanity can, however, work together with God towards his ultimate purpose for creation. Through the grace of God, we can help to bring about anticipations of God's coming kingdom. Moltmann suggests five areas of liberation which would work towards such anticipations, areas which do not seem to include a recognition of human embodiment In the light of God's promised salvation, how is the Christian to live with the limitations of embodiment? Is it right to attempt to solve our limitations, or should one simply accept them? Can medicine, genetic medicine in particular, be used to bring about anticipations of God's kingdom? What is it we should expect of medicine? How should a Christian approach the reality of bodily imperfections and mortality, of disability and premature death?

These questions must be considered in the light of today's Western culture in which 'health' has become an idol, and people are obsessed with bodily perfection.[1] I have noted how salvific language is often used in relation to genetic technologies. There is also a tendency to view medicine and/or health in a similar way.[2] In this chapter I aim to provide a Christian perspective to these issues. Consideration is given to the appropriate expectations of medicine, to the meaning and significance of 'health', and to theological approaches which could enable one to live amongst disability and premature death.

5.2 Towards a theology of medicine

A number of theologians believe that our expectations and our hopes of medicine today have become too great.[3] This is the result of attempts by (Western, rich) human beings to escape their limitations; the limitations of finitude, of weakness, of age, of mortality. In a self-reinforcing circle, medicine has also changed its aim and emphasis. Traditionally medicine recognised death as its limit (and so withdrew or changed its strategy to that of caring), but now the primary task of medicine seems to

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1 McKenny, *To Relieve the Human Condition,* p.2.

2 *Ibid.* p.201.

3 Lammers and Verhey (eds), *On Moral Medicine,* Introduction, p.3.

be "to extend our lives indefinitely".[4] Medicine's other main aims are those of relieving suffering and increasing choice.[5] In contrast, traditional medicine, based on the Hippocratic oath, was concerned with 'healing' in the context of the sanctity of life.[6] The distinction between 'healing' and 'relief of suffering' may seem insignificant until a situation arises in which suffering can only be relieved through the cessation of life. Traditional medicine was based on the principle *primum non nocere* (above all do no harm).[7] Hauerwas points out the irony that, in attempting to eliminate suffering, we can end up by eliminating the sufferer.[8]

This approach to medicine is, at least in part, a result of holding a particular model of illness. The 'medical' model, which is most often applied in medicine today, is based on the assumption that illness can be fully accounted for by deviations from the norm of our bodily functioning.[9] Something is seen to have gone wrong with our body, and medicine can correct it through drugs or surgery (rather as a mechanic would mend a broken-down car). As a result of this model, we are becoming increasingly dependent upon evermore sophisticated medical technologies. Twenty years ago Illich suggested such an attitude was having a disabling impact on people's health. He suggested medicine is often harmful to people's health and is leading to a new "iatrogenic epidemic"[10]. He claimed that the pain and disability resulting from technical medical intervention rivalled that due to traffic accidents or even military conflicts.[11] No statistical support is found for Illich's claim,[12] nevertheless the reality holds that high technology medicine can cause more harm than good. This is due partly to the harmful effects of medical treatments,[13] and partly because the idolising of health, ironically, leads to a less healthy society.[14] And yet, medical technologies continue to increase in number, scale and complexity. Towards the forefront is

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4 McKenny, *To Relieve the Human Condition,* p.30. Compare Hauerwas, *Suffering Presence* p.36 and *Naming the Silences* p.101.

5 McKenny, *To Relieve the Human Condition,* p.5. Cameron, *The New Medicine* p.132 and p.48.

6 Cameron, *The New Medicine,* p.59f.

7 *Ibid.* p.60.

8 *Suffering Presence,* p.24. The situation referred to was that of allowing an infant to die on the grounds that a life of suffering lay ahead - the irony is equally felt in the case of 'therapeutic abortion'

9 Pattison, *Alive and Kicking,* pp.22ff.

10 From the Greek; *iatros* meaning physician, and *genesis* meaning origin.

11 Ivan Illich, *Limits to Medicine,* p.26.

12 Hauerwas, *Truthfulness and Tragedy,* p.188.

13 Hauerwas, *Naming the Silences,* p.108.

the field of genetic medicine. The scrabble continues to identify the genes responsible for diseases and disabilities, to design tests, to screen individuals and populations, and to mend dysfunctional genes. A theology of illness, health and medicine is needed in order to establish how, and to what extent, such technologies should be used.

Hauerwas suggests that the aim of medicine should be that of caring not curing. His understanding is that the primary aim of medicine is not to cure people of their illnesses (thus avoiding suffering or death), but rather it is to care for people in their illness. He observes that the pain of illness (not necessarily physical pain, but pain nonetheless) results in isolation from others and from oneself.[15] For this reason those who are ill try to hide their sickness and pain in order not to be alienated, but this only increases their loneliness. Hauerwas concludes (with reference to Job's comforters) that the role of the medical profession is; "to be in the presence of those who are in pain", to be a bridge between the world of the sick and the world of the healthy, to care not to cure.[16] If the primary role of medicine is to care for people in their illness, rather than in striving to effect a cure, how could this principle be applied in the context of genetic disease? At first glance it would appear to suggest that no attempt should be made to cure people of genetic disease. Treatments which care for the symptoms of the genetic disease would appear more appropriate. Admittedly someone suffering from hereditary diabetes can live a normal life with regular injections of insulin, but most inherited diseases have no such effective treatment. Young people suffering from cystic fibrosis and muscular dystrophy are helped through physiotherapy and surgery, but premature, debilitating deaths are still inevitable. Babies affected by Tay Sachs syndrome, and middle-aged people who have Huntington's disease, have no treatments to ease their plight. For this reason the possibility of 'gene therapy' has been received with great enthusiasm. To cure cystic fibrosis by regular inhalations of a spray containing 'good' copies of the 'CF gene', to cure muscular dystrophy or Tay Sachs disease by the genetic manipulation of embryos, would seem far more beneficial than years of painful, and ultimately ineffective, treatments. Yet, this would definitely be a case of 'cure not care'.

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14 Moltmann, *God in Creation*, pp.273f.

15 *Suffering Presence*, p.75f.

16 *Ibid.* p.78.

A closer look at the meaning of Hauerwas' words is needed. He most certainly does not suggest that caring for, being 'in the presence of', those who are ill, implies that no effective treatment should be sought.[17] The slogan 'care not cure' was used in order to discourage the use of aggressive medical techniques, which can cause as much pain as they prevent, and result in the alienation of patients from their loved-ones and the medical staff. The slogan offers guidance in those situations where a choice must be made between aggressive alienating technologies, or the personal touch of human care. Hauerwas' concern was to treat the whole person, not just the sum of their symptoms, and he recognises that to do so may sometimes mean not working towards a cure.[18] It would, therefore, appear to be possible to maintain the 'care not cure' attitude and yet to work towards gene therapy for debilitating and life-threatening diseases (on the condition that the gene therapy did not cause the patient significant suffering and alienation).

Consideration must be given here to those people for whom gene therapy will never be possible. Babies who are born already having been affected by a genetic anomaly during their development in the womb, or those whose condition is caused by the loss or duplication of significant sections of one or more chromosomes, will not be able to have their condition reversed by gene therapy. For these people the priority to 'care not cure' will be vital.

The primary role of medicine can be seen as that of caring for people in their illnesses. Such caring may, but will not always, involve curing. In this light, technological medicine becomes part of a broader practice of care. An understanding of the form such care should take will inevitably be influenced by our understanding of what it is to be healthy. It is to a theological exploration of health that we now turn.

5.3 Towards a theology of health and wholeness

The WHO definition of health as: "a state of complete physical, mental and social well-being and not merely the absence of disease" has already been described.[19] Many commentators today regard

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17 *Suffering Presence*, p.81.

18 'Care' in "*Encyclopedia of Bioethics*", (1978, pp.145-150), in Lammers and Verhey (eds), *On Moral Medicine*, pp262-265.

19 See Ch.2.3 (iii) c, above.

such a definition as an unattainable ideal, like 'heaven on earth'.[20] Nevertheless, it is the WHO ideal which most people expect medicine to be able to meet, resulting in excessive expectations and demands of the medical profession.[21]

At the opposite extreme, in terms understood by industrial society, is the definition given by Freud and others around the turn of the century. According to the values of production and consumption, health was seen to be "the capacity for work and for enjoyment".[22] Is it possible to define 'health' more fully, even theologically, without arriving at the utopian WHO definition which is so roundly criticised? A satisfactory theology of health would require the inclusion of two important aspects; a recognition that a healthy life will still be a limited life, and a recognition than humans are more than living machines.

i) Health within limitations

Today the common concept of health seems to imply an escape from many of the limitations of human life. The pressures which are being put on the medical profession are the result of people not wanting to be restricted by their limitations, and wanting more choice about their 'quality of life'. Barth, however, recognises that the healthy life is still limited; life has a beginning and an end, it is something over which we do not have complete control.[23] Equally, in an attempt to escape the 'iatrogenic epidemic', Illich defines human health in terms of a task, a responsibility. This is a task which requires us to be able to live within our limited nature, with growing and ageing, with healing and suffering, with living and dying. The ability to deal with pain, sickness and death are seen as natural components of a 'healthy' life.[24] Human beings are embodied, limited and mortal just as all animals are. However, our differences from all other living beings have given us the knowledge and the ability to develop high technology medicine. Our responsibility is to establish the appropriate way of using such medicine. Part of this is expressed in recognising that human beings are complex creatures, not just automated machines.

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20 Thomas Szasz, in Lammers and Verhey (eds), *On Moral Medicine*, p.172. Also in the same publication, Leroy Walters, p.157, and Daniel Callahan, p.168. However, I recently heard a representative of the Department of Public Health Sciences say of the WHO definition; "to challenge is almost heresy" (Sarah Cunningham-Burley at the Church of Scotland day conference "Bio-Ethics for the Millennium" 12.1.99.)

21 Moltmann, *God in Creation*, p.271.

22 *Ibid.*

23 From *"Church Dogmatics III/4"* in Lammers and Verhay (eds), *On Moral Medicine*, p.156.

24 From *"Medical Nemesis"* in Lammers and Verhey (eds), *On Moral Medicine*, p.160.

ii) On being human as a whole

The medical model of illness would see health simply in terms of all the parts of the human body functioning normally. Humans are healthy as long as there is nothing which has 'broken down'. A more helpful understanding of health may need to recognise that human beings are not just living machines.

Karl Barth acknowledges the spiritual and bodily unity of humans by defining health as "the power to be as man exercised in the powers of the vital functions of the soul and body".[25] Tillich suggests that health should be considered under the multi-dimensions of: mechanical, chemical, biological, psychological, spiritual and historical, and that it is necessary to ensure that successful healing in one dimension does not imperil health in another dimension.[26] Similarly, Moltmann suggests a set of dimensions involving the interaction between elements of human life which need to be considered;

> "Health" must be defined in several different dimensions if the concept of health is to be conducive to the life of human beings. It must find its definition in the flux of history between persons and society, society and nature, past and future, immanence and transcendence.[27]

Moltmann observes that health is a complex phenomenon, having social and biological dimensions, that healing takes time, that it involves past memories and future hopes as well as present predicaments. Perhaps most significant in Moltmann's words, is the recognition that there is a 'now' but 'not yet' element to health. Our health will only ever be complete in the context of the world which is to come. This has tremendous implications for all those who strive for perfect health today.

Each of these groups of dimensions are useful in as much as they recognise that a person is a complex, integrated being. Humans are far more than collections of organs functioning together. In rejecting the 'medical model', however, any definition of health begins to resemble that of the WHO. To

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25 From "*Church Dogmatics III/4*" in Lammers and Verhey (eds), *On Moral Medicine,* p.155.

26 From *"Perspectives in Biology and Medicine"* (Vol.5, Autumn 1961) in Lammers and Verhey (eds), *On Moral Medicine,* pp.162ff.

27 *God in Creation,* p.271.

include mental, social and other dimensions to health can result in explaining away the world's problems in terms of 'sickness'.[28] 'Wholeness' may be a more appropriate model to use than 'health'.

iii) On being a whole human

Today people strive to achieve a healthy and long life, this is what matters. A better emphasis, an emphasis which has been held in the past, would perhaps be for people to strive towards achieving a 'morally worthy', a 'good', life.[29] There is no intention here to patronise those with illness or disability, but to recognise that health is not of supreme value in the human life, and until we begin to live our lives as God intends, we shall never be truly 'healthy'. Perhaps 'wholeness' is the term we can use in the place of health in this respect.

In this connection, it may be helpful to read what Moltmann says about 'health' in terms of 'wholeness'. Health (wholeness) is not so much an 'objectively ascertainable *state* of the human being's physical, mental and social well-being' but rather it is more 'a subjectively ascertainable *attitude* on the part of the person concerned to his fluctuating condition'.[30] Influenced by Barth's concept of the 'power/strength to be as man', and a suggestion that 'Health is not the absence of malfunctionings. Health is the strength to live with them'[31], Moltmann produces the pithy definition: "health [wholeness] is the strength to be human." As with all pithy definitions, it needs spelling out a bit.

> The strength to be human is displayed in the person's capacity for happiness *and* suffering, in his acceptance of life's joy *and* the grief of death.....if we understand health [wholeness] as the strength to be human, then we make being human more important than the state of being healthy. Health is not the meaning of human life. On the contrary, a person has to prove the meaning he has found in his own life in conditions of health *and* sickness. Only what can stand up to both health *and* sickness, and ultimately to living *and* dying, can count as a valid definition of what it means to be

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28 Daniel Callahan quoted from *"Hastings Centre Studies"* (Vol.1, no.3, 1973, pp.77-87) in Lammers and Verhey (eds), *On Moral Medicine* p.167.

29 McKenny, *To Relieve the Human Condition*, pp.9ff. and p.115.

30 *God in Creation*, p.272.

31 D.Rossler quoted in *God in Creation*, p.273.

human..... *The strength to be a human person lies in the acceptance, the affirmation and the love of frail and mortal life.*[32]

The key to this passage would seem to be "Health is not the meaning of human life ..... a person has to prove the meaning he has found in his own life.....". To be whole is to live one's life aiming not at physical perfection, but at moral goodness. To be whole is to recognise one's limitations and the tremendous gift of life and love given through God's mercy. To be whole means living as one can, not as one cannot, in response to the love of God. This concept is explored further in terms of narrative approaches to death and disability.[33]

This concept of wholeness brings with it a promise and a problem. The promise can be seen in terms of society's attitudes towards anyone who is ill or disabled. If wholeness is seen as 'the strength to be human', then it is perfectly possible to be 'disabled', or suffering from a hereditary disease, and yet to be 'whole'. What matters is one's attitude towards one's situation, not the mechanical functioning of one's body, "being human is more important than the state of being healthy". If this understanding of wholeness were to gain wider acceptance, then society's attitude towards long-term illness and disability could be greatly changed. It is less likely that there would be pressure (explicit or implicit) to abort foetuses carrying genetic differences. Parents who choose to allow a handicapped child to come to term may not be discriminated against for their decision. People with mental or physical limitations may not be marginalised, but rather welcomed into society and encouraged to find that 'strength to be human'. In such a society there may well be a greater incidence of limitations and sickness caused by genetic effects, yet the attitude of this society could be far healthier. No longer would sickness or disability be feared or marginalised. A far healthier approach to life, pain and death could result.

The problem with this approach, however, is that it could lead to a rather 'gnostic' attitude towards physical suffering. Would the 'strength to be human' imply 'grin and bear it'? If health is more a matter of attitude than a matter of physical well-being, would it be better if illness were simply accepted rather than fought? Where in this understanding of health would one find the place of medical treatment? Yet we are embodied people, the state of our bodies does matter. The reality of suffering caused by

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32 *God in Creation*, pp.273 & 275. Moltmann's emphasis.

33 See section 4.

genetic diseases must be acknowledged. David Biebel writes from the personal experience of having two sons suffer, and die prematurely, from a severe inherited condition;

> [o]n a purely human level, to experience genetic disease in one's children is to be immersed in a boiling cauldron of almost pure pain, with a generous helping of surprise, confusion, disappointment, anger, and guilt thrown in.[34]

It will be important in this connection to have a satisfactory theological approach to the reality of disability and premature death.

5.4 Towards a theology of disability and premature death

It is my intention in this section to consider two 'test cases', the cases of persons with disabilities, and of terminally ill children. I present some theological reflections of those involved with such cases, and explore possible theological approaches to these situations.

There are a number of ways in which genetic technology can impinge on the lives of disabled or terminally-ill children. More than half of all cases of severe mental disability have an inherited cause.[35] Many of these people also suffer from physical disabilities. Gene therapy will not be able to help these people, but screening will be able to detect embryos and foetuses affected by such genetic differences. Our attitudes towards the 'disabled' (whether such disability is mental, physical or both) will influence the number of such foetuses ever brought to term, and the way in which we treat disabled people throughout their lives. Many genetic diseases cause death in infancy, childhood or early adulthood. Through genetic advances, more effective medical treatments are being established for some of these diseases, and the possibility of gene therapy is always before us. In the meantime 'therapeutic abortion' and genetic counselling are used to prevent the birth of children affected by such genetic diseases. A consideration of theological reflections prompted by contact with disabled people or with terminally ill children may help approach these genetic situations. Reflections made by Stanley Hauerwas, Jürgen Moltmann, and Frances Young are used.

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34 *"The Riddle of Suffering"* in Kilner, Pentz and Young (eds), *Genetic Ethics*, p.3.

35 Jones, *The Language of Genes*, p.285.

i) Theological test cases

a) The 'disabled'

It is through considerable personal contact with handicapped people that theologians have been inspired to publish their own theological reflections. Having played an active part serving on the board of a 'Council for the Retarded', Stanley Hauerwas wrote the third part of *Suffering Presence,* entitled *"Caring" for the Mentally Handicapped.* Moltmann was involved in issues concerning the rehabilitation of disabled people for a number of years, before he gave his lecture "The Liberation and Acceptance of the Handicapped", later published in *The Power of the Powerless.* It was the experience of loving and living with her son, Arthur, which led Frances Young to her own theological reflections concerning handicap.[36]

Hauerwas questions the assumption that the mentally disabled suffer so much that it would be better for them not to be born. Firstly, he asks whether our desire to prevent/eliminate such disability is not because we are concerned about their suffering, but rather because their very existence causes us suffering.[37] This suffering is caused by our inability to sympathise with those who are different to ourselves, and also by the consequent fear this produces in us when faced with our own limitations. Secondly, he suggests that if the mentally disabled do suffer, then it is not so much from being disabled *per se,* but rather from living in our society. Their suffering is caused less by their particular situation as by the way in which they are marginalized, ignored and handicapped by our society. Thus it is not that we should prevent suffering by preventing mental disability, but that we should change our world in order to prevent the needless suffering which we impose on these people.[38] Finally, Hauerwas questions whether it is even right to attempt to eliminate suffering from our lives. The reality of life, healthy or not, normal or not, is that all will suffer.[39] If a foetus should be allowed to die in order to prevent it from suffering, then none would ever be brought to birth. Suffering is not something we can eliminate,

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36 *Face to Face; A narrative essay in the theology of suffering,* Edinburgh, T&T Clark, 1990. Arthur is profoundly mentally and physically handicapped. Note that an earlier book of the same title (Epworth Press, 1984) contained mainly their story to date, and little theological reflection.

37 *Suffering Presence,* p.165.

38 *Ibid.* pp.171f. See also Tom Shakespeare's comments Ch.3, p.25f.

39 *Suffering Presence,* p.168 and p.172.

instead we must learn to live with it.[40] Thus for Hauerwas the question of whether death could ever be seen to be preferable to suffering, or vice versa, is the wrong question.

> Rather our decisions must turn on what we think our lives are for, and not how much suffering they contain or how long we can avoid death.[41]

This concept links in with the consideration of a moral life being a whole life, discussed in the previous section. All three theologians suggest the disabled have a unique (moral) role in reflecting the image of God to others. If God's image is reflected through a person's relationship with him, rather than through a particular human attribute, then disabled people are not excluded from this occurrence.[42]

Hauerwas suggests that in meeting mentally disabled people we meet God, and are also made to recognise our own limitations.

> The challenge of learning to know, to be with, and care for the retarded is nothing less than learning to know, to be with, and love God. God's face is the face of the retarded; God's body is the body of the retarded; God's being is that of the retarded. For the God we Christians must learn to worship is not a god of self-sufficient power, a god who in self-possession needs no one; rather ours is a God who needs a people, who needs a son.....That is why in the face of the retarded we are offered an opportunity to see God, for like God they offer us an opportunity of recognising the character of our neediness..... That the retarded are singled out is only an indication of how they can serve for us all as a prophetic sign of our true nature as creatures destined to need God and, thus, one another.[43]

This suggestion is challenging both theologically and practically. It is not an orthodox/traditional view to consider God as not being self-sufficient. But here Hauerwas refers (with reference to the work of Arthur McGill) to the 'need' God the Father has of his Son, and the 'need' the Trinity has of a people to love.

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40 *Suffering Presence,* p.24, also p.172.

41 *Ibid,* p.35.

42 Indeed, Vanier suggests the disabled may be particularly gifted in this capacity, as they are more aware of their need and more willing to trust God (*Becoming Human*, p.97).

43 *Suffering Presence,* p.178f.

The practical challenge is for people to see in the distorted faces and bodies of the disabled, the face and body of God. In the reflection of the 'neediness' of God, Hauerwas claims we also begin to see our own neediness.

Moltmann suggests that disabled people act in a prophetic way, in that they "help us to achieve true humanity. For they compel us to stop basing our self-confidence on health and capability, and to seek it through trust in God".[44] Whatever mental or physical disability we may bear (and may continue to bear throughout our lives), this does not prevent us also from reflecting the image of God. Through disabled people, others can come to know "the real, the suffering, the living God who loves them too with an infinite love".[45] 'Wholeness' is found in the experience of being loved by God, and reflecting his image.

> Human love looks for beauty and flees from what is ugly. But God's love makes sinners righteous and ugly people lovely. So because we are from all eternity God's beloved, we can also love ourselves, and find ourselves good and true and even beautiful, and can find pleasure in what we are. Everyone of us is a reflection of God in this world.[46]

We are encouraged to go beyond the external form of a body (be it beautiful or broken) and to see the internal person. The internal person is beautiful because they are loved by God.

After twenty one years of caring for, and living with, her son Arthur, Frances Young wrote the book which was both their story and her theological reflections of that story.[47] She writes from her heart of her own experience of receiving something of God from Arthur, despite the hard work entailed in caring for him.[48] She sees this sense of the disabled contributing to others' lives as being of great importance. Rather than simply being the 'objects' of charity, they need to be allowed to help others; "if they are to be persons, we must learn to 'receive' from them".[49] Young goes on to explore a communal aspect to the reflecting of God's image. Rather than seeing individuals reflecting God's image each in

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44 *The Power of the Powerless*, p.145. A similar view is expressed in Young, *Face to Face*, pp.179-182.

45 *The Power of the Powerless*, p.151.

46 *Ibid.* p.149.

47 *Face to Face.*

48 *Ibid*, p.178f.

49 *Ibid.* p.186.

their own way, she sees the fuller image reflected in the community of Christians, the 'body of Christ' (just as his image was fully reflected in the life of Christ himself). Each individual is important for the part they have to contribute to the total image "but no-one can claim to be the image of God on their own".[50] The reflection of God seen through the disabled is crucial, a reflection only they can give.[51]

There is an important role for 'normal' people to play then, in being open and ready to receive from the disabled, to receive God, to receive value. This concept is not meant to be patronising, but realistic about the contribution the disabled have to make to other peoples' lives, and realistic too about the effort other people must make to strike up relationships sufficient to be in a position to receive. Including disabled people in a community (family, church, locality) will not be an easy thing to do.[52] Young admits; "no-one should imagine it is easy. Yet there can be no doubt that those who do not have the experience of relating to the handicapped have missed one of the most beautiful and transforming experiences of life".[53]

Faced with a severely disabled person one might be prompted to think about whether death could ever be preferable to suffering, but Hauerwas suggests the real question one should be asking is; what do we think our lives are for? 'To reflect the image of God to others' would seem at least part of the answer to this question. This ties in with the concept of a 'morally good' life, and challenges society's values today of success and achievement. To be able to reflect God's image requires us all, able and disable, to accept our neediness, to rely on God, receive from him his love, mercy and healing, and within our brokenness to share these gifts with others.

It will be important not to use these 'nice' theological concepts to cover over the reality of the struggle which is the lot of the disabled and those who care for them. Young writes of the very real anger and frustration of a mother who could not see how on earth her severely disabled, and deteriorating, son could bear the image of God.[54] She writes too of the painful road both she and Arthur have travelled over the years. One of the ways in which we can begin to take this reality seriously is by asking ourselves

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50 *Face to Face*, p.192. Compare Moltmann, *God in Creation*, p.222.

51 *Face to Face* p.193.

52 The role of the local church is explored in Ch.7.

53 *Face to Face*, p.183.

54 *Ibid*, p.174.

whether a person's disability is simply the result of their physical and mental limitations, or whether it is in any way a result of our attitudes and structures.

We have explored something of the theological reflection sparked by relationships with disabled people, and turn now to that inspired by people whose lives are cut tragically short.

b) Death in children

Facing the terminal illness of a child is a particularly painful experience. This is partly because we feel that their death is so untimely, and partly because we are faced with our own limitations (both our own mortality, and our inability to help). Hauerwas suggests that the pain of such experiences can create silences which come between people, silences which cannot be shared. He suggests that modern medicine can be used as a desperate attempt to fill these silences,[55] but only succeeds in isolating children from their families and the medical staff.[56]

Hauerwas quotes extensively from the anthropological work of Myra Bluebond-Langner and her study of leukaemic children.[57] She suggests that children, parents and medical staff each enter into relationships of mutual pretence, keeping secret the reality of the child's impending death. The mutual pretence is important because only in this way can each of them appear to fulfill the roles society expects of them. The role for children is to grow up and to have a future, the parent's role is to be a guardian, a protector, and the medical staff's role is to cure illness. Only by maintaining relationships of mutual pretence can these three groupings appear to fulfill the roles expected of them, and so they can keep their places within society. But, the practice of mutual pretence is a very costly one, because it inevitably leads to children dying terribly alone - because only in this way can the mutual pretence be maintained. It is, however, important to note that there were two children in Bluebond-Langner's study who did not practice 'mutual pretence'. The families of these children appeared no better equipped to cope with their child's death than did the others.[58] How is it possible to name those silences which terminal illness produces, rather than to hide them with aggressive medical intervention? Hauerwas suggests this can

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55 *Naming the Silences*, p.xi.

56 *Ibid.* p.127.

57 *The Private Worlds of Dying Children,* Princeton University Press, Princeton, 1978. Referred to in *Naming the Silences*, pp126ff.

58 *Naming the Silences*, p.143.

only be achieved in the context of a 'community constituted by a truthful narrative that can comprehend such deaths without denying their pointlessness'.[59] The meaning and significance of this statement is explored below under 'The Story of Tragedy and Hope'.

Twisted bodies and clouded minds, young lives never given the chance to explore their full potential, these situations have prompted much theological reflection. Does this reflection offer one a framework within which to set such lives and one's own life? Such suffering may seem totally meaningless and a complete waste, it may seem better never to have lived at all (the implication behind the offer of 'therapeutic abortions'). Is there a theological approach that can help us to cope with life's brokenness and limitations? The following section will explore two such approaches.

iii) Theological approaches

I explore two, quite contrasting, approaches; that of seeing disability as 'gift', and that of a narrative context for illness.

a) Disability as gift

The disabled, by definition, do have their own (often severe) limitations. Nevertheless, the part which they can play in a community has already been explored. Perhaps more controversial, even shocking, is the concept that disability can be a gift.

Moltmann suggests that, in thinking about those with disabilities, we are often too busy concentrating on what they have been deprived of, and this prevents us from recognising that 'handicap' can also be an 'endowment'.[60] The gifts and energies of the Holy Spirit include "sufferings, setbacks and sorrows"[61], and in the body of Christ (the church) it is to the ill-equipped members that God gives most

59 *Naming the Silences*, p.147.

60 *The Power of the Powerless*, pp.150f.

61 With reference to II Cor.4.7ff. - although it could be questioned whether Paul is actually referring to gifts of the Spirit here.

'glory and splendour'[62]. It is in the light of this that Moltmann sees disability as endowment, an endowment which acts as a reflection of the image of God.[63]

Another example of disability being seen as gift, albeit from a slightly different theological angle, can be found in an address given by Dr. Mary Weir, a Canadian theologian who has been profoundly deaf all her life.[64] Weir has come to regard her deafness as a blessing, not an accident or a misfortune, but as 'created goodness'. Deafness is not primarily the lack of something essential to being human. It is interesting to note that it is only in adulthood that Weir has come to hold this view, as a child she found her deafness hard as it cut her off from other people. Despite this view of deafness as blessing, Weir is still realistic about the limitations deafness brings, referring to it as "a very human mixture of opportunity and dilemma, giftedness and limitation" and "to be accepted - and loved, even if it cannot always be liked". It could be argued that the inability to hear is a fairly minor disability compared, say with the inability to organise one's thoughts, communicate one's feelings and control one's body movements. Significantly, Weir does not apply her theological understanding of deafness to other disabilities, but Harrison suggests that to do so would be perfectly valid.[65] Harrison does not expand on this thought, which is a shame because it is a very difficult concept. Can it truly be regarded as a gift of God that a child should be born with Tay Sachs disease, and after two or three years of mental and physical deterioration, pain and isolation, give up his short life? Would David Biebel regard his experience of having two sons die of a genetic disorder as a gift?[66] Similarly, Young asks; "[i]s it not offensive that Arthur was born handicapped for my spiritual benefit?".[67] The reality is that such a suggestion would be offensive to many. The concept of 'gift' is a difficult one when put in terms of God deliberately making someone suffer from a particular disability for the benefit of others. God's providence is a mystery. Biebel provides what may be the key to this question in saying; "I have come to

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62 With reference to I Cor.12.24.

63 *The Power of the Powerless*, p.151.

64 Quoted in Ted Harrison, *Disability; Rights and Wrongs*, p.124-131. In this context it is also challenging to learn of a deaf couple who regarded deafness as superior to hearing, and specifically wanted a deaf child. (Liz Hepburn, *Genetic Counselling: Parental Autonomy or Acceptance of Limits?* in Junker-Kenny and Cahill, *The Ethics of Genetic Engineering*, p.36).

65 *Disability*, p.132.

66 See section 3 (iii).

67 *Face to Face*, p.216.

see both the experiences and what I have learned through them as a trust, a gift".[68] In reflecting God's image, the handicapped have something unique to offer. This is God's gift to us, not a person's disability, but the gift of his image through the brokenness of disability.[69] This may be a less shocking idea, but it still leaves us with a difficulty. If God gives us a (unique) gift through those who are handicapped or ill, is this a gift that should not be refused? Should one's attitude towards an inherited disease be to 'bear it patiently' (as instructed in the *Book of Common Prayer*), thus allowing God's gift to be given to others? Would any attempts at gene therapy, or even two carriers of a genetic disease avoiding having children together, be seen as thwarting the gift of God?

b) The story of tragedy and hope

Hauerwas suggests there are two different ways of looking at life, each resulting in a very different approach to illness. One view is to regard life as fundamentally constituted by chronicity - a series of discrete events which are open to manipulation by ourselves and others. Such a view leads to the assumption that suffering, life and death have no real point. Alternatively, one can regard life as being fundamentally determined or constituted by narrative. According to this view life is not so much something which we create for ourselves, but rather it is something which we discover; it is a recognition that we are part of something far greater than the sum of our days.[70] Hauerwas believes that it is this view which will help us to understand illness and the purpose of medicine, and which will help us to be present to those who are ill.[71] The narrative context for illness, ties in with Hauerwas' suggestion that what we need to ask about is the purpose of our life, not whether or not it may be worth living.[72] He says little concerning the nature of this narrative other than; "we are creatures of a gracious God".[73] Perhaps two features of the Christian narrative which are particularly relevant are the elements of tragedy and of hope.

THE STORY OF TRAGEDY

The tragedy of this life is the intractability of human nature - or as has already been considered,

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68 *"The Riddle of Suffering"* in Kilner, Pentz and Young, *Genetic Ethics*, p.5.

69 This is perhaps what Michael Beates means when he says; "Genetic anomalies .... are not good in an *absolute* sense. Rather, for believers they are good in an *ultimate* sense". (*"God's Sovereignty and Genetic Anomalies"* in Kilner, Pentz and Young (eds), *Genetic Ethics*, p.58).

70 *Naming the Silences*, p.112.

71 *Ibid.* p.108.

72 *Suffering Presence*, p.35.

the limitedness of human nature.[74] This concept is explored by Donald MacKinnon, reflecting on the tremendous technological achievement in splitting the atom and discovering nuclear power, and the outrageous way in which the knowledge has been used to create nuclear weapons capable of wiping humanity off the face of the earth.[75] He explores the theme of tragedy further in "Ethics and Tragedy", through reflections on the unsuccessful plot to assassinate Hitler in 1944 and on the works of tragedy by Shakespeare and Sophocles.[76] He sees the "sheer intractability of human life" in a number of areas over which we have no control; that our moral responses can turn us into something we cannot foresee, that the issues we wrestle with are not within our power to solve, and that we sometimes do the right thing from the wrong motives or can even be tricked by our virtues into destructive courses.[77] In other words, we humans are not of the same substance as God, we are of the same substance as all other creatures and are in limited control. The result of this reality is conflict, moral conflict. We find ourselves facing tremendous dilemmas, intolerable moral choices, often the conflict is between right and right, MacKinnon suggests we can but learn to count the cost and only then go forward.[78]

Hauerwas picks up on this theme of tragedy, recognising that; "honesty and faithfulness do not always lead to good results and consequences, but sometimes to tragic choices".[79] He believes it is important to view medicine as a tragic profession, that it should be committed to "care in the face of death".[80] Other examples of tragedy within medicine are to be found in conflicts between a doctor's commitment to his patient and to the institution within which he practices, conflicts concerning the preservation of life not knowing what quality the life may have, and recognising the reality of the limits to medical treatments.[81] Thus the narrative context for illness should be "a story that can help us contain the tragic without trying to explain it away or find a solution for it".[82] Is part of this story not to be found

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73 *Naming the Silences*, p.126.

74 See Ch.3.2, above.

75 *"The Future of Man"* in *Explorations in Theology 5*, p.6.

76 *Explorations in Theology 5*, pp.182-195.

77 *Ibid.* p.186, p.187, p.189, p.190.

78 *Ibid*, p.185.

79 *Truthfulness and Tragedy*, p.69f.

80 *Ibid.* p.185f.

81 *Ibid.* pp.192ff

82 *Ibid.* p.200.

in the Christian understanding that, despite all our wonderful discoveries and greater understanding of the way the world is, nevertheless, we are not god? Does not our story require a recognition of ourselves as created beings within a created order, creatures with responsibilities but also with limitations, creatures with mixed-motives we may not even be aware of, with the capacity to be corrupted and misguided, the capacity to dream dreams and also to make mistakes?[83]

THE STORY OF HOPE

There is an element of tragedy in the Christian story, but there is also an element of hope. There is an element of hope because neither we, nor our world, are irredeemable. There is an element of hope because the brokenness of this age is not all that there is to be. There is an element of hope because through the death and resurrection of Jesus Christ, creation is to be both restored and transformed. God is creating even now, doing a new thing. There is an element of hope because a new heaven and a new earth is our promise in Christ, a place where there shall be no more death or mourning or crying or pain.[84] There is an element of hope because this promise can be anticipated even today through those who work together with God, who through their relationship of love and worship with him, reflect the image of God in the world. There is an element of hope.

In the light of both the tragedy and the hope in the Christian story, Young suggests that neither optimism nor pessimism is appropriate, but rather the Christian virtues of faith, hope and love.[85] Perhaps it would also be appropriate to add the Christian virtue of humility to this list. Humility is needed to recognise our limitations as people, but also (despite our great advances) the great limitations to our knowledge. For the Christian story to be of any value, for it to have any effect, it must be lived by a community of people.[86]

There may be a way in which both these theological approaches may be seen as a whole. The concept of disability as gift is a difficult one. Should one instead think in terms of the gift which God gives through those who are disabled? In this there is both tragedy and hope. It is tragic that a person's life can be so much more limited, so much more painful, so much shorter than our own. It is tragic that a

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83 Also Young, *Face to Face*, p.196ff.

84 Rev. 21.4.

85 *Face to Face*, p.215.

single change in a person's DNA can wreak so much havoc. It is tragic that despite our treatments, our drugs and our surgery, despite our prayers and our anointing, there are times when nothing makes any difference. It is tragic to be helpless. Yet within the tragedy there is hope. Hope is seen whenever we see something of God in the brokenness of disability. Hope is seen whenever we are prompted to laugh, to cry, to play, to dance, with someone otherwise unable to communicate with us. Hope is seen whenever another person helps us to see our own limitations and need of God, whenever we experience an anticipation of that which God has in store for us. The tragedy and the hope, the gift of God.

Theological understandings of the role of medicine, the nature of health and wholeness, and approaches to disability, illness and premature death have been considered. Some implications for the use of genetic medicine have been discussed *en route*. Consideration will be given below to the question of the use of genetic medicine in principle.

5.5 Implications for genetic medicine

I recognised, in Chapter 2, a 'central tension, almost a necessary paradox', in the light of Christian belief, to our approach to medicine.[87] Is illness to be regarded as being within God's providence and so accepted, or are we called to continue Christ's healing ministry in our love of our neighbour? This same tension or paradox, perhaps with increased intensity, is to be found when considering the possibilities of genetic medicine. Should we regard genetic anomalies as a gift from God, not to be refused, or should we seek to prevent the (often acute) suffering of those affected by genetic illness?

On the one hand theologians argue convincingly for the valuable, even crucial, role which disabled people can play in our society. Bringing us unique reflections of the image of God, revealing to us our own limitations and neediness, and helping us to see that success and achievement are not the most important things in life - disabled people have much to offer if only we are willing to receive. However, not all cases of 'genetic disability' are alike in their effects or their severity. Those affected by achondroplasia may have severely stunted growth and misshapen facial features, but they are otherwise

86 See Ch.7, below.

whole in mind and body. Babies suffering from Tay Sachs disease suffer brain and muscle deterioration from the age of about six months and rarely survive beyond the age of four. Those with sickle cell amaemia can suffer chronic pain throughout their lives. Down's syndrome people have specific physical characteristics, and other physical and mental disabilities, the severity of the disability varying significantly from one individual to another. Can all situations of 'genetic disability' be understood in terms of a unique part of God's revelation? Perhaps it is easier to receive from those whose disability is less obvious, less distressing. Yet it may also be the case that those with the greater disabilities have the most to offer.

On the other hand, the pain, frustration and loneliness which genetic disability can bring to sufferers and carers alike cannot be denied. The desire to love one's neighbour, to reflect God's mercy and healing power, can be expressed in our desire to use genetic technology to prevent or relieve such suffering. Genetic medicine appears to offer immense hope. It offers the possibility of having children unaffected by genetic disability. It offers the possibility in the future of being able to 'mend' genetic anomalies. It offers a greater understanding of the cause of genetic disability, and so opens up the possibilities of improved preventative medicine and conventional treatments. Genetic technology offers great hope through its great power. We must however treat this power with tremendous care, recognising the tragedy of the limitedness of the human condition. The tragedy is that we may misuse power, wittingly or unwittingly. The tragedy is that there may be some conditions over which we never can gain mastery. The tragedy is that we could possibly make genetic changes over which we subsequently have no control. The tragedy is that already we are turning health and perfection into the purpose of life. The dilemma we are faced with involves how much is it appropriate to grasp hold of and utilise the hope offered by genetic medicine. At the same time we must not forget to explore the (undoubtedly less dramatic) alternative ways in which the life of the disabled can be helped. Working towards inclusiveness in social conditions and attitudes, changing priorities in health-care allocations, conducting research on the prevention rather than the treatment of disease, can all contribute towards such help.

So, how do we find the delicate balance between using genetic technology to bring about anticipations of God's kingdom, without worshipping health and perfection? How do we affirm that

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87 See Ch.2.3 (iii) a, above.

what is important in life is not its duration and physical quality (but rather finding the strength to be human, to know what the purpose of life is, to be able to reflect God's image to others), and yet use responsibly the knowledge that that certain genetic differences give rise to people with severely restricted lives, with a great deal of physical pain, and/or with tragic brevity of life? Should we ever do anything to prevent the birth of someone suffering from a genetic anomaly, or should we simply accept their life as a gift from God? Would it be appropriate for potential parents who have a significant chance of having an affected child to choose not to have children, or to seek egg or sperm donation? Would it be appropriate to screen embryos *in vitro* or foetuses *in utero*, and reject those who would be affected by genetic disability? Would it be appropriate to seek to prevent or treat disability through genetic manipulation? Should we ever seek to improve our genetic situation? Or would each of these actions be a rejection of God's gift to us through the genetically disabled? Space prevents a detailed investigation into each of these possibilities. It is the intention of the following chapter to consider the specific instances of the possibilities offered through genetic therapy and enhancement, with reference to the theological explorations made in these last three chapters.

Chapter 6:
TOWARDS ETHICAL GUIDELINES IN THE USE OF GENE THERAPY

Having explored theological themes relating to human nature, to deliberate evolution, and to health and wholeness, it is necessary to draw these themes together and use them to address a particular genetic technology. In the light of this theology I address the moral issues raised by the deliberate addition of DNA into the genetic make-up of human beings. Loosely the technology has been referred to as 'gene therapy', although it could involve genetic enhancement rather than the therapy of genetically-based diseases. Genetic alterations could be made in a person's somatic cells (so that no change is inherited by future generations) or in a person's whole body, including their germ cells (so that the alteration is carried on into the genetic make-up of offspring).

A brief summary of the theological conclusions made previously is given. These conclusions are applied to a number of issues relating to 'gene therapy'. I address first the principle of whether it is ever right to alter the genetic material of a human being. Subsequently, I consider the theological implications of using genetic manipulation to cure genetic disease and to enhance personal characteristics, either in somatic cells or germ line cells. Finally, I draw up suggestions for guidelines in the use of 'gene therapy'.

6.1 Theological summary

i) Human nature

In exploring the theology of human nature in chapter 3, four major areas were addressed. Firstly, it was recognised that human beings are part of the created order. As such we are limited, we are mortal, we are embodied, and we are not in complete control (neither of ourselves nor of the world in which we live). Secondly, however, humans are unique in reflecting the image of God. This image is not substantial to human life, it cannot be identified as a particular physical or mental capacity. Rather, the image of God is relational, it is seen reflected in the relationship humans have with God (as a result of his grace) and (in consequence) with their neighbours. Reflecting God's image brings responsibility; responsibility towards one's neighbour, towards the rest of creation, and for oneself. This responsibility towards, stewardship of, the whole of creation was the third area explored concerning human nature.

Finally, it was recognised that difference and variety are vital aspects of human existence, as such they are to be affirmed and enjoyed. Difference in others should engender responsibility and co-operation rather than domination and competition.

ii) Deliberate evolution

In chapter 4 I considered two extreme theological views which could be taken towards the concept of humans altering their genetic future. The theologies of progress suggest that humans (unique in their capacity for self-examination and alteration) can work towards the improvement, even the redemption of the world.

The theologies of realism destroy any such dreams. Human beings are not only limited like all other creatures, but they are also limited in their ability to do what is right. The human heart is recalcitrant, rebellious, selfish. Power tends to be misused, freedom tends to result in captivity, progress can in reality be slipping back. There is nothing humankind can do to save itself, we are reliant totally on God's grace.

Some theologians are able to hold aspects of these two theologies in a paradoxical whole. The work of Moltmann illustrates one example. He sees the salvation of humankind as having been won now but not yet, the result of God's work alone yet together with the cooperation of human beings, something which is not predictable yet can be anticipated, including yet involving more than our physical nature. The 'theology of anticipation' is a paradox not easily grasped, nevertheless it may hold the key to approaching the genetic manipulation of human beings. The anticipation of our salvation is experienced in and through Jesus Christ, and in our striving for liberation in this life; liberation from exploitation, oppression, and alienation (alienation from each other, from the environment, and from God). This anticipation is found as we identify with victims, rather than with the strong and powerful.

iii) Health and wholeness

The treatment of disease can be seen both as a way in which God's image is reflected (in caring for our neighbour) and as an anticipation of our ultimate salvation (which will include our physical bodies). It is important, however, that 'health' (or physical perfection) does not become divinized, or our supposed source of salvation.

An understanding of health must include dimensions other than just the mechanical functioning of the body, but a utopian understanding which would imply permanent happiness and well-being is not helpful. Limitation and suffering are a natural part of human existence. Wholeness of life is of greater importance than health of mind and body. In caring for those who are ill, the aim is to care for the whole person, rather than eliminate the disease irrespective of cost.

The desire to cure people of disease does not imply that they, nor those suffering from incurable afflictions, are worth-less. All human beings can reflect God's image despite, or even from within, their disabilities. The Christian story of tragedy and hope provides a useful context from which to approach illness, disability and death.

6.2 The principle of human genetic manipulation

DNA has become something of an icon of our age, it is understood to make us what we are. Would it therefore ever be appropriate to alter the genetic make-up of human beings? This question may be asked for two different reasons. Firstly, it may appear that our genetic material makes us (humans as against other creatures) uniquely who we are. Secondly, each individual human has a unique, given, genetic make-up. For both these reasons it may be considered wrong to alter our self-defining material. Can science or theology help consider this issue?

i) The uniqueness of humanity

As creative, curious, and self-aware beings, who are capable of abstract thought, of handling tools, and of communicating through word and symbol - as these beings, humans have found themselves in the unique position of being capable of altering their own nature. If our very uniqueness is to be found in the sequence of human DNA, then should this DNA be considered sacrosanct? If we were to alter human genetic material at all, would this violate what it is to be human?

SCIENTIFIC REFLECTION

Recent investigations into the DNA from human beings and from other living things, have shown some remarkable results. It appears that human beings share a number of DNA sequences with other creatures, including (to varying extents) baboons, bears, butterflies, and even bacteria. In comparing different genomes, it would appear that humans and chimpanzees are more similar than

willow warblers and chiff chaffs.[1] Almost 75% of human genes have some counterpart in the genomes of tiny soil-dwelling worms called nematodes![2]

The uniqueness of humanity is not to be found in a particular length of DNA, certainly not the 1.5% which differs between chimps and humans. Any living creature is more than the sum of their DNA, especially a creature as complex as a human being.[3] John Habgood cautions us not to confuse the building blocks with the finished product.[4] Molecular genetics highlights the common origins of humanity and all life on earth, rather than highlighting the uniqueness of humanity.

THEOLOGICAL REFLECTION

The theological understanding of the uniqueness of humanity ties in with the observations made above. The uniqueness of human beings is found in their ability to reflect the image of God. This ability is not found within the substantial nature of humans (not in physical characteristics, nor particular sequences of DNA), rather the ability is due to the grace of God, and is found in the relationship a human being has with God.

Both scientific and theological insights suggest that the uniqueness of humanity is not to be found in a particular stretch of DNA. The human genome is not sacrosanct, it has very much in common with all other genomes. Altering aspects of the human genome will not necessarily mean that we are altering what it is to be human.

ii) The uniqueness of the individual

The particular genetic make-up an individual is born with could be seen as a gift. A gift to be accepted graciously, not fought against or evaded, the life which God intends one, uniquely, to live. Is this a gift which should not be rejected?

SCIENTIFIC REFLECTION

A person's genome is the result of the chance meeting of chromosomes from two different people. Each person has two sets of 23 chromosomes. When reproductive cells are formed, each pair of

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1 See Ch.2.3 (i) b, above.

2 "The greatest apes" in *New Scientist*, 15.5.99, p.26-30.

3 See Ch.3.4 (ii), above.

4 Quoted in Nelson, *On the Frontiers of Genetics and Religion*, p.92.

chromosomes separates and moves at random to opposite ends of the cell. Division occurs so that two sperm or egg cells are produced, each carrying one set of 23 chromosomes. The reproductive cells from one individual can thus carry a wide variety of combinations of the 23 chromosomes.[5] When a sperm cell fuses with an egg cell a unique combination of genetic material occurs. It can truly be said 'there is no-one like me'.[6] Yet transplant surgery, which is now widely accepted, involves the transplantation of tissue with a different genetic make-up into a patient. This is the very reason rejection occurs. The uniqueness of an individual is not seen to preclude this medical intervention today.

THEOLOGICAL REFLECTION

Theologically, it is generally accepted that life is a gift from God.[7] Health too can be regarded as a gift of God's grace.[8] Should this theme be extended to understand one's particular genetic make-up as being God's gift too, a gift which should be graciously accepted? The particular combination of genes which result in inherent artistic or musical ability, natural athletic prowess or quick wit, can easily be considered a gift from God. But this would equally require one regarding the combination of genes which result in a person suffering from Huntington's Disease or muscular dystrophy, in someone having an increased likelihood of developing breast cancer or heart disease, or in having learning difficulties or physical deformities..... in one regarding these combinations of genes <u>also</u> as gifts from God.

The Christian story of tragedy and hope help us to put the reality of genetic differences into context.[9] It is tragic that a chance event can bring about a particular combination of genes which seriously affects a person's health and wholeness (at least in this life). It is tragic that genetic disease can cause such suffering, that we can be so helpless in its presence, or even contribute to that suffering. Yet we see hope in the good which God can bring from the tragedy; in the revelations of himself and ourselves he opens up to us, in the ways we can receive from the brokenness of others. We see hope in the recognition that this life, and our physical state in it, is not of eternal significance. We see hope in the anticipations of the life to come which we can help bring about, even within this world, with the grace of

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5 If all combinations are possible, the number would be expressed mathematically as 23^{23}.

6 Except in the cases of identical twins, when a single fertilised egg divides into two after a few rounds of cell division.

7 Hauerwas, *Suffering Presence,* p.36. The Catholic Bishops' Report, p.18.

8 Barth, from *Church Dogmatics III/4,* in Lammers and Verhey (eds), *On Moral Medicine,* p.155.

9 See Ch.5.4 (ii) b, above.

God. This hope is God's gift to us from within the tragedy. It does not mean that God has 'chosen' people to be as they are, and that to change their lot would be to refuse his gift. It would not necessarily be ungracious to try to alter a person's genetic lot, but rather it may be a valid way to exercise our stewardship and to reflect God's image in caring for our neighbour. The difficulty may come in attempting to decide which applications of genetic manipulation are appropriate. This is explored below.

6.3 Therapy for genetically-based diseases

Those genetically-based diseases which are most suitable for gene therapy are those which are caused by a single gene defect. There are a large number of such diseases, but their occurrence is quite rare. Cystic fibrosis and SCIDS are examples of diseases for which gene therapy is already being explored.[10] Issues relating to health, and the role of medicine, are raised by this technology.

i) The reality of genetic disease

Genetically-based diseases may be rare, but their effects are difficult to ignore.[11] The death of an infant due to SCIDS or Tay Sachs disease, the struggle for breath of a child with cystic fibrosis, the wasting away of a teenager with muscular dystrophy, the fearful wait of a middle-aged person with Huntington's disease, and their subsequent mental and physical degeneration - each of these situations are tragic. Conventional medicine currently offers little or no hope in relieving the inevitable fate of those with genetic disorders.

ii) Caring through gene therapy

High-technology medicine has rightly been criticised whenever its intensity results in a lack of care. Medicine can incur as much pain and suffering as it relieves. The research involved in developing gene therapy does, without doubt, involve high-technology; including isolating and sequencing genes, and developing methods for introducing DNA into appropriate cells. The actual treatment of gene therapy may be far less intensive. This could involve regular inhalations for cystic fibrosis, regular injections for muscular dystrophy, while for SCIDS a single bone-marrow transplant could be sufficient. The harvesting and transplanting of bone-marrow cells admittedly involve major operations, but this would involve less intrusive technology than having to live one's life in a sterile bubble. The technology

10 See Ch.2.2 (ii) a, above.

11 See also Ch.5.3 (iii), above.

of gene therapy is relatively simple and unintrusive. The results could be spectacular. If 'good' genes could be introduced into, and expressed in the tissues of those suffering from monogenic diseases, they could effectively be cured of their disease.

iii) The dimensions of health

Gene therapy as a concept depends on a mechanistic view of disease, the 'medical' model.[12] This model assumes that illness is accounted for by deviations from the norm of our bodily functioning, and that health can be restored by correcting the deviation. The principle of gene therapy assumes; 'Gene 'X' has suffered a mutation which means that it no longer produces protein 'x'. The lack of protein 'x' means a vital structural or functional component is missing. The malfunction of the body caused by the lack of 'x' is called disease '×'. If only gene 'X' or protein 'x' could be introduced into the body at the right place at the right time, then the symptoms of the disease will not occur'.

In many ways this mechanistic model of genetic disease is an appropriate one. For example, each step in the process has been identified in the case of cystic fibrosis. The 'CF' gene has been identified and sequenced. The nature of many of the mutations causing cystic fibrosis have been identified, the most common involves a change to just one unit of information in the CF gene. From the sequence of the gene, it was possible to work out the structure of the protein which it encoded. This protein was found to have the sort of structure expected of a protein which spanned a cell membrane and acted as a pump between the inside and the outside of the cell. This function tied in with, and now explains, many of the symptoms observed in cystic fibrosis sufferers. If a good copy of the CF gene could be introduced into cells of the digestive system and the lungs, then the pump could be made for the cell membranes, and the sticky mucus would no longer accumulate in the lungs and correct digestive function would be restored. The cystic fibrosis sufferer would be cured.

The dangers of reductionism through the medical model of illness, however, need to be borne in mind. Even cystic fibrosis has environmental factors which can influence the severity of the disease.[13] One of the dangers of the medical model is that a patient could become regarded simply as a defective

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12 See Ch.5.2, above.

13 Francis Collins, *"The Human Genome Project"* in Kilner Pentz and Young (eds), *Genetic Ethics*, p.95.

gene. If only the gene can be mended then everything will be alright. It is important to remember Ramsey's injunction to treat a patient as a whole person.[14]

iv) The limitations of gene therapy

Gene therapy is described above as the introduction of a 'good' gene to compensate for a 'defective' gene, thus restoring the normal functioning of a body. The restoration of 'normal' functioning is an important concept. The aim of gene therapy is simply to correct that which is defective, it is not to enhance that which already exists. Gene therapy is therefore limited to the usual lot of human life; not striving to defeat death, not aiming to create the 'perfect' human. It does recognise its limitations.

Another limitation to gene therapy is that not all monogenic diseases could be cured simply by adding 'good' copies of a gene. For dominant diseases (e.g. Huntington's) all the copies of the defective gene also have to be destroyed. This would be a far more complicated, if at all possible, matter.[15]

The limitations to gene therapy are also seen in diseases which are caused by a more complex genetic interaction, or the interaction of genes and the environment.[16] For diseases such as these, it will not be possible to achieve a complete cure through gene therapy, either because of the environmental factors involved or because of the complexity of the genetic involvement. In addition, there will still be babies born with congenital disorders. These can be caused by chromosomal abnormalities or by environmental factors affecting the foetus[17]. For these individuals gene therapy will offer no hope. Even if gene therapy becomes a successful medical technique, it will not be able to cure all those people affected by a congenital or inherited disease. Disability something the human race will always have to live with. We cannot assume that gene therapy will cure all our ills. It is important, therefore, that we encourage those affected by disability to live their lives to the full, to find the 'strength to be human'. Equally it will be important not to stop seeking alternative approaches to the treatment and prevention of

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14 *The Patient as a Person.*

15 See Ch.2.2 (ii) a, above.

16 E.g. heart disease, diabetes.

17 The developing foetus may be affected by exposure to certain drugs (eg. Thalidomide), or viruses (eg. Rubella), or lack of oxygen or certain nutrients.

illness. Rifkin argues for the use of ecological insights, and explorations of the interaction between genetic variations and the environment.[18]

6.4 Enhancing human life through genetic alterations

The possibility of 'mending' dysfunctional genes has led to speculations concerning the possibility of 'improving' our genetic lot. Human beings already 'improve' themselves (and their children) via a variety of means; education, exercise, cosmetics, surgery, and drugs. Genetic enhancement is unlikely to be feasible for complex characteristics like facial features, body form, intellectual ability and general fitness. There are other characteristics, however, more amenable to genetic alteration. Increasing our natural resistance to infection, delaying the ageing process, protecting the body against the toxic effects of pollution or cancer-causing agents, increasing our memory capacity are all possibilities.[19] Would it be right to attempt to enhance our genetic lot?

i) Striving for perfection

Today's society is based on standards of success, achievement, perfection.[20] It is in this culture that the possibility of genetic enhancement will be financially possible. Will we then strive to create the genetically perfect man and woman?

SCIENTIFIC REFLECTION

There are two immediate scientific comments to be made in response to such an idea. Firstly, it is impossible to define, let alone design, the genetically 'perfect' human being. Secondly, genetic variability is a vital part of all life on earth.

If asked to define the perfect human being one would have to ask: 'perfect for what?'. Ebony may be the perfect skin colour for a person living in the heart of Africa, but fair skin is far better for an Icelander. A stocky build may be best for someone involved in regular, demanding manual work, but will be something of a handicap to a potential highjumper. The butterfly-mind and creative imagination of a poet will not necessarily be helpful to an accountant. A single copy of the gene for sickle cell

18 *The Biotech Century*, p.228 and p.233.

19 Ch.2.2 (ii) c, above.

20 Vanier, *Becoming Human*, p.45.

disease has proved vital for those living in areas affected by malaria, but is of no value to those in colder climes. It is impossible for us to specify, even in theory, the genetic make-up of a perfect human being.

'Biodiversity' has recently been recognised as one of the essential aspects of life on earth. The 'Earth Summit' in Rio de Janeiro in 1992 collected together leaders from around the world in order to discuss strategies for preserving the great variety of life in existence. Not only can we see variety in the different species of creatures, but also in the genetic variation within species. This variation contributes to the diversity of life to be seen, but is also essential for the continuation of life on earth. Conditions for living are always changing; drought and flood, heat and cold, famine and plenty, different germs bringing infection, different predators aiming to kill, different places to inhabit. The only way a species (including *Homo Sapiens*) can hope to survive the many variations of life, is by having enough genetic variability within the species so that some members will thrive in any given condition. 'Perfection' is found in variety rather than uniformity.

THEOLOGICAL REFLECTION

Speaking theologically, human perfection will be found in a complete reflection of the image of God. Jesus Christ is the only perfect human being ever to have lived, only he has reflected the image of God to this extent. The image of God is a relational, not a substantial, matter.[21] So Jesus' genetic make-up is irrelevant. Human perfection does not require one to be of Middle-Eastern stock and male. Jesus bore the image of God in his earthly life through the love which he had for his Father, love which was expressed in obedience, even to death on the cross. Jesus' relationship with his Father was seen in his times of prayer, in his understanding of God's will, and in his relationships with other people; bringing them God's healing, wholeness and hope. Only through this was Jesus not blaspheming to declare: "anyone who has seen me has seen the Father" and "The Father and I are one".[22]

There is a parallel (and yet a significant difference) to be found between the hopes of genetic enhancement and the promise of God's Holy Spirit. Perhaps we should concentrate not on DNA, but on the power of the Holy Spirit. Aiming not to bring about genetic modification, but rather spiritual transformation. Seeking not the products of genes which might change a person's character, but the love,

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21 Ch.3.3 (ii), above.

22 John 14.9 and John 10.30.

the humility, the prayerful-life, the insight, which are the fruits and the gifts of the Spirit. If human perfection is to be found in our reflecting the image of God, then genetic enhancement offers no hope at all, but the Spirit of God can bring about changes thought totally impossible.

It is also significant at this point to recall Frances Young's suggestions about the reflection of God's image being a communal project.[23] No individual reflects God's image on their own, but only in community with other, different, people. 'Perfection' will be found in variety rather than uniformity.

ii) Enhanced health

Even if we were to leave behind any thoughts of human perfection, then genetic enhancement can be seen as a means of enhancing human health. Genes could be used to increase resistance to infectious diseases, to offer protection from poisons or carcinogens, to delay or eliminate the debilitating effects of age. This is no striving for perfection, but an attempt to increase the health of the general population. Would this be a valid use of genetic enhancement?

a) The limitations of health

Good health has limitations. Even healthy people age and die. This is the natural process of life on earth, it is one of the realities of the created order. Life has a natural span and ends in death. To seek to prevent or treat disease (and its resultant pain and suffering) can be seen as working together with God. To seek to resist or overcome the limitations of ageing and death would be more like working to be as god.

A recognition of the limitations to health is expressed in the widespread criticism of the all-inclusive WHO definition.[24] To be healthy does not necessitate experiencing complete physical, mental and social well-being (such perfection is not possible). Wholeness, rather than health, is of most importance. A person can be whole despite the limitations of disability or disease.[25]

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23 Ch.5.4 (i) a, above.

24 Ch.5.3, above.

25 Ch.5.3 (iii), above.

b) Anticipation not prediction

The ultimate redemption of the world will involve both a restoration and a transformation of this world.[26] A foretaste of our restoration may be experienced in any medical technique which 'mends that which is broken' (recognising the limits of mechanistic language!). Gene therapy, restoring gene function, is thus seen as a foretaste of our ultimate redemption. The transformation element of redemption, however, will involve something so new it cannot be predicted. Prediction is not possible, but anticipation is.[27]

The anticipation of our coming redemption has already been given to us in Jesus Christ. We can continue this anticipation, in Christ, by continuing his work. Moltmann sees this in terms of two activities; identification and liberation. Anticipating God's kingdom involves identification with the victims of society's progress, rather than with those at the forefront of that progress. Thus an anticipation of God's kingdom will be achieved more by our identification with, and our representation of, the genetically disadvantaged, rather than our striving to join the genetic elite.

Anticipating God's kingdom also involves the work of liberation, the work of liberating others from exploitation, oppression and alienation. If genetic enhancement of health is available to all people equally, then perhaps there will be no need of such liberation. The far more likely scenario is that of rich, successful people being able to buy their own genetic health, which could in turn lead to the exploitation, oppression and alienation of those unable to afford such treatment. This would be working against, rather than anticipating, our future hope.

c) Salvation of, but not from, creation

A concept which may be crucial to our understanding of the morality of genetic enhancement is that of our ultimate salvation being 'of creation, not from creation'.[28] The Christian promise of redemption does not involve the redemption of human souls <u>from</u> the created order. Our redemption will not simply be a spiritual experience. It is not the case that human souls will somehow fuse or become united with God, and the rest of creation will disappear or become unimportant. Rather, the Christian eschatological hope involves hope for the <u>whole</u> <u>of</u> God's created order. Redemption will not just

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26 Ch.4.3 (ii) and Ch.4.4 (iv), above.

27 Ch.4.4 (v), above.

involve human souls, but also their bodies and the whole environment in which they live. This is why our bodies are important, and also why it is important that human beings exercise their responsibility of stewardship over creation.

In as much as we are able to anticipate redemption within history, this anticipation will necessarily mirror the pattern 'of creation, rather than from creation'. Thus if we are able to bring about anticipations of redemption through genetic manipulation - it could be understood that the redemption of creation would involve restoring that which is dysfunctional (i.e. gene therapy). Any attempts to 'improve' the genetic nature of humanity (i.e. genetic enhancement) could, by contrast, be understood as attempts to anticipate redemption from creation, and so should not be made. It could be argued that, if one understands our final redemption to involve "an end to death, and to mourning and crying and pain, for the old order has passed away"[29] then any genetic alteration which fights death will be an anticipation of this. However, such a suggestion fails to recognise that our final redemption is to involve something far more than an end to death, but rather it will be a fulfillment of our created structures.

6.5 Genetic alterations in somatic cells

All the trials for gene therapy which are currently being made, involve treating only those cells which are known as somatic cells. This means that none of the genetic alterations which are made can be passed on to any subsequent offspring. In the case of gene therapy for cystic fibrosis, only the mucus cells lining the lungs (and possibly the gut) will be altered.[30] To treat SCIDS through genetic manipulation, a child's bone marrow cells are removed, the extra DNA added, and then the bone marrow transplanted back. In neither case will the reproductive cells of the patient be affected. This approach is seen as being much safer, and to have far less implications in terms of eugenics. No difference is seen between this process and that of other medical treatments.[31] In reality, this method of gene therapy will have implications for the genetic make-up of future generations. The birth-rate of children suffering from genetic diseases may increase as parents see gene therapy as a successful form of treatment.

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28 See Ch.4.3 (ii), above.

29 Revelation 21.4.

30 The extra DNA is probably not even incorporated into the genome of the cells. (Storrar and Torrance (eds), *Human Genetics*, p.16).

31 Jones, *The Language of Genes*, p.294. The Catholic Bishops' Report, p.28.

Dysfunctional genes may be perpetuated in a population as people treated with somatic gene therapy live long enough to have children and pass on their faulty genes. Neither of these effects are likely to be hugely significant in numerical terms, and are therefore not sufficient to prohibit the use of somatic cell gene therapy. This is not necessarily the case when one comes to consider the manipulation of germ line cells.

6.6 Genetic alterations in germ line cells

Manipulating the genetic make-up of the reproductive cells of a person will necessarily affect their children, and subsequent generations. If the safety of this procedure could be guaranteed, would it be morally right to alter the genetic constitution of future generations? Utilitarian conclusions to this question have been presented.[32] A theological perspective from which to look at this issue, which offers moral guidance is needed.

Theologies of progress which suggest that humans are capable of contributing to the advancement of the world, even the world's ultimate salvation, are flawed.[33] They are over-optimistic about human capabilities, and fail to take into account the human condition. Human beings cannot of themselves help themselves.[34] However, the Christian story means that we need be neither over-optimistic nor over-pessimistic. The Christian story is a story of tragedy and of hope.[35] The tragedy is that human beings are limited creatures, we are not 'masters of the universe', the problems of our world will not be solved through changes to the human line of inheritance. The tragedy is that with the best of intentions we could easily cause more harm than good, unwittingly bringing changes to the human genome which would wreak havoc in future generations, we could deliberately use the power of genetic technology to harm others, through discrimination, oppression, even destruction. Yet there is hope. There is hope because we have the promise of ultimate redemption, because we can bring about anticipations of this redemption here and now in Christ. There is hope because we have before us both the possibility of changing our society (to be more caring, more open to disability and difference) and changing our genomes. The element of both tragedy and hope in the Christian story would seem to point

32 Ch.4.1, above.

33 Ch.4.2, above.

34 Ch.4.3, above.

35 Ch.5.4 (ii) b, above.

towards caution in advancement in terms of altering the genetic make-up of germ line cells. One way to keep this balance would be to limit germ line alterations to instances of single-gene changes for therapeutic purposes.

6.7 Recognising 'grey' areas

It is tempting to draw neat, clear-cut lines of moral guidance. Considering the anticipation but not prediction of redemption, that it is redemption of but not from creation, and considering the limited nature of health, one might conclude that it is appropriate to conduct gene therapy, but not genetic enhancement on individuals. Considering the theologies of progress, of realism and of anticipation, one might conclude that such therapy should be conducted in somatic but not germ line cells. This would provide moral guidance with a sound theological base and with clear boundaries. The reality, however, is that these boundaries are not always so clear. Genetic manipulation has grey areas just as many other moral issues do. These arise from difficulties in distinguishing between therapy and enhancement, and between somatic and germ line cells.

i) Distinguishing therapy from enhancement

There is an obvious difference to be seen between inserting an operational CF gene into the lung cells of someone suffering from cystic fibrosis, and inserting a gene promoting increased memory capacity into the brain cells of a 'normal' person. The former clearly involves therapy whilst the latter clearly involves enhancement. Other genetic manipulations may not be quite so clear-cut.

It may be possible to encourage the healing of severely broken bones by introducing, to the site of the break, multiple copies of a gene which occurs naturally and promotes healing.[36] In a similar way, it has been shown that genes (normally only active in embryos) injected into the legs of patients suffering from blocked arteries can stimulate the creation of new blood vessels, thus preventing gangrene and amputation.[37] A DNA-gel could be used to promote the growth of teeth in adults after loss due to injury or disease.[38] In each of these cases medical problems would certainly be treated, but in none would it be a simple matter of replacing a dysfunctional gene. The healing of the broken bones involves

36 "Broken bones heal better with DNA", *New Scientist*, 22.6.96.

37 "Gene cure unblocks arteries in the leg", *The Times*, 10.11.97.

38 "Teeth regrow to order", *The Sunday Times*, 28.2.99.

supplementing a functional gene. Promoting the growth of blood vessels, or of teeth, would involve turning on genes not normally functional during adult life. In a similar way it may be possible to treat cancer or AIDS through genetic manipulation involving the introduction of new sequences of DNA.[39] Are these situations to be understood as gene therapy or gene enhancement?

ii) Distinguishing somatic from germ line cells

In any particular case of gene therapy, it may be the intention simply to alter the genetic make-up of certain somatic cells, but it may also be inevitable that unintentionally germ line cells are also altered. To treat Duchenne muscular dystrophy with gene therapy would involve inserting enough copies of the dystrophin gene into all the muscles of the body. How will it be possible to ensure that the therapeutic DNA targets muscles cells and avoids reproductive cells?

This difficulty will particularly be the case in any examples of gene therapy involving foetuses or embryos. One of the American pioneers in gene therapy (French Anderson) has suggested that to conduct genetic manipulation on foetuses is likely to be far more effective than attempts after birth[40]. This is partly because of the small size of the foetus, and partly because cells which stop dividing after birth may still be dividing in the foetus.[41] Such early manipulation would be particularly useful for diseases which start to cause irreversible damage in the womb, for example Tay-Sachs. Suggestions have even been made that genetic manipulation could take place in embryos created through IVF and before implantation.[42]

6.8 Conclusions

The theology explored in chapters 3-5 has been applied to the principle of altering the genetic make-up of human beings, to gene therapy, genetic enhancement, and to the manipulation of somatic and germ line cells. Clear-cut distinctions between therapy and enhancement are not always possible. Equally, restricting some manipulations solely to somatic cells may be difficult to achieve. What conclusions are to be drawn?

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39 Ch.2.2 (ii) a, above.

40 "Catch them young", *New Scientist*, 27.6.98.

41 Some methods for introducing new DNA into cells depend on cell-division taking place.

42 Nelson, *On the New Frontiers of Genetics and Religion*, p.57.

i) The regulation of genetic manipulation

There is nothing wrong in principle with making alterations to the genetic make-up of human beings. This does not imply that everything that is possible is permissible. Realistic theology recognises the selfishness of human beings. Human nature tends to misuse power, for selfish reasons and at the cost of others. Genetic manipulation is a very powerful technology, containing the power to heal, to change, to discriminate, to elevate, and to dominate. Acknowledging human limitations in self-control and self-discipline, regulations need to be formulated to impose recognised restrictions to the use of this powerful technology. Therefore, I make suggestions, in the light of Christian theology, as to the form these regulations could take.

ii) The manipulation of somatic cells for gene therapy

In the case of a serious disease, caused by a single gene defect, having no effective alternative treatment, I conclude that somatic cell therapy would be an entirely appropriate treatment.[43] The medical technology is not greatly invasive and yet could be hugely effective. Such action would involve good stewardship of genetic knowledge, and an expression of love for one's neighbour.

'Gene therapy' should be regarded, not only as the introduction of 'good' genes to function in the place of defective ones, but also as the introduction of new genes, and the turning-on of genes not usually functioning at a particular stage of life, for the specific purpose of treating medical conditions.[44] Babies and children could receive gene therapy to their somatic cells, with the permission of their parents or guardians, in the same way as they can be given drugs or be operated on.

This form of manipulation will have no eugenic implications in the sense that no future generations will inherit the change. The use of gene therapy to cure monogenic diseases will benefit very few people (as the diseases are so rare). The perpetuation of their defective genes is unlikely to make a significant difference to a population. Nevertheless it would seem appropriate to offer genetic counselling to all recipients of somatic cell gene therapy when they consider having a family.

Educating the public with respect to the limitations of gene therapy will be important. Firstly, in connection with attitudes towards disability, and secondly, in connection with one's own responsibility to

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43 Compare *The Clothier Report*, 4.3-4.4, 7.4.

health. Gene therapy will not be a cure-all. There will still be disabled, diseased and deformed people living in our world. The fact that some people can be cured of a genetic disability must not affect our response to those who cannot be cured. All human beings are of worth, are capable of reflecting God's image, deserve to be loved as our neighbour. In this respect I would consider it immoral for the health profession or an insurance company to discriminate against a person of disability on the grounds that their parents chose not to terminate their life during pregnancy.

Many diseases which have a genetic factor also have environmental influences. It is not as simple as saying "I have gene X therefore I will develop disease x, and this can be cured by gene therapy". It is more like "I have gene X therefore I have an increased likelihood of developing disease x, especially if I am exposed to environmental factors Y and Z". The danger with gene therapy, is that people will assume that they can rely on it to avoid certain diseases. For the many cases of multifactorial diseases, it will be important to educate people to understand that taking responsibility for their environment is likely to have more effect on their health than any opportunities for gene therapy. Making the effort to exercise, to eat a healthy diet, to be a non-smoker, can have far more influence than genetic manipulation. Gene therapy cannot be a short-cut to health.

iii) The manipulation of somatic cells for genetic enhancement

Individuals already work hard to enhance their appearance and nature through a variety of means, surgery and hormonal treatment being the most invasive. In the light of this reality, I believe it would be consistent to allow genetic manipulation for enhancement purposes within limited situations.[45] These limitations would be that only somatic cells are treated[46], and only in consenting adults. In this sense the genetic manipulation becomes purely cosmetic. There should be no possibility that the enhancements could be passed to future generations, nor that enhancements could be inflicted on children without their knowledge or understanding.

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44 This begs the question of how to define a 'medical condition'. For all its limitations, perhaps the medical model of illness is the best one to use in this situation.

45 Contrast the recommendations made by *The Clothier Report* (7.5) and the BMA (*Human Genetics,* p.198). However, surgery is routinely accepted as a means of breast enhancement. If the same effect could be achieved safely with a hormonal cream, it would be welcomed. I do not believe that enabling breast tissue to generate its own hormone through the use of a DNA cream would be significantly different.

46 Recall the DNA may not even be incorporated into the cell's genome (note 30).

Genetic cosmetics will never be simple because of the complex genetic interactions involved, and the need for effective ways of introducing genes into specific cells. Possibilities in this area include; promoting the growth of a new set of teeth rather than having one's own capped and straightened, boosting one's metabolic rate and so decreasing the likelihood of laying down excess fat, preventing balding or greying hair. If it becomes possible to increase muscular bulk through genetic cosmetics this will have obvious implications for sports councils and competitions. DNA tests may become as widespread as those for drugs in competitors.

The use of genetic manipulation for cosmetic purposes is not ideal, it is likely to perpetuate society's hankering for perfection, and negative attitudes towards those not seen to be 'normal'. A far better emphasis would be that of the purpose of life. This cannot be legislated for, but the Church could reveal its value to society.[47]

There may be occasions when distinguishing between therapy and enhancement is difficult. This is crucial (in the manipulation of somatic cells) only in cases involving children. Gene therapy could be allowed following parental consent, genetic enhancement could not. Consider the gene for human growth hormone (hGH). Children lacking this gene will have severely stunted growth. The addition of the gene for hGH would involve gene therapy. Other children may have a normal hGH gene, yet their projected height (due to a variety of other genetic and environmental factors) may be considerably below average. Would it be therapy or enhancement to give these children extra copies of the hGH gene? Similarly, in future the gene(s) involved in skin colour may be identified. If a child is to be brought up in a racist area, would it be considered therapy or enhancement to alter her skin colour early in life? Short stature and dark skin do not in themselves constitute medical conditions, but it could be argued that the discrimination could affect mental health. To use genetic manipulation to escape discrimination, however, would not solve the problem, but rather perpetuate it. Therefore these are cases in which it is society which must be changed, not the genetic make-up of individuals.

Whenever there is a difficulty in distinguishing between therapy and enhancement, it would seem appropriate to err on the side of caution. Until evidence to the contrary, these cases should be considered as enhancement and therefore restricted to consenting adults.

iv) The manipulation of germ line cells for gene therapy

There will be some cases in which gene therapy needs to occur so early in life, or so extensively, that it will be inevitable that not only the somatic cells, but also the germ line cells of the patient are altered. It could be considered more effective to alter germ line cells anyway, to prevent the perpetuation of defective genes. The manipulation of germ line cells has obvious and far-reaching implications for future generations, implications to which these generations are incapable of giving consent.

The first questions one asks in relation to the manipulation of germ line cells are concerned with safety. Any negative effect in such manipulation cannot easily be retrieved, and may not be apparent until after a number of generations have passed. For this reason caution is encouraged. If one can be assured of the safety of such manipulation, what about the principle of altering the genetic make-up of future generations?

I conclude that germ line therapy would be an appropriate thing to do in the case of serious monogenic diseases. SCIDS, Tay Sachs, muscular dystrophy, cystic fibrosis, could be treated in this way, and the perpetuation of defective genes prevented. Theologically this would seem to be a way of anticipating (rather than predicting) our ultimate redemption, as the genetic manipulation is repairing the defective (not designing anew).

Possible alternatives to germ line gene therapy must always be kept in mind. Potential parents, both known to carry defective genes for a particular disease, do have alternative ways of having children free from genetic disease. They may choose to adopt, seeing the decision not to have their own children as the responsible stewarding of their particular situation. They may choose to have children via sperm and/or egg donation from non-carriers.[48] Tay Sachs disease, among the Ashkenazi Jews, illustrates the way genetic disease can be reduced through screening and genetic counselling.[49]

The limitations to germ line gene therapy must be acknowledged. Even if germ line manipulation were used in all cases known to need it, this would not eliminate monogenic diseases.

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47 See Ch.7, below.

48 The options of having their own children through IVF and screening the embryos before implantation, and of conceiving naturally but screening the developing foetus with a view to 'therapeutic abortion' are also currently available. These options depend on the assumption that it is better for an embryo or foetus to die than to develop into an individual with a genetic disease.

49 Ch.2.2 (i) b, above.

Imagine all those couples known to carry defective genes for a particular disease had their babies screened and subjected to gene therapy if necessary. This would reduce to nil those babies suffering from genetic disease born to known carriers. But one also has to take into account the spontaneous mutations which occur all the time in the germ cells of individuals. It has been estimated that about a third of the cases of Duchenne muscular dystrophy arise from new mutations[50]. The mothers of such children would not show up as carriers, it just so happens that one or more of their egg cells, in development, acquired the mutation which causes this disease. As genetic diseases become less prevalent (due to gene therapy) it would become less worthwhile to screen all babies for spontaneous mutations, by the time the symptoms begin to show it may be too late for gene therapy. Even germ line gene therapy will not rid the world of genetic disease.

If germ line gene therapy can be proven to be safe (through experiments with animals and our experience of somatic therapy in humans), then its use would seem appropriate in cases of serious monogenic diseases. Scientifically this will serve to prevent the perpetuation of defective genes, and often will be the only means by which any gene therapy can be achieved. Theologically it may be seen as an anticipation of our redemption, in restoring that which is defective. Alternative options to having a family which are open to carriers of genetic defects must not be forgotten. The limitations of germ line therapy will necessitate maintaining a positive attitude towards those who do suffer from genetic disease, and not abandoning research into alternative treatments.

v) The manipulation of germ line cells for genetic enhancement

The most extreme possibility of genetic manipulation in humans (barring cloning) is that of genetic enhancement to germ-cells. In order to maintain the advantage of any enhancements, individuals who have received new genes will need to inter-breed with each other. Otherwise the advantages will soon be diluted in the general population. The interbreeding of manipulated individuals will produce a genetic elite. There are some who see no objection to this concept,[51] but a number of theological reasons argue against it. These reasons include a realistic view of human limitations, matters of justice, and our ability to anticipate (but not predict) our redemption.

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50 Nuffield Council on Bioethics, *Genetic Screening - Ethical Issues*, p.109.

51 In particular Harris (*Clones, Genes and Immortality*, p.203f.) and Silver (*Remaking Eden*, p.236). Both argue that we control all other aspects of our children's lives.

Genetic manipulation is a very powerful tool, the most powerful expression of it could create a special breed of people. It is this form therefore which is most open to misuse. The tragedy of the intractability of human life has already been discussed.[52] As the power of nuclear fission was used to destructive ends, so too can the power of genetic manipulation be used. Human beings can be selfish, self-concerned, seeking to dominate rather than co-operate with those who are different. The possibility of creating people with special pre-ordained advantages will only serve to increase this tendency. Those with power and money will seek to perpetuate their advantages throughout the generations, to the detriment of all others. Genetic manipulation could also be used to create disadvantages. In a worst case scenario similar to *1984,* special breeds of people with reduced intelligence could be deliberately produced to create a work-force with no rights. To engineer elite stocks of human beings (or even disadvantaged stocks) would deny the Christian principles of justice, mercy and love. Particularly pertinent at this point is Moltmann's belief that the Christian is called to identify not with the strong and the successful, but with the victim.[53]

Our inability to predict the nature of redemption also argues against the genetic enhancement of germ line cells. There is no possibility of us manipulating our species closer to perfection, to fulfillment, to God. It is impossible to decide which genes are necessary for the 'perfect' person. God is going to do a 'new thing', a surprising thing, his final redemption of the whole world will be so different that it could never have been predicted. Our bodies will be included in this redemption, but it will not be achieved through any changes to our bodies. There are no simple genes for mercy, humility, love or self-sacrifice. These are qualities which cannot be genetically manipulated in a person, they are the fruit of the work of God's Holy Spirit.

In the light of the theology above, I conclude that human beings should never seek to genetically enhance germ line cells.

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52 Ch.5.4 (ii) b, above.

53 Ch.4.4 (v), above.

vi) Summary

1. The principle of modifying the genetic make-up of human beings is not in itself wrong.

In recognition of the 'intractability' of human nature, there needs to be legal limitations to the use of the technology.

2. The genetic manipulation of somatic cells for the purpose of treating medical conditions can take place, even in children with parental consent. This is an expression of good stewardship of our genetic knowledge, a means of loving our neighbour and working towards the restoration of creation.

3. Genetic enhancement in somatic cells requires individual, adult, consent. It should not be permitted in children. It is not ideal in as much as it will perpetuate society's striving for 'perfection', but having purely cosmetic effects, it can be left to individual choice.

4. Gene therapy which affects germ line cells should take place with caution, restricted to the treatment of serious monogenic diseases. The cautious approach recognises both the tragedy (human limitedness) and the hope (anticipations of redemption) of the Christian story.

5. Genetic enhancement which affects germ line cells should not be permitted under any circumstances. To do so would be to attempt to predict, rather than anticipate, our redemption. It would ignore the reality of the limitedness of humanity.

Having made suggestions regarding the regulation of gene therapy and enhancement, I turn in the final chapter to consider matters which cannot be subject to legislation. I offer suggestions to the Church of ways in which the Christian story can be applied practically, and positively, to the reality of human genetic difference.

Chapter 7: A POSTSCRIPT FOR THE CHURCH

7.1 Introduction

An exploration has been made of theological themes which help us to consider the moral issues raised by human genetic manipulation. This theology has been applied to the situations of gene therapy and enhancement, and suggestions have been made regarding the possible legal boundaries in using such technology. Legal limits are protective measures, guarding against dangerous or mischievous uses of genetic manipulation, they do not represent the ideal situation. Allowing the addition of genetic material in adults for cosmetic purposes has already been acknowledged as less than ideal.[1] Such action would perpetuate society's hankering for perfection in individuals. There are, however, situations which cannot be legislated against. It is illegal to discriminate against someone, in terms of employment opportunity, on the grounds of their race or their gender, but it is not illegal to harbour racist or sexist thoughts in one's heart. This chapter is written as a postscript to the Christian Church, to those who form the body of Christ on earth today. It is written to apply some of the theology which has been explored, but which cannot be incorporated into laws of this country. It is written for those people, touched by the Christian story of tragedy and hope, who seek to obey not just the law of the land, but also the two great commandments; to love their God and their neighbour.[2] Difference, disability and disease caused through genetic factors are the focus of this chapter, but matters discussed will obviously have implications for other areas too. The postscript begins with a consideration of purpose.

7.2 The meaning of life

For many people today 'meaning' is found in their lives through success, through achievement, through recognition, through being best. This results in those affected by disability and disease being marginalised.[3] These people are not expected to achieve much, they have no future, others find them difficult to relate to. But the Christian story of tragedy and hope reminds us that the goals of success and achievement are in reality meaningless. The tragedy of human existence is that we do not accept our

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1 See Ch.6. 8 (iii), above.

2 Mk.12.30f.

3 Vanier, *Becoming Human*, p.45f..

natural limits.[4] We reject the way which is best and the One who is perfect. The tragedy is that we try to do it our way, and it does not work. We are not in control, we cannot do everything, even that which we can do we tend to make a mess of. So the dreams of utopian master races result either in great suffering for those who do not 'fit', or in a weak, isolated, inbred group of people.[5] The 'sheer intractability of human life' means that perfection is not within our grasp.[6]

The story of hope, however, tells us that meaning is to be found not in success but in failure, not in strength but in weakness, not in perfection but in a recognition of our brokenness. Meaning is given to us, not through achievement, but through the grace, the unconditional love, the forgiveness and the mercy of God. Meaning is given because of the value which God gives to our lives despite ourselves. Meaning is found not in a C.V. full of achievements, but in the empty hands outstretched to receive from the abundance of God. Meaning is found as our lives reflect something of God, through our relationship of trust with him. Meaning is found as different members of the body of Christ together reflect the image of God.[7]

Through this story of tragedy and hope, those people whose lives are severely restricted through disability or disease, are seen to have no less meaning to their lives than those who are apparently successful. Those who are weakest may find it easiest to trust God, to live in relationship with him, to reflect his image to others.[8] Those who are most aware of their brokenness, are most in a position to receive. This understanding of meaning and purpose turns upside-down the standards of many in society around us. The Church has a vital role to play in living out this understanding; living it out for the sake of those in its midst who are more vulnerable, and also for the sake of society as a whole in challenging its values. What are the practical ways in which a local church can do this? What implications are there for those usually marginalised?

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4 See Ch.3.2 (ii), above.

5 See Ch.2.3 (ii) a, above.

6 See Ch.5.4 (ii) b, above.

7 See Ch.5.4 (i) a, above.

8 Vanier, *Becoming Human*, p.91f.

i) Towards the practice of meaning

If a local church is going to live its life believing that purpose is found not in being successful, but living a life of trust in God and reflecting his image to others, then changes may need to be made. The following suggestions are not exhaustive.

CO-OPERATION NOT COMPETITION

One human reaction to those who are different to oneself is that of competition.[9] If the meaning of human life is to be found in a relationship of trust with God, rather than in being better than everyone else, then this attitude of competition is empty and destructive. To live out this reality, local churches will need to let go of any desire to be a 'better, more successful' church. Often churches live as though they are competing with those around them, of the same, or different, denominations. We are affected by the success-orientated attitudes of society. To live in genuine mutual co-operation with other churches, not minding who gets the credit, or the extra members, would bear witness to the true meaning of the life of the church.

Competition can also occur within churches. Which house-group has the most members? Who invited the most people to the last evangelistic event? Which member of the choir has the best voice, and sings all the solos? Who leads the intercessions, arranges the flowers, reads the lessons the best? Who has the best job, runs the best car, has the best behaved children? Even if these questions are never articulated, they are asked in individual's hearts. To change the competitive attitude we inherit from society, to gain the Christian attitude of humility, mutuality and co-operation, will demand a change of heart. This change will come about when we discover anew our weakness, vulnerability and total dependence on God. Such a discovery can come about through genuine friendships with those who are more obviously weak and vulnerable (see below).

Competition can be expressed through jokes and ridicule at the expense of those who are different. Churches should be places of humour and fun, but such humour should never be expressed in order to put down others. To laugh about someone's big nose, bald head or excess weight is unchristian in itself, but also sets the precedent that one can also laugh at someone's mongoloid features, struggle to

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9 See Ch.3.5, above.

articulate or inability to control one's body. Attempts at fun would be far better made at laughing 'with' (and therefore including someone) than laughing 'at' (and excluding).

ENCOURAGING INVOLVEMENT

All members of a church are equally children of God, members of the body of Christ. Accepting that success and perfection are not important criteria for church life opens up an opportunity to enable all members to contribute to the life of the church. Receiving and valuing the contribution of all people, whatever their abilities, bears witness to their being part of the body of Christ.[10] It is not only the prominent or most obvious parts of the body, but also the weaker, humbler parts which have a vital contribution to make to the whole.[11]

In our church, a partially-sighted person has read aloud, albeit haltingly, by having script computer-printed in large type. The congregation listened much more attentively than to others who read beautifully. A person affected by Down's syndrome acts as server or crucifer in another church. The congregation has come to accept that things in the sanctuary do not have to be perfectly executed. A deaf person could 'read' or pray in sign language, and be interpreted into the spoken word. If contributions need to be made under supervision, welcoming people as they arrive, handing out service books, or helping with the offertory procession, are possibilities. Nor is it always in church services that members of the body of Christ have a contribution to make. Helping to distribute leaflets, folding the church magazine, looking after the gardens, helping in the kitchen, designing posters, would all add to the life of the church. There are many ways in which the church can recognise and value the contributions which all its members can make, thus helping them to feel they belong.

REMOVING BARRIERS

Many churches today make significant efforts to remove the physical barriers which exclude people from church life. Wheelchair ramps instead of steps, loop-systems to help those with deaf-aids, large-print hymn books for the partially-sighted, all help to include people. Sometimes, however, the barriers are more to do with peoples' attitudes than physical obstacles. People are made to feel unwelcome if their behaviour is unusual. Uncontrolled movements or noises are tolerated in babies, but

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10 Young, *Face to Face*, p.186.

11 ICor.12.12-27.

are often 'tutted', 'hushed' and not tolerated in a disabled child or adult.[12] Disruption can be even more difficult to accept from an adult who has hitherto been a 'respectable' member of the church. This change could result from a stroke, or the onset of Alzheimer's or Huntington's diseases. The church needs to recognise that it is not the perfection of worship, but the ways in which it can include all its members, which is important.

These are but a few examples of ways in which the local church can live out the belief that meaning is found not in success, but in a relationship of trust with God. To live in this way will result in the local church taking on a prophetic role within its local community, challenging others to examine their values. To live in this way will also bring about anticipations of the kingdom of God as we identify, not with the strong and successful, but with the weak and dependent.[13] Other ways in which the church can bring about these anticipations are examined below.

7.3 The Church and genetics

The church can minister to those affected by genetic differences, bringing about anticipations of God's kingdom, through being a befriending , a supporting and a celebrating church.

i) A befriending church

The church can play a vital role in a community through being a place in which genuine relationships can be built with people often marginalised by society.[14] The church can be a place where people of all abilities are welcomed, loved, included and valued. The development of true mutual friendships allows people to get behind the labels, coming to know others for who they really are.

There is often a fear in attempting to communicate with disabled or diseased people, because of uncertainty and not wanting to appear to fail.[15] In the safe environment of the church, where failure can be accepted, people can overcome their fear, and begin to receive as well as give. Intellectually disabled people are gifted in relationships, they have much to give in terms of love, trust and friendship.[16] The

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12 Marsha Fowler, *"The Church as a Welcoming Community"* in Kilner, Pentz and Young (eds), *Genetic Ethics,* p.246f. and Young, *Face to Face,* p.95.

13 See Ch.4.4 (v) and 4.5 (iii), above.

14 Moltmann, *The Power of the Powerless,* p.153.

15 Vanier, *Becoming Human,* p.76.

16 *Ibid,* p.2.

image of God is reflected by disabled people in a unique way, they can bring gifts of the Spirit to a church community not possible through more capable or successful people. Disabled people also help us to see our own weaknesses and dependencies, our own need to live a life of trust.[17] Forging such relationships, and including disabled people in church life will not be an easy process, and it will be important to be realistic about each others limits and failings.

There is much a church can receive by including in their fellowship those who usually are marginalised, and there is much the church can teach society through this process. Any situation which illustrates the value, and the contribution, of people with genetic handicaps, will challenge the attitude that such lives are not worth living.

ii) A supporting church

A church which proclaims the equal value of all people, which proclaims that everyone is loved unconditionally by God and called to love their neighbours, such a church will need to be a supporting church.

Support will be needed for those people caught up in the tragedies of genetic difference. The prospective parents who are faced with genetic knowledge which precipitates difficult decisions, and feel pressurised by the medical profession or 'what other people think'. The couple who choose not to have children because of their defective genes, and find it hard to remain childless. The parents who choose not to have their foetus genetically tested, or choose not to have a therapeutic abortion, and struggle to bring up their child suffering from Down's syndrome or cystic fibrosis. The parents who feel unable to care for a child with a disability, and so terminate their pregnancy, offer their child for adoption, or place their child in permanent care. All of these people will need of a variety of support. Emotional support; in someone to talk to and cry with. Practical support; in offers to sit-with, meals made, washing done, transport provided. Financial support; allowing special equipment, or holidays, or care to be provided. Spiritual support; in dealing with feelings of guilt, inadequacy, anger, grief and frustration. The church is a place which can offer this support through its prayer, through its welcome, through its friendship and ministry. The wider church can also play its part. The Church of Scotland has a number of centres which offer residential and respite care to young people with profound mental and physical problems, and their

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17 See Ch.5.4 (i) a, above.

families. They also provide care in small groups for adults who would otherwise be hospitalised for life.[18]

Support is also needed for those people at the 'other end' of genetic technologies; the doctors, genetic counsellors and research scientists. It is vital that these people are not regarded as 'baddies'. They have tremendous skill and knowledge, and do their best to use it for the benefit of individuals and populations. They have difficult decisions to make, bad news to impart, limitations to accept. They can also have great hope to offer, good news to tell, new treatments to try. As the church becomes aware of the role which genetics plays in our lives, it should also become aware of the need to support those developing and applying this technology. These people need patience, wisdom, humility, and many other spiritual gifts in order to do their jobs. They also need the prayers of the church, and the personal support offered wherever appropriate.

iii) A celebrating church

The Christian story of tragedy and hope is celebrated, and anticipated, regularly in the form of the Eucharist. As bread and wine is shared, the church is reminded of the tragedy and the hope in God's relationship with humanity, in particular through Jesus Christ. There is tragedy in the love spurned, the generosity taken for granted, the gifts misused. There is tragedy in the mistrust, the rejection, the betrayal, and the denial. There is tragedy in the broken body and the spilt blood. Yet, within this tragedy we see the unconditional nature of God's love, something which can never be earned or won. Within this tragedy we see God having entered into the brokenness and the suffering of this world, God going before us in all we experience. Within this tragedy we see God doing a new thing, something totally unexpected, something unpredictable, something which breaks into the tragedy and brings us hope.

We are given hope as we rejoice in Jesus' victory over death, recognising his resurrection as an anticipation of that which is in store for all. We are given hope as we come before God with empty hands, recognising our weakness and our failure, and recognising God as the One in whom we can trust. We are given hope as we eat the bread and drink the wine, recognising in our action an anticipation of the heavenly banquet still to come. We are given hope as we experience the healing presence of God,

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18 Storrar and Torrance (eds), *Human Genetics*, p.59.

recognising in our growth towards wholeness, anticipations of that day when all shall be made completely whole.

"Christ has died. Christ is risen. Christ will come again."[19] The tragedy and the hope. This is our story, this is our celebration. Whenever the church meets at the Lord's table, we are reminded that true meaning in life is found not in success and winning, but in weakness and dependence. We are nourished and fortified, that we may go on trusting in God and reflecting his image to the world. We are sent out, in the name of Christ, to love and serve the Lord.[20] Our love and our service can be expressed to, and with, those with genetic disabilities; through our prophetic inclusion of all in our church life, through our loving relationships which involve both giving and receiving, and through our support of those caught up in the tragedy and the hope of genetic difference. In the name of Christ, let us love and serve.

19 From "The Order for Holy Communion: Rite A", *The Alternative Service Book,* p.132.

20 *Ibid.* p.145.

Glossary

AID: artificial insemination by donor.

AIDS: acquired immune deficiency syndrome.

amniocentesis: a foetal test taken between the 14th and 16th weeks of pregnancy. A needle extracts fluid from the cavity surrounding the foetus, this fluid contains a small number of foetal cells which provide genetic material for analysis.

Ashkenazi Jews: Jews originally of central and eastern European descent. This ethnic group is particularly prone to the inherited **Tay Sach's** disease.

carrier: a person with one normal copy and one altered copy of a gene associated with a recessive disease. Carriers are unaffected by the disease, but can pass on the altered gene to offspring.

chorionic villus sampling: a foetal test taken between the 8th and 10th weeks of pregnancy. A needle removes a small number of cells from the developing placenta, these provide genetic material for analysis.

chromosomal abnormality: arises during the formation of reproductive cells, taking the form of duplication or deletion of entire chromosomes, or parts thereof. **Turner's** and **Down's syndromes** are examples.

congenital abnormality: found at birth or within a few weeks of birth. A genetic defect, chromosomal abnormality, or an environmental factor in foetal development may be the cause.

cystic fibrosis: a recessively inherited disease which affects mainly the Caucasian population (about 1 in 20 are carriers, and 1 in 2,000 births are affected). Lungs and digestive systems are dysfunctional, sufferers being particularly prone to chest infections. The average life span is about 30 years.

dominant: the form of inheritance in which a genetic disorder shows itself when only one of the two copies of the gene is abnormal (e.g. **Huntington's disease**).

Down's syndrome: a genetic condition due to the presence of an extra copy of chromosome 21. The seriousness of the condition varies, but is associated with specific physical characteristics and severe learning disabilities. The occurrence increases with maternal age, rising sharply for those over 35 years..

Duchenne muscular dystrophy: a disorder caused by a gene on the X chromosome, thus boys are affected, and girls act as carriers. Approximately 1 in 3,500 male births are affected. The disease is characterised by a progressive weakening of muscles and loss of coordination. The affect is first observed around 18 months of age, boys become wheelchair-bound and die in their early twenties.

eugenics: the science of improving the quality of a species through selective breeding. Positive eugenics encourages the perpetuation of 'good' characteristics, while negative eugenics seeks to prevent the perpetuation of 'bad' characteristics.

gene: a stretch of DNA occupying a fixed position on a chromosome, which contains the instructions for the production of a particular protein. There are about 100, 000 genes in the human genome.

genome: the total genetic material of an organism.

genotype: the genetic constitution of an individual organism.

germ cell: the cells from which reproductive cells develop (sperm cells in males, egg cells in females).

haemophilia: a group of blood disorders, in which the symptom is a reduced blood clotting ability. The disease is linked to the X chromosome and so affects males, and females are carriers. The most common type, haemophilia A affects about 1 in 10,000 live male births. Bleeding episodes can be limited by prompt infusion of the appropriate blood-clotting factor.

HFEA: The Human Fertilisation and Embryology Authority.

HGAC: The Human Genetics Advisory Commission.

Huntington's disease: a dominant disease which is lethal but does not begin to manifest its symptoms until middle age. Progressive dementia and loss of motor control result in death about 15 years after the onset of the disease.

IVF: in vitro fertilisation. That which occurs outside the body, in a 'test-tube'.

monogenic: a disease or characteristic which is controlled by, or associated with, a single gene.

phenylketonuria: (PKU) a recessive disorder affecting 1 in 10,000 live births. A missing or defective enzyme causes an inability to metabolise a particular substance, which in turn results in severe mental handicap. Screening all babies at birth, and following a strict diet for those affected, has reduced the effect of this disorder.

recessive: the form of inheritance in which both copies of a gene must be defective for the disorder to present itself. Those with a single copy of the defective gene are unaffected, and act as **carriers**.

SCIDS: severe combined immunodeficiency syndrome. A recessive condition, affecting 1 in 250,000 births, in which the ability to fight infection is lost. Infant death is inevitable without treatment, attempts at which have included sterile living conditions, bone-marrow transplants or injections of the lacking enzyme.

sickle cell disease: a recessive disorder most common in those of African origins, affecting 1 in 400 African-Americans. An abnormality in haemoglobin causes the red blood cells to be misshapen. These cells are destroyed by the body, causing amaemia, or may block blood vessels and cause other complications. Death in early adulthood is likely.

somatic cells: all body cells except the **germ cells** and the reproductive cells to which they give rise.

Tay Sachs disease: a lethal, recessive disease occurring most commonly in **Ashkenazi Jews** (where it occurs in 1 in 3,600 live births). Developing a few months after birth, progressive mental and physical deterioration lead to death by the age of 6.

thalassaemia: a recessive disorder affecting haemoglobin production for red blood cells. The most severe cases cause still births. The less severe cases develop chronic anaemia which can be treated with blood transfusions or bone marrow transplants.

transgenic organism: one whose genetic material contains DNA from a foreign source which has been inserted artificially using genetic manipulation.

Turner's syndrome: a chromosomal disorder in which girls have only one X chromosome, rather than the usual two. It occurs in 1 in 5,000 girls, and causes short stature and heart defects. Intelligence is usually normal.

Bibliography

BOOKS

The Church of England. *The Alternative Service Book 1980.* London, Hodder & Stoughton, 1980.

Abrecht, Paul (ed.) *Faith Science and the Future.* Geneva, World Council of Churches, 1978

Barbour, Ian. *Ethics in an Age of Technology* (Gifford Lectures, Vol.2). London, SCM, 1992

Bauckham, Richard. *The Theology of Jürgen Moltmann.* London, SCM, 1995.

Berkouwer, G.C. *Man: in the Image of God.* Grand Rapids, Eerdmans, 1962. Chapter 3; "The Meaning of the Image".

Bonner, Gerald. *St Augustine of Hippo: Life and Controversies.* Norwich, The Canterbury Press, 1986.

British Medical Association. *Human Genetics: Choice and Responsibility.* Oxford, Oxford University Press, 1998.

Brunner, Emil and Barth, Karl. *Natural Theology: Comprising 'Nature and Grace' by Professor Dr. Emil Brunner and the reply 'No!' by Dr. Karl Barth.* Trans. Fraenkel, Peter. London, Geoffrey Bles: The Centenary Press, 1946

Burley, Justin (ed). *The Genetic Revolution and Human Rights: The Oxford Amnesty Lectures 1998.* Oxford, Oxford University Press, 1999.

Cameron, Nigel M de S. *The New Medicine.* Sevenoaks, Hodder & Stoughton, 1991

Clark, William. *The New Healers.* Oxford, Oxford University Press, 1997

Cole-Turner, Ronald (ed). *Human Cloning: Religious Responses.* Louisville, Westminster John Knox Press, 1997

Deane-Drummond, Celia. *Genetic Engineering for a New Earth.* Cambridge, Grove Books, 1999.

Deane-Drummond, Celia. *Theology and Biotechnology: Implications for a New Science.* London, Geoffrey Chapman, 1997

Dixon, Patrick. *The Genetic Revolution.* Eastbourne: Kingsway, 1993

Dobzhansky, Theodosius. *Heredity and the Nature of Man*. London, George Allen & Unwin, 1965.

Dobzhansky, Theodosius. *The Biology of Ultimate Concern*. New York, New American Library, 1967.

Eiesland, Nancy L. *The Disabled God: Toward a Liberatory Theology of Disability*. Nashville, Abingdon Press, 1994.

Fletcher, Joseph. *The Ethics of Genetic Control: Ending the Reproductive Roulette*. New York, Anchor Books, 1974

Harris, John. *Clones, Genes and Immortality: Ethics and the Genetic Revolution*. Oxford, Oxford University Press, 1998

Harrison, Ted. *Disability: Rights and Wrongs*. Oxford, Lion, 1995

Hauerwas, Stanley. *Naming the Silences: God, Medicine and the Problem of Suffering*. Edinburgh, T&T Clark, 1990

Hauerwas, Stanley. *Suffering Presence*. Edinburgh, T&T Clark, 1988

Hauerwas, Stanley. *Truthfulness and Tragedy*. Notre Dame, University of Notre Dame Press, 1977

Illich, Ivan. *Limits to Medicine*. London, Marion Boyars, 1976

Jones, D.Gareth. *Brave New People*. Leicester, InterVarsity Press, 1984.

Jones, Steve. *The Language of the Genes*. London, Flamingo, 1994

Junker-Kenny, Maureen, and Sowle Cahill, Lisa (eds). *The Ethics of Genetic Engineering*. *Concilium*, 1998/2. London, SCM, 1998

Kilner, John, Cameron, Nigel M de S and Schiedermayer, David L. (eds). *Bioethics and the Future of Medicine*. Carlisle, Paternoster, 1995

Kilner, John, Pentz, Rebecca and Young, Frank (eds). *Genetic Ethics: Do the Ends Justify the Means?* Carlisle, Paternoster, 1997

Kimbrell, Andrew. *The Human Body Shop: The Engineering and Marketing of Life*. London, Harper Collins, 1993

Küng, Hans. *Eternal Life?* Trans. Quinn, E. London, SCM, 1984.

Lammers, Stephen E. and Verhey, Allen (eds). *On Moral Medicine: Theological Perspectives in Medical Ethics*. Grand Rapids, Eerdmans, 1987

Linzey, Andrew. *Animal Theology*. London, SCM, 1994.

Loades, Ann. *Feminist Theology: A Reader*. London, SPCK, 1990. Ch.20, Farley, Margaret, "Feminist Theology and Bioethics".

McCormick, Richard A. *How Brave a New World?: Dilemmas in Bioethics*. London, SCM, 1981

McFague, Sallie. *The Body of God*. London, SCM, 1993

McFague, Sallie. *Super, Natural Christians: How we should Love Nature*. London, SCM, 1997

McKenny, Gerald. *To Relieve the Human Condition: Bioethics, Technology, and the Body*. New York, State University Press, 1997

MacKinnon, Donald. *Explorations in Theology* (5). London, SCM, 1979

Mehlman, Maxwell J. and Botkin, Jeffrey R. *Access to the Genome: The Challenge to Equality*. Washington DC, Georgetown University Press, 1998

Meilaender, Gilbert. *Bioethics: A Primer for Christians*. Carlisle: Paternoster, 1997

Midgley, Mary. *Science as Salvation: A Modern Myth and its Meaning*. London, Routledge, 1992

Moltmann, Jürgen. *God in Creation: An Ecological Doctrine of Creation*. (The Gifford Lectures 1984-1985). London, SCM, 1985

Moltmann, Jürgen. *The Future of Creation*. London, SCM, 1979

Moltmann, Jürgen. *The Power of the Powerless*. London, SCM, 1983

Moltmann-Wendel, Elisabeth. *Autobiography*. London, SCM, 1997

Moltmann-Wendel, Elisabeth. *I am My Body: New Ways of Embodiment*. London, SCM, 1994.

Nelson, J.Robert. *On the New Frontiers of Genetics and Religion*. Grand Rapids, Eerdmans, 1994

Niebuhr, Reinhold. *Faith and History: A Comparison of Christian and Modern Views of History.* New York, Charles Scribner's Sons, 1949

O'Donovan, Oliver. *Begotten or Made?* Oxford, Clarendon Press, 1984

O'Donovan, Oliver. *Resurrection and Moral Order: An Outline for Evangelical Ethics.* Leicester, InterVarsity Press, 1986

Pattison, Stephen. *Alive and Kicking: Towards a Practical Theology of Illness and Healing.* London, SCM, 1989

Polkinghorne, John. *Science and Christian Belief: Theological Reflections of a Bottom-Up Thinker.* London, SPCK, 1994.

Radford Ruether, Rosemary. *Gaia and God: An Ecofeminist Theology of Earth Healing.* London, SCM, 1993

Radford Ruether, Rosemary. *Sexism and God-Talk: Towards a Feminist Theology.* Boston, Beacon, 1983

Rahner, Karl. *Theological Investigations Vol.9,* Ch.14, "The Problem of Genetic Engineering". London, Darton, Longman & Todd, 1972

Rahner, Karl. *Theological Investigations, Vol.21,* Ch.1, "Profane History and Salvation History". London, Darton, Longman & Todd, 1988.

Ramsey, Paul. *Basic Christian Ethics.* London, SCM, 1950

Ramsey, Paul. *Fabricated Man: The Ethics of Gentic Control.* New Haven, Yale University Press, 1970

Ramsey, Paul. *The Patient as a Person: Explorations in Medical Ethics.* New Haven, Yale University Press, 1970.

Rifkin, Jeremy. *The Biotech Century: Harnessing the Gene and Remaking the World.* London, Victor Gollancz, 1998

Russo, Enzo and Cove, David. *Genetic Engineering: Dreams and Nightmares.* Oxford, OUP, 1998

Silver, Lee. *Remaking Eden: Cloning and Beyond in a Brave New World.* London, Weidefeld & Nicholson, 1998

Singer, Peter and Wells, Deane. *The Reproduction Revolution: New Ways of Making Babies.* Oxford, OUP, 1984.

Spallone, Pat. *Generation Games: Genetic Engineering and the Future for our Lives.* ?, The Women's Press, 1992

Storrar, William and Torrance, Iain (eds). *Human Genetics: A Christian Perspective.* (A Church of Scotland Board of Social Responsibility Publication). Edinburgh, Saint Andrew Press, 1995

Teilhard de Chardin, Pierre. *Christianity and Evolution.* London, Collins, 1971

Teilhard de Chardin, Pierre. *Hymn of the Universe.* Glasgow, Fount Paperback, Collins, 1977

Teilhard de Chardin, Pierre. *The Phenomenon of Man.* London, Fontana, 1965

Teilhard de Chardin, Pierre. *Toward the Future.* London, Collins, 1975

Vanier, Jean. *Becoming Human.* London, Darton, Longman and Todd, 1999.

Vanier, Jean. *The Challenge of l'Arche.* London, Darton, Longman and Todd, 1982.

Ward, Keith. *God, Faith and the New Millennium: Christian Belief in an Age of Science.* Oxford, Oneworld, 1998

Watson, James. *The Double Helix.* London, Penguin, 1970.

Wilkie, Tom. *Perilous Knowledge: The Human Genome Project and its Implications.* London, Faber & Faber, 1993

Wright, N.T. *New Heavens, New Earth: The Biblical Picture of Christian Hope.* Cambridge, Grove Books, 1999.

Wyatt, John. *Matters of Life and Death: Today's healthcare dilemmas in the light of Christian faith.* Leicester, InterVarsity Press, 1998.

Young, Frances. *Face to Face; A narrative essay in the theology of suffering.* Edinburgh, T&T Clark, 1990.

REPORTS

Board of Social Responsibility, Church of Scotland. *Report to the General Assembly 1998*. Edinburgh, St Andrew Press, 1998

Cloning Issues in Reproduction, Science and Medicine - A Consultation Document. The Human Genetics Advisory Commission and the Human Fertilisation and Embryology Authority. January 1998.

Cloning Issues in Reproduction, Science and Medicine - A Report from The Human Genetics Advisory Commission and the Human Fertilisation and Embryology Authority. December 1998.

Genetic Intervention on Human Subjects. The Report of a Working Party of the Catholic Bishops' Joint Committee on Bioethical Issues. (The Catholic Bishops' Report) London, The Linacre Centre, 1996.

Genetic Screening - Ethical Issues. Nuffield Council on Bioethics. 1993.

Report of the Committee of Inquiry into Human Fertilisation and Embryology. (The Warnock Report) HMSO, 1984.

Report of the Committee on the Ethics of Gene Therapy. (The Clothier Report) London, HMSO, 1992.

The Church among Deaf People. A Report prepared by a Working Party of the Committee for Ministry among Deaf People for the General Synod of the Church of England's Advisory Borad of Ministry. London, Church House Publishing, 1997.

ARTICLES

"Consumer response to Clothier". (Review article). *Bulletin Medical Ethics* June 1992, p.13-20.

O'Donovan, Joan E. "Man in the Image of God: The Disagreement between Barth and Brunner Reconsidered", *Scottish Journal of Theology* (39), 433-459, 1986.

Shakespeare, Tom. "Eugenics? Slipping down the slope", *Splice*, Vol.5, Issue 2, Dec.1998/Jan.1999.

White, Lynn Jr. "The Historical Roots of our Ecological Crisis", *Science*, (155), 1967, p.1203-1207.