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People with Down Syndrome - Part of Our Community

This article briefly examines the history and genetics of Down syndrome. Contemporary prenatal testing practices are described as is the effect of testing on the birth prevalence of children with Down syndrome. The analysis of a series of articles on families with a child with Down syndrome provides a touching insight into these families. It demonstrates that each person – including those with Down syndrome – make a unique and valuable contribution to their family and the world.

People with Down syndrome are a part of all races and ethnicities and all socio-economic groupings. It is the most common chromosomal condition diagnosed in infants and is linked to physical and intellectual disability, occurring in approximately one in every 700 to 900 births worldwide.¹

History

Down syndrome was first described by a physician named John Langdon Down in 1866, in an essay in the London Hospital Reports.² In this report he noted that the physical appearance of some of his patients was so similar that they could have been siblings. Unfortunately, by the beginning of the twentieth century the term Mongolism was widely utilised to label those first described by John Down. In 1961 the *Lancet* published a letter from a group of genetic experts asking that the designation of the term Mongoloid no longer be assigned to this group of people.³ Of the alternatives provided to the *Lancet* editor, Down's syndrome⁴ was chosen. The World Health Organisation endorsed this change in 1965 after the People's Republic of Mongolia contacted the Director General with their concerns regarding the use of the unacceptable term "Mongolian Idiot."⁵ Down is described by both Ward and Wiedemann as a man who advocated for those who were excluded from society, and who genuinely cared for those in his care - a fitting person to have a syndrome named in his honour.⁶ It was in the 1950s that it was discovered Down syndrome was caused by the presence of three copies of chromosome 21.⁷

Genetics

In all human cells there are 46 chromosomes, 23 pairs, except for human gamete (egg and sperm) cells which contain one of each chromosome pair, thus they have 23 chromosomes. The chromosome pairs are numbered by size from 1 to 22 and there is one pair of sex chromosomes. In a female the sex chromosomes are XX, and in a male they are XY. A person with Down syndrome has 3 copies of chromosome 21, so, therefore, they have

47 chromosomes, instead of the usual 46 found in most of the population. When this extra chromosome 21 is present in all of the cells a random error in the chromosome division may have occurred during the production of a gamete cell, or at fertilisation. This is the case for 95% of people with Down syndrome. In 1% of cases an error in chromosome distribution during cell division after fertilisation, results in some of the cells of a person having 46 chromosomes and other cells having 47 chromosomes. This is known as mosaic Down syndrome.⁸ In the other 4% of cases the extra chromosome 21 is translocated (attached) to another chromosome. This form of Down syndrome can be inherited and is known as the translocation type of Down syndrome, where a person has three copies of chromosome 21, with two being individual copies and the third copy is attached to another chromosome.⁹ It is now realised that older mothers have babies with Down syndrome with greater frequency than other mothers as meiotic nondisjunction (random errors in cell division) increases with age.¹⁰

Each person with Down syndrome is unique just as each of us who do not have Down syndrome is unique. They will have their own personality, likes and dislikes, gifts and talents. Just as every person's genetic makeup partly determines their physical characteristics and health, the genetic makeup for a person with Down syndrome partly determines their physical characteristics and health issues,

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some of which are particular to a person with Down syndrome. For a person with Down syndrome, there is some level of intellectual disability which results in some delays in physical and intellectual developmental with a degree of learning disability. However, as with all of us who learn and succeed at different levels, the significance of the disability will vary in each individual person and outcomes are often shaped by what happens to a person after birth.

If not diagnosed pre-natally, a child with Down syndrome can often be recognised at birth and the diagnosis is confirmed by a blood test.

Prenatal Testing

Pre-natal testing is divided into screening, diagnostic and pre-implantation testing. Screening tests in early pregnancy (ultrasound, nuchal translucency ultrasound with or without testing of the mother's blood) and second trimester testing that screens the mother's blood, can identify a child that may have an increased risk of an abnormality. If nuchal translucency is done without a blood test, about 75% of children with Down syndrome have an increased risk result and 25% will not be identified. With a blood test, 80-90% of children with Down syndrome will have an increased risk result, and 10-20% will not be identified.

A result from a screening test indicating an increased risk of an abnormality can place the parents in the position of deciding whether or not to proceed with diagnostic testing. Chorionic villus sampling (CVS) performed at 10-12 weeks, tests chorionic villus (placental tissue) or chorion, or amniocentesis performed at 16 weeks, tests amniotic fluid. These tests can provide a reliable answer to certain concerns parents may have regarding their unborn child. In both CVS and amniocentesis the child's cells are tested and if present Down syndrome can be confirmed. There is a less than 1% risk of miscarriage with both tests.¹¹

Pre implantation genetic diagnosis (PGD) testing is available under certain restrictions.¹² These restrictions do not allow PGD to be used for the prevention of conditions that do not seriously harm the person to be born.¹³

Many in the community are concerned that pre-natal testing will only lead to the termination of a pregnancy. This concern may be justified if alternatives to termination are not presented to the couple or they are encouraged to think that this may be the only choice they have. This is particularly so, if there is little guidance offered to understand the significance of prenatal testing prior to the couple undertaking the testing. The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), *Guidelines on pre-natal for trisomy 21, and 18 as well neural tube defects*, states that pre-natal testing should begin with pre-testing counselling and information, with follow-up post-test interpretation, counselling and support during decision making.¹⁴ Although termination is noted as an option, the

continuation of pregnancy as a valid option is also noted, as well as care in preparation for birth. Why then does Kirsten Deane need to take up a challenge to the medical profession in *The Age* that the medical profession is "denying parents a real choice about Down syndrome babies?"¹⁵ Deane questions whether couples fully understand pre-natal testing and its possible implications. Does the referral for pre-natal testing include the pre-testing counselling as recommended by RANZCOG so that an informed choice can be made? The Victorian Law Reform Commission, *Law of Abortion: Final Report* comments: "As a community we have probably not yet directly confronted the full social ramifications of the increased use of fetal testing."¹⁶ As women delay the beginning of their childbearing years, pre-natal testing which was generally only offered to those over 35 years of age is now becoming almost routine, as the RANZCOG prenatal testing statement notes, "All pregnant women should be advised of the availability of prenatal testing."¹⁷

Provided certain criteria are satisfied, prenatal testing is accepted by the Catholic Church. *Donum Vitae (Respect for Human Life in Its Origin and on the Dignity of Procreation)*, states, "If prenatal diagnosis respects the life and integrity of the embryo and the human fetus and is directed toward its safeguarding or healing as an individual, then the answer is affirmative."¹⁸ Further in *Evangelium Vitae (The Gospel of Life)*, prenatal testing is accepted, "when they do not involve disproportionate risks for the child and the mother, and are meant to make possible early therapy or even to favor a serene and informed acceptance of the child not yet born."¹⁹ Both of these statements value prenatal testing in being able to inform prospective parents to prepare for the birth of their child. If the birth brings challenges then parents have been provided with the time to educate themselves and if required at the birth of their child, have ready a medical team to provide the highest quality care for the best outcome for their child.

Birth Statistics

Approximately 92% of women from five countries who were given a definitive prenatal diagnosis that their child had Down syndrome elected to terminate their pregnancy.²⁰ The study by Loane et al of European pregnancy and birth statistics from 1990-2009 concluded that the increase in maternal age in Europe has seen an increase in the prevalence of pregnancies with a child with Down syndrome (as well as other trisomies). In countries where terminations are accepted on the basis of a prenatal diagnosis of a foetal abnormality the number of terminations due a diagnosis of Down syndrome was greater than or equal to 80%, except the Ukraine where it was 58%.²¹ However, the birth prevalence remained constant since 1990, with a steady increase in births to mothers aged over 35 years from 13% in 1990 to 19% in 2009.²²

Collins et al reviewed Victorian data from 1986 to 2004 to determine the number of babies born with Down

syndrome. As with the European study by Loane et al, the increase in maternal age has had a substantial effect on the pregnancy prevalence of Down syndrome. The number of births decreased between 1986-1996, however, since then the birth prevalence has stabilised fluctuating between 45-60 births.²³ With prenatal testing being more widely available to all age groups, the birth prevalence dropped quite dramatically in the under 35 age group from 60 in 1986 to 22 in 2004. For the same period birth prevalence in those older than 35 years was stable at 25 births in 1986 to 26 in 2004.²⁴ Over the study period, only 5.3% of pregnancies with a prenatal diagnosis of Down syndrome were not terminated.²⁵

A Child With Down Syndrome In Our Family

Brian Skoto et al in 2011 published a series of articles in the *American Journal of Medical Genetics* on Down syndrome. He evaluated responses from parents and siblings who have as a member of their immediate family a person with Down syndrome. He also evaluated the responses from a self-perception aspect of the person with Down syndrome. One of the aims of these studies was to provide information to share with new and expectant parents of a child with Down syndrome.²⁶

Probably the most important comment in these articles was that mothers who have a child with Down syndrome could recall with 82% accuracy the original words utilised by their doctor to describe their child's diagnosis.²⁷ This illustrates how words can be influential, and can have a resounding effect on the couple, with the content sometimes determining the decision to continue a pregnancy or to terminate a pregnancy. Whether the information is relevant, historically correct, or accurate, these words are powerful as they provide the information a lifetime's decision is made upon. Hodgson and Spriggs suggest that body language and word choices can be directive when providing information to expectant parents.²⁸ Sheets et al recommends information should be provided in a respectful and supportive manner and information is balanced with what a child can achieve as opposed to what a child will not be able to achieve.²⁹

The studies by Skoto et al interviewed over more than 2000 parents from six US, with almost all parents responding that they love their child and find themselves proud of their child's accomplishments. Parents themselves have learnt "patience, acceptance, and flexibility" and have become more "tolerant, kind and empathetic." "Laughter, joy and celebration" were regularly noted as important aspects of their family life. How proud a parent felt about their child's achievements was not linked to the independence of their child. Parents also believed that their other children's lives were enhanced by their sibling with Down syndrome, that it was a positive sibling relationship and was not marred by a child who had more complex health problems. While approximately 11% of parents felt their marriage was under some strain parenting a child with Down syndrome, only 4% regretted having their child: this was

mainly found in parents of older children with Down syndrome. Skoto et al suggest that this may be because these children had fewer social and educational opportunities and less support than is offered to a child with Down syndrome in recent times.³⁰

When compared to a set of matched controls, siblings who had a brother or sister with Down syndrome, displayed more "empathy and kindness," and "less conflict and more warmth in their relationships."³¹ Less than 10% were embarrassed by their sibling. Less than 5% would swap for a brother or sister who did not have Down syndrome. Eighty-eight per cent felt they were better people. As siblings became older they took on more responsibility for their sibling with Down syndrome. They did not see this as a burden, but regarded it as a positive experience.³² The most popular information that these brothers and sisters of a child with Down syndrome wanted to give to expectant parents was that they wanted to let them know of the "joy and rewards that would come with having family member with Down syndrome."³³

Lastly Skoto sought information from those who were born with Down syndrome. Two hundred and eighty-four people over the age of 12 were interviewed. Almost 99% said they were happy with their lives and a similar number expressed love for their families. A small percentage expressed sadness about their life and approximately 14% felt they couldn't make friends easily. Most significantly these people wanted to encourage parents to love their baby with Down syndrome as their baby with Down syndrome would love them. They also wanted health professionals to value them, as just like all humans they have their own hopes and dreams.³⁴

Further....

A reading of Jan Gothard's book *Greater Expectations – Living with Down syndrome in the 21st century* provides many examples of families who live with a person with Down syndrome on a daily basis.³⁵ A number of contributors were families who did not follow medical advice of a generation ago and kept their children within their family unit and thus began the battle to have their children accepted as contributing members of society. These families as well as families of children born in recent decades have fought for the right for their children to attend mainstream school, to access health services irrespective of the health professional seeing their child's syndrome before the fact that they are a child, and for them to become full and active participants in the communities in which they live.

A number of these families had prenatal testing and continued with their pregnancy. They have fought hard and long to achieve what they have for their children, to begin the change in society's perception that a person with a disability can be active within society, with support and acceptance. Let us hope that this information can be passed onto those who have a child diagnosed with Down syndrome, so they can continue to be part of

this legacy of encouraging participation of all in our communities.

Conclusion

There is a well known tale by Emily Perl Kingsley of preparing during your pregnancy to travel to Italy. You

find that on completion of your journey your flight path changed and you disembarked in Holland. You are not prepared for this new location.³⁶ However, those who have fought for people with Down syndrome to be included have found the joy in Holland, they have enabled the tulips to blossom. Let them continue to do so.

Down Syndrome Resources

Down Syndrome Victoria	www.downsyndromevictoria.org.au/
Down Syndrome Association Queensland	www.dsaq.org.au/
Down Syndrome Association NSW	www.downsyndromensw.org.au/
ACT Down Syndrome Association	actdsa.org.au/
The Down Syndrome Association of WA	dsawa.asn.au/
Down Syndrome Association N.T.	www.rapidcreekbusinessvillage.com/index.php/tenants/66
Down Syndrome Tasmania	www.downsyndrometasmania.org.au/
Down Syndrome Society of South Australia Inc	www.downssa.asn.au/
Club 21 (Adult group)	http://www.downsyndromevictoria.org.au/DSAV/My_Voice/Club_21/DSAV/MyVoice/Club_21.aspx#.UMefSqxU18E
e.motion21 (Dance group)	emotion21.org.au/about
Jan Gothard	<i>Greater Expectations – Living with Down syndrome in the 21st century.</i> Fremantle: Fremantle Press, 2010.

ENDNOTES

¹ Down Syndrome Victoria, “Information - What is Down syndrome?” Down Syndrome Victoria, http://www.downsyndromevictoria.org.au/DSAV/Information/About_Down_syndrome/What_is_Down_syndrome/DSAV/Information/What_is_Down_syndrome.aspx?hkey=8593b017-ec7a-47f1-b949-e7e9801b4c39

² J. Langdon H. Down, “Observations on an Ethnic Classification of Idiots,” *London Hospital Clinical Lecture Report* 3 (1866): 259-262, <http://th-hoffmann.eu/archiv/down/down.1866b.pdf>

³ O. Conor Ward, “John Langdon Down: The Man and the Message,” *Down Syndrome Research and Practice* 6, no. 1 (1999): 19-24 at 20. Almost all people with Down syndrome have a slight upward slant of the eyes. There can also be a small fold of skin on the inside of the eye (epicanthic fold), similar to that found in some Asiatic races. Mongolism was a term designated to the group of people originally described by John Langdon Down in his original paper which he based on the work of Blumenback who attempted to classify the races of the world.

⁴ The name officially became Down syndrome after a change in name was considered in 1974 at a conference held at the US National Institute of Health, “The possessive form of an eponym should be discontinued, since the author neither had nor owned the disorder.” Gradually other countries embraced the naming protocol for all diseases and conditions established at this conference. Len Leshin, “The “Mongol” Debate,” *Down Syndrome: Health Issues*, <http://www.ds-health.com/>

⁵ Ward, 22.

⁶ Ibid., 23: H. K. Wiedemann “The Pioneers of Pediatric Medicine – John Langdon Down (1828-1896),” *European Journal of Pediatrics* 151, (1992): 137.

⁷ Three copies of a chromosomes instead of the usual two in a cell is known as a trisomy.

⁸ The number of cells or organs of the carrying the extra chromosome 21, may affect the characteristics of the condition. Centre for Genetics Education, “Trisomy 21 Down Syndrome - Fact sheet 28,” *The Australasian Genetics Resource Book* - © 2007, www.genetics.edu.au

⁹ Ibid. When translocations are inherited, the mother or father is a balanced carrier of the translocation. This means that one of the parent’s chromosomes are not arranged in the typical format and but they do not carry any extra chromosomal material. A balanced carrier has no signs or symptoms of Down syndrome, but he or she can pass the translocation on to children.

Translocation type of Down syndrome is a Robertsonian location which is where the chromosomal material is exchanged between chromosomes 13,14, 12, 21 and 22. For example a balanced translocation can be when one copy of chromosome 21 may have attached itself to chromosome 14, but the person still has two copies of 21 and two copies of 14, thus their chromosomal material is balanced, or just re-arranged. Down syndrome results when two normal copies of chromosome 21 are inherited as well as a chromosome (usually 14 or 15) that has a translocated 21. Centre for Genetics Education, “Changes to Chromosome Structure- Translocations - Fact sheet 7,” © Centre for Genetics Education, www.genetics.edu.au

¹⁰ Disjunction is the name given to the process when each pair of chromosomes split during meiosis (the process of halving of the number of chromosomes to produce gametes – sperm and eggs). In non-disjunction this process is not successfully completed and random errors occur.

¹¹ Centre for Genetics Education, “Prenatal Testing - Fact sheets 17 & 17c,” © Centre for Genetics Education, May 2012,

www.genetics.edu.au

¹² PGD is available to some women undergoing IVF treatment. It involves, one or two cells being removed from the developing embryo at either day 3 or day 5 for testing.

¹³ Australian Government, National Health and Medical Research Council, *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research 2004 (As revised in 2007 to take into account the changes in legislation)*, (Canberra: Commonwealth of Australian, June 2007), 55.

¹⁴ The Royal Australian and New Zealand College of Obstetricians and Gynaecologists, *Prenatal screening tests for trisomy 21 (Down syndrome), trisomy 18 (Edwards syndrome) and neural tube defects*, College Statement, March 2010, http://www.ranzcog.edu.au/component/docman/doc_view/938-c-obs-04-prenatal-screening-tests-for-trisomy-21-trisomy-18-and-neural-tube-defects.html?Itemid=341

¹⁵ Kirsten Deane, "The future in our hands," *The Age*, December 14, 2008.

¹⁶ Victorian Law Reform Commission, *Law of Abortion: Final Report, Chapter 3 Current Clinical Practice*, (Melbourne: Victorian Law Reform Commission, 01 Mar 2008), Section 3.90, pg 45.

¹⁷ RANZCOG, 1.

¹⁸ Congregation for the Doctrine of the Faith, *Respect for Human Life in Its Origin and on the Dignity of Procreation (Donum vitae)*, sec. I, #2, Holy See, http://www.vatican.va/roman_curial_congregations/cfaith/documents/rc_con_cfaith_doc_19870222_respect-for-human-life_en.html

¹⁹ John Paul II, *The Gospel of Life (Evangelium Vitae)*, #63 Holy See, http://www.vatican.va/holy_father/john_paul_ii/encyclicals/documents/hf_jp-ii_enc_25031995_evangelium-vitae_en.html

²⁰ This data was obtained from a meta-analysis of data from UK, USA, New Zealand, France and Singapore. Brian G Skoto, "With new prenatal testing will babies with Down syndrome slowly disappear?" *Archives of Disease in Childhood* (15 Jun 2009), 1-14 at 3.

²¹ The range was 58% in Ukraine to 97% in Spain. Loane et al., "Twenty-year trends in the prevalence of Down syndrome and other trisomies in Europe: impact of maternal age and prenatal

screening," *European Journal of Human Genetics* (2012): 1-7 at 3.

²² *Ibid.*, 1.

²³ Veronica R. Collins et al., "Is Down Syndrome a Disappearing Birth Defect?" *The Journal of Paediatrics* (January 2008): 20-24 at 21, Figure 1.

²⁴ *Ibid.*, 24, Figure 2. ²⁵ *Ibid.*, 22.

²⁶ These studies were subject to a selection bias. The sample was taken from those on the lists of families who belonged to Down Syndrome non-profit organisations in the United States. The cultural diversity of the United States was not well represented. There was also an over representation of those from a higher income bracket than the national average salary.

²⁷ Skoto et al., "Having a Son or Daughter with Down Syndrome: Perspectives From Mothers and Fathers," *American Journal of Medical Genetics Part A* 155 (2011): 2335-2347 at 2335. These words were recalled up to 21 years later.

²⁸ Jan Hodgson and Merle Spriggs, "A Practical Account of Autonomy: why Genetic Counselling is Especially Well Suited to the Facilitation of Informed Autonomous Decision Making," *Journal of Genetic Counseling* 14, 2 (2005): 89-97 at 91.

²⁹ Kathryn B. Sheets, "Practice Guidelines for Communicating a Prenatal or Postnatal Diagnosis for Down Syndrome: Recommendations of the National Society of Genetic Counselors," *Journal of Genetic Counseling* 20 (2011): 432-441 at 432,435. ³⁰ Skoto et al., 2342.

³¹ Skoto et al., "Having a Brother or Sister with Down Syndrome: Perspectives From Siblings," *American Journal of Medical Genetics Part A* 155 (2011): 2348-2359 at 2356.

³² *Ibid.*, 2349, 2356. ³³ *Ibid.*, 2356.

³⁴ Skoto et al., "Self-Perceptions from People with Down Syndrome," *American Journal of Medical Genetics Part A* 155 (2011): 2360-2369 at 2360, 2366.

³⁵ Jan Gothard, *Greater Expectations – Living with Down syndrome in the 21st century* (Fremantle: Fremantle Press, 2010).

³⁶ Emily Perl Kingsley, "Welcome to Holland," (1987), <http://www.our-kids.org/Archives/Holland.html>

All on-line resources accessed 10 December 2012.

Kerri Anne Brussen ✨

Lessons from the Death Zone

British political strategist Philip Gould was diagnosed with cancer early in 2008. He died towards the end of 2011. Challenging community attitudes about dying with cancer, he insisted in a book-length memoir that this was "the most important ... the most fulfilling and the most inspirational time of my life." This article reflects on Philip's testimony.

There are five sections to this article. Over the centuries, the culture of Western civilisation has reminded us of the tremendous importance and significance of death. It has also advised us about how to die well. The first two sections of this article reprise this traditional wisdom. The third and longest section of this article then presents Philip Gould's account of his own experience. A fourth section invites us to see serious illness and dying as a spiritual quest. A final section draws lessons from all of this about living and dying well when we face a serious and possibly terminal illness.

The Shadow of Death

All of us die. As they say, the statistics on death are very impressive: one out of every one people die. It makes sense therefore for each one of us to contemplate death and dying, so as to understand what the reality of death should mean for us and so as to be as prepared as we can be for something which inevitably lies ahead of each one of us.

As thoughtful people have done this over the centuries, they have recognised the tremendous importance and significance of death. The Twenty-Third Psalm includes

the phrase, “though I walk through the valley of the shadow of death.” (Ps 23:4) Over the centuries, thoughtful people have recognised that we *all* walk through the valley of the shadow of death, and therefore that death casts its shadow over all of our lives.

In traditional Catholic piety, this awareness of the reality of death was identified by the Latin phrase *Memento mori* (the remembrance of death). When Catholics receive ashes at the beginning of the season of Lent, we are still advised, “Remember that you are dust, and to dust you shall return.”

When we first begin to think about this, we may instinctively feel that this shadow of death could only be something which threatens us, which depresses us, and which could only deaden our spirits. Nothing could be further from the truth. There is a tremendous paradox here. Far from deadening our spirits, the shadow of death actually enlivens us.

We are teleological beings. This means we sense that we feel called to achieve some purpose through our lives - to make a difference in the world and also to make something of ourselves. The shadow of death gives urgency to this task. We recognise that we cannot delay in working out our purpose in life and in taking decisive steps towards achieving this. The *Catechism of the Catholic Church* expresses this well:

Death lends urgency to our lives: remembering our mortality helps us to realise that we have only a limited time in which to bring our lives to fulfilment. (#1007)¹

How to Die

Along with reflections about the significance of the shadow of death for how we should live, our society over the centuries has also produced many guides on how to die well. Bruce Rumbold, an academic from La Trobe University who is also a Baptist minister, has identified four distinct narratives about death and about dying well:²

The most ancient of these is the **traditional Catholic narrative**. While its origins predate this, this narrative was enormously developed in medieval Europe between the twelfth and fifteenth centuries. In its image of a good death, the person dies full of years surrounded by their loving family. They have reaffirmed their Christian faith in God and in Jesus Christ. They have made their peace with God and with all people. It was enormously significant that they had received the Sacraments of the Church: Penance to absolve their sins, the Anointing of the Sick to strengthen them in their struggle with sickness, and *viaticum* or Holy Communion as food for their final journey home to God. Their family and their faith community assist them on their journey with their prayers both before and after their death.

After the Reformation in the sixteenth century, the **traditional Protestant narrative** also developed. This

narrative does not have the Catholic focus on the Sacraments of the Church. Instead, the focus is on the individual’s reaffirmation of their Christian faith in God and in Jesus Christ. This is recognised both as the culmination of the individual’s journey of faith in this life, and as the grounding of their journey home to God in the life to come. With this individual focus, there is less sense that the prayers of those who remain are able to assist those who have died.

Modern medicine with its enormous capacity to treat disease and to cure people began to develop in the nineteenth century. From this time, the central authority in deathbed accounts changes from religious authority to medical authority. The story in this **medical narrative** is of death being prevented (or at least delayed) through the knowledge and skill of doctors. This narrative, however, falls silent when death becomes inevitable.

The traditional Catholic and traditional Protestant narratives have not been forgotten, particularly within communities of faith. From the beginning of the twentieth century, however, the dominant account of dying and death within mainstream Western civilisation has been the medical narrative.

It is most significant that this narrative treats death “primarily as a medical event.” The dominance of this narrative has therefore meant that “discussion of death and dying as part of human experience disappeared within society at large.”³ This in turn has had serious consequences. As dying and death have become more unfamiliar, they have also become much more fearful for many people. This exaggerated fear of death has probably contributed to recent calls for the legalisation of euthanasia and physician assisted suicide.

Something new – a **contemporary narrative** about death and about dying well – is now developing. One source of this change is the hospice movement which began in the 1960s, along with modern palliative care. These forms of care eschew a merely medical approach, and instead recognise and treat the uniquely personal experience of each person at this stage of their life. Another source is the influence of the Baby Boomers - that generation born between 1946 and 1964 - as they move toward death. This generation has always insisted that, rather than their fitting into the system, the system must fit in with them. Given that they have from this perspective revolutionised many aspects of modern life, it is not surprising that they are now changing our narrative of dying and death.

The contemporary narrative differs from the medical narrative because it does not view death merely from a medical perspective. It differs from the traditional Catholic and traditional Protestant narratives because its focus is on the personal experience of dying and death. If we are people of faith, we would say that it looks for God not just in *supernatural* events like the sacraments, but also in *natural* events like the care given by health professionals, and the movements of the human spirit as an individual makes sense of this stage of his or her life.

To illustrate this contemporary narrative of death and dying, let us turn to a very fine example of it:

When I Die

Philip Gould (1950-2011) was a political strategist who advised the British Labour Party between 1985 and 2010. He worked with focus groups to deeply understand the concerns of the British people. From this perspective, he – more than anyone else – persuaded the Labour Party that it needed to reinvent itself as New Labour. He was particularly associated with Tony Blair, British Prime Minister from 1997 to 2007, who described Gould as his “pathfinder.”⁴ For his services, Gould was made a life peer on 7 June 2004.

Philip’s wife Gail Rebeck is CEO of Random House UK. They had two children, Georgia and Grace Gould, who are now young adults.

Philip was diagnosed with gastro-oesophageal cancer on Tuesday 29 January 2008. He died just over three and a half years later on Sunday 6 November 2011. This book is about what happened in between. It is certainly about what Philip went through, and it does not sugar-coat the hardships which he sometimes endured. But it is also about what Philip learnt about life through his cancer journey, and how both he and his family were transformed by this experience. These experiences are recorded in *When I Die: Lessons from the Death Zone*.⁵

After a Foreword by editor Keith Blackmore, the book contains thirteen chapters. The first nine are from Philip Gould. The remaining four are by his wife Gail Rebeck, their young adult children Georgia and Grace Gould, and Philip’s lifelong friend Alastair Campbell. Georgia wrote about Philip’s last days; Grace wrote about her relationship with her father. Alastair Campbell contributed a letter which he wrote to Philip just before his death. Philip’s wife Gail Rebeck provided her account of Philip’s cancer journey, and what that journey was like for her. The book concludes with a list of acknowledgements, a short report about gastro-oesophageal cancers, Philip Gould’s obituary from *The Times*, and a list of the cancer specialists who were involved in Philip’s treatment and care. The book is just over 225 pages, and just over 50,000 words.

Chapter One, titled **The Glory of the Ride**, traces events from the diagnosis of Philip’s cancer on 29 January 2008, through initial chemotherapy, to his first major surgery on 1 May. Philip wrote of the diagnosis: “In a second I have lost control of my world. I am.... now a cancer patient.” (p. 10) In this first manifestation of cancer, the focus of Philip and his family was on the hope of cure.

Chapter Two, The Courage of the Small, is about the chemotherapy after the first surgery. More precisely, it’s about treatment which made Philip very, very sick, and it’s about his finding the courage to take each small next step in this treatment. He wrote, “This is the reality of the cancer fight: not some massive heroic battle but a thousand small skirmishes, tiny victories, winning the

war one pill, one drink, one minute at a time. The courage of the small.” (p. 41)

Later, Philip reflected on how he was transformed by this experience. He wrote, “You learn how to cope with these challenges, one after another. There is more in the human body than you will ever understand, more physically, more emotionally, more spiritually more religiously, even.... In the end, you lose your fear of the next step because you know you will be able to take it.” (p. 121, 123)

This experience transformed him in other ways too. He found new courage to think honestly about the lights and shadows of his own life, and new courage to reach out openly and honestly to his wife, his adult children, and his friends. He wrote, “This is when you surge forward and grow. I feel I am surging forward and growing at a pace that I have never experienced before.” (p. 133)

Chapter Three is titled **A Very Small Boat** because the time after cancer treatment is like being “in a very small boat, floating in a very large sea.” What leaves people feeling isolated and adrift, of course, is “the possibility that the disease would recur.” (p. 46)

Philip began to change his life. Among other things, he was confirmed into the Church of England, moving from “being inchoately spiritual to more emphatically religious.” He noted that his parish church “became a place of sanctuary” for him. (p. 48-49)

Philip’s first cancer treatment was over by August 2008. The cancer came back just under two years later in June 2010. Again, the focus of Philip and his family was largely on the hope of cure. After several months of chemotherapy, a second major surgery was scheduled for Tuesday 26 October 2010.

But something new was developing. Midway through the chemotherapy, Philip asked Tony Blair why the cancer had come back:

Tony paused for a second and said, ‘Because the cancer has not finished; it is simply not done with you, it wanted more. You may have changed but not by enough, now you have to go on to a higher spiritual level still. You have to use this recurrence to find your real purpose in life.’ (p. 56)

Philip sensed that Tony was right: “I had to find meaning in this recurrence, had finally to come to terms with the purpose of this cancer.” (p. 56)

Much later, just over a week before he died, Philip continued his reflections on this critical time. He wrote that when the cancer reappeared, “I did not know what to do. I had no sense of purpose. I was lost. But I found a purpose. To begin with, it was just to find what it was in this new stage of life that would give me meaning. In other words, finding a purpose became my purpose.” (p. 124)

Chapter Four is titled **The Bottom of a Murky Sea**. It is about Philip’s painful recovery from his second

surgery - two days in intensive care, three weeks in hospital, another month as an outpatient. He admitted, "I have never been so close to pain, death and severe suffering before." (p. 71) At the same time, however, he wrote of the pain that "every time you are able to defeat it your body and spirit become stronger. I still hate pain but I can now tolerate it in ways unimaginable three years ago." (p. 73)

Chapter Five, The Unfinished Life, begins with the post-surgery meeting, which took place towards the end of December 2010. After so much pain, it was bad news: "Seven of the twenty-three lymph nodes extracted had been contaminated with cancer.... [T]here was a very high chance that the cancer would come back.... [H]e has only a slim chance of a cure." (p. 82, 86)

Early in 2011, Philip had six weeks of chemotherapy. Knowing that this would render him at least temporarily unable to eat, his doctors inserted a feeding tube. This treatment again made Philip profoundly sick:

By the last couple of weeks... the pain was acute and accompanied by persistent vomiting - not of food, as I was not eating, but of phlegm caused by inflammation. This process of pain and vomiting went on for days. So my life became the familiar business of grinding on." (p. 89)

Philip's scan in June 2011 found him cancer-free. "Of course," he added, "the odds were still against me." (p. 91)

Chapter Six, The Cancer Odyssey, is Philip's reflections on his cancer journey to this point. It concludes his first piece of writing about his experience, and these first six chapters were serialised by *The Times* over a week in July 2011. Philip's honesty, his courage, and his affirmation of the positive transforming effect of his cancer journey left a deep impression. Keith Blackmore, Deputy Editor of *The Times*, wrote that "the serial was extremely well received" and "the message boards and our letters department were inundated." (p. 2)

Philip wrote:

The journey... was one that had changed me in many ways - I hope for the better. I now had a different conception of myself, of cancer... of my family and friends, and perhaps above all of my wife, whom I now appreciate in new and different ways. (p. 93)

Philip continued:

[I]t is the personal journey of cancer that really matters. I have learnt that fear can be defeated and, if it is, then human possibility is unlocked; that we are stronger than we think and as we overcome what seems to be an impossible challenge then we get stronger still; that the power of community is limitless and gives us courage we did not

know we had; that optimism and hope can help to defeat fear and darkness; that the human spirit within us all is more powerful and more resolute than we can ever imagine, and that although cancer is a terrible disease, it has the capacity to transform us. (p. 96-97)

He concluded:

I would not have chosen cancer but I do not regret it. And certainly I would not have wanted to have died the person I was before the recurrence. I believe that somehow or other in the second stage of cancer I discovered a sense of purpose that I had never found before. (p. 98)

Chapter Seven is titled **The Tall Black Cloud**. The cancer recurred for the third time in August. Philip was told that he probably had only three months left to live. Being told this, he wrote, was "like being hit by a ten-ton truck... The reality, the possibility, the certainty of death suddenly became absolutely real." (p. 106)

He started chemotherapy again; had a new feeding tube inserted; had his third major surgery; and again endured intense and excruciating pain as he recovered.

More significantly, Philip and his wife Gail experienced what Philip described as "three of the most extraordinary days of my life" (p. 110) - three days of remarkably open and honest communication. With death so near, Philip broke down his usual barriers, and wept with his wife for all the times over the years when he had put other things before being with her and with their children. Gail angrily told him how he had done wrong by her, while Philip acknowledged his failings and said he was sorry. And with these hard words spoken and heard, they discussed the future together, including Gail's future without Philip. Gail described it as "three days of reckoning between Philip and me." (p. 195) Philip wrote, "I believe this was a transcendent moment in our marriage, after which we moved to a new level of understanding of each other." (p. 115)

Perhaps even more significantly, Philip continued to discover the meaning and purpose of this stage of his life. Indeed, he found a number of things. He wrote, "I saw now that the purpose I had been seeking was to give as much love as I could." (p. 125) But there was another purpose too: "I was dying, I had to make the most of that and my purpose was explicit.... [B]ecause I am defining myself now through death, I'm giving meaning to myself through death." (p. 125-126) And for this man there was yet another purpose: Philip wanted to communicate what he had experienced and what he had learnt. He wrote, "I want to write and talk about dying. (p. 126).... I am endeavouring to be honest about the reality of death. I am trying to make clear its importance and help inspire others as they move towards it." (p. 143)

Philip was interviewed on BBC television on 18 September 2011. He was interviewed again two days later for *The Guardian* newspaper. On both occasions,

“his calmly courageous acceptance of his imminent death caused a considerable stir.” (p. 4)

He then gave two more long interviews on Thursday 27 October – about ten days before he died. An edited version of these interviews is available as a 9 minute YouTube video.⁶ Another edited version of these last two interviews makes up **Chapter Eight, The Death Zone**. One of these interviews took place with Philip standing over the grave which he had chosen at Highgate Cemetery: a photographic portrait of him taken at the same time has since been accepted into the permanent collection of Britain’s National Portrait Gallery.⁷

What is the Death Zone? Many patients even with terminal cancer of other conditions deny that they are near to death. According to Philip, people enter the Death Zone when they cast off this denial and accept that they are about to die - when as Philip did they are able to say, “I am going to die. My death is inevitable.... This is going to happen in months or weeks.... perhaps even within the next few days.... but it *is* going to happen.” (p. 117)

Philip reports that this acceptance of death gives a tremendous intensity, vitality and excitement to life. He wrote, “Intensity comes from knowing you will die and knowing you are dying.... Suddenly you can go for a walk in the park and have a moment of ecstasy.... I am having the closest relationships with all of my family.... I have had more moments of happiness in the last five months than in the last five years. (p. 127-129).... I have no doubt that this pre-death period is the most important and potentially the most fulfilling and the most inspirational time of my life.” (p. 143)

Philip also reports that this acceptance of death paradoxically frees us from death: “I absolutely feel that the moment I accepted death and looked it in the eye and faced it, then I had – not defeated death, you cannot defeat death – freed myself from death.... Maybe I cannot beat death, but death cannot beat me.” (p. 119)

Would Philip have preferred – as many people do – just to have dropped dead one day, or to have died unexpectedly in his sleep? He wrote, “I certainly do not think that a sudden, unexpected death – dropping dead, as they say – would be better than what confronts me. You would lose so much.... To have three months, or two months, or one month, or even a week in which to actually sit down and fulfil and complete your relationships is almost the greatest gift that death can offer.” (p. 133)

This is the deep mystery: “I am enjoying my death,” Philip wrote. “I am having the most fulfilling time of my life.” (p. 128)

Chapter Nine is titled **Going to My Grave**. This title has two meanings. The chapter is about Philip going to select, purchase and stand upon his grave at Highgate Cemetery. But it is also about Philip metaphorically going to his grave: as the chapter concludes, he is told

that he probably has only three to five days left to live. This is the final chapter written by Philip Gould, and it concludes with a statement of hope: “I am approaching the door marked Death. What lies behind it may be the worst of things. But I believe it will be the best of things.” (p. 143)

Chapter Ten, Four Days Left to Change the World, is written by Philip’s elder daughter Georgia. It is an account of Philip’s last days. Just a few days after his long interviews on Thursday 27 October, Philip went to hospital for the last time on Tuesday 1 November 2011. Until he died, his family spent the days with him, and many of his close friends (including Tony Blair) visited. Georgia wrote of Wednesday 2 November: “Every conversation, every smile, took on a new significance. I felt the most pain and the most joy I have ever felt.... I remember announcing in the evening that this was the happiest day of my life.” (p. 160, 159) On Saturday, he received a religious blessing from his sister Jill, who is a Church of England priest. He then set out with passionate intensity to complete his book. No longer able to write or type, he dictated his testimony to his wife Gail, completing the last chapter of his memoir on the day before he died. In the evening, he received “the most beautiful letter” from his lifelong friend Alistair Campbell. (p. 172)

He was no longer conscious on Sunday 6 November. His family sat with him all day. Many friends visited. All too soon, it was evening. Georgia wrote that around 9.30 pm:

The Gregorian chant fills the room and as it reaches its last note, Dad gives a shudder and lets go. And the room is for a microsecond full of a powerful energy. Mum feels a flash of joy. She is sobbing, overcome, repeating in awe: ‘Philip, I didn’t know it would be so beautiful.’ (p. 178)

What did happen in that last moment of Philip’s life? We do not know. Philip’s wife Gail Rebeck wrote that “my rational self says that I probably imagined” whatever happened – “but I would like to believe that it was Philip’s last gift to me as his soul departed.” (p. 201-202)

Dying as a Spiritual Quest

To increase our understanding both of Philip’s story and of the experience of dying, let us turn to an insight from a man named Arthur Frank who survived both cardiac disease and cancer. Frank has observed that our experience of serious illness may be shaped by three different narratives:⁸

The first of these is the **restitution narrative**. If we fall sick, this is the story we all want: ‘I got sick; I got treated; and now I’m completely recovered.’ It is the story that our health professionals want for us too.

We want to live. We want to be well again. It is entirely appropriate that we try reasonable treatment hoping for a

restitution narrative in our lives. The danger is that we might want this too much. Catholic teaching reminds us that we may legitimately refuse extraordinary or disproportionate treatment which is either futile or overly burdensome.⁹ If however we want cure and a restitution narrative too much, we may decide to try treatment which has very little chance of success, which imposes significant burdens on us, and which ultimately over-medicalises our dying and adds substantially to our suffering at the end of life. Our health professionals may also want the success story of a restitution narrative too much. They may continue to propose treatment aimed at cure at a time when it would really be more appropriate to provide treatment aimed at symptom management and palliation. They may propose treatment which has very little chance of success and which imposes significant burdens, and they may even effectively talk their patients into trying this treatment. Far too many doctors are notorious for tending to do this.¹⁰

Did unrealistic hope for cure and a restitution narrative affect Philip's treatment? Without direct involvement in this case, we cannot be certain. It was almost certainly reasonable to have chemotherapy and surgery when the cancer first appeared in August 2008. It was most probably reasonable to have chemotherapy and surgery again when the cancer reappeared in June 2010. When the cancer had not cleared, it was probably reasonable to have chemo-radiotherapy early in 2011. But when the cancer reappeared in August 2011, was more chemotherapy and a third major surgery still a reasonable option? One would have to wonder.

Discussions about the goals of care, advance care planning, end-of-life decision-making, and palliative care are all important strategies to ensure that we are not bound by a restitution narrative, that we do not choose extraordinary, futile and burdensome treatments, and that we do not over-medicalise our dying. It is striking that there is no mention of these approaches to care anywhere in Philip's memoir.

When a restitution narrative no longer seems possible, many people experience a **chaos narrative**. Nothing makes sense any more. They cannot insert their present reality into a story which connects their past and present to a meaningful future, and which therefore gives them hope. They are instead trapped in a hopeless and unbearable present. Philip Gould experienced something of this particularly after his cancer came back in June 2010. He wrote, "I did not know what to do. I had no sense of purpose. I was lost." (p. 124)

There are at least two inauthentic ways to try to escape the ontological distress of a chaos narrative. One is to try to return to a restitution narrative by placing one's hope in some form of miracle cure. This is one reason why some people try extraordinary, futile and burdensome treatments. It is also a reason why some people fall prey to charlatans and quacks. A second inauthentic solution is to escape through euthanasia or physician assisted suicide.

The authentic way forward from a chaos narrative is a **quest narrative**. As I have written elsewhere, "This is the story of the man or the woman who journeys to a strange land in search of a treasure.... This time, though, the strange land is the world of suffering and sickness. But there is treasure there too."¹¹ Bruce Rumbold describes this quest narrative well:

A quest narrative constructs illness as a journey – neither an aberration nor a dead end. It is a journey that begins with a call to leave the safety of the known and journey into the unknown experiences of serious illness. Responding to the call involves initiation into suffering and trial, then (hopefully) transformation...¹²

After Philip's cancer reappeared in June 2010, it was Tony Blair who called him to a quest. "You have to use this recurrence," he said, "to find your real purpose in life." (p. 56) And indeed, most of Philip's book is testimony to what he learnt on this quest and how he was transformed by it.

Before moving to the next section, we should also note from Philip's story that these three narratives can simultaneously and rather paradoxically co-exist within us. While Philip's treatment choices were informed by a restitution narrative, his life choices and his writing were informed by a quest narrative. At times too, chaos and quest narratives warred within him as he tried to decide whether or not there was meaning and purpose in his sickness.

Finding Purpose and Meaning

To find purpose and meaning in serious and terminal illness is not easy. It requires all our strength, all our courage, all our creativity. Even so, while very few people are as eloquent as Philip Gould, many do succeed in finding *their* purpose and *their* meaning. It is rarely one thing; it is usually an amalgam of a number of things. Where do people look as they search for meaning and purpose?

Many people begin by drawing on those things which have given them purpose and meaning throughout their lives. These include what the sociologists call 'cultural repertoires' – that is, the values and beliefs which are embedded in any particular culture. For example, that cohort of English people who were elderly in the 1980s had endured during their lifetimes two world wars and the Great Depression. Stoicism, independence and sociality were the cultural values which over their lifetimes had guided them through the many challenges which they faced. Stoicism, independence and sociality were therefore also important values for them as they faced the decline and frailty of extreme old age.¹³

Many people also find purpose and meaning particularly in their families (or, for some, their friends). Thus, for example, Philip wrote that part of his purpose was "to give as much love as [he] could" to his family. (p. 125) In the ways of love, this involved both loving trust in

depending on them, and loving generosity in trying to care for them. Thus, Philip reported that he relied on his family “enormously, almost completely,” but that he also tried “to lead them,” “to inspire them,” “to show them a way forward.” (p. 126) Another man dying of cancer in his mid-fifties found in his family motivation for dying well. He said, “I want to make this, the way I die, my final act of love for my family.”¹⁴

People of faith find great support and encouragement in that faith. They sense that God is with them in their struggles. They find hope in God’s promise of eternal life after death. For Catholics, the Sacrament of the Anointing of the Sick is “intended to strengthen those who are being tried by illness.”¹⁵

People also find purpose and meaning in work. They may feel very pleased that they have been able to mow the lawn one more time, or that they have prepared another meal for their family. They may have a number of things which they would like to complete before the end. Rita Magris was an artist whose output was prodigious during the years that she lived with cancer. “Each day is urgent and important,” she said. “I have fitted so much into the last 10 years.”¹⁶ In the same way, Philip Gould’s work with his focus groups was to discover and report on the deep things which were happening inside people. As he struggled with cancer, he realised that he had one more report to prepare.

Along with these perennial sources of purpose and meaning, people also either draw on new things or draw on old things in new ways. Above all, they engage with the challenges of serious illness. Rita Magris wrote, “Illness brings out the best in people. They have to find courage that they never knew they had.... I didn’t realise how much power I had until I had to dig.”¹⁷ Philip Gould’s book is a moving testimony of how we can grow and be transformed by the experience of serious illness. These experiences and the transformation which they bring are indeed a powerful source of purpose and meaning.

As their time grows short, many people learn much more to live in the present moment. As Philip reported, “Suddenly you can go for a walk in the park and have a moment of ecstasy.... I am having the closest relationships with all of my family.... I have had more moments of happiness in the last five months than in the last five years.” (p. 127-129)

Another powerful source of purpose and meaning is the attempt to complete unfinished business. People often carry unresolved or even previously unexpressed grief, guilt, anger or loss. They may have unresolved disputes or separations either within their family or with other significant people. The attempt to resolve these concerns – or, in some cases, at least to let go of them – can become very important for people as their end draws close. For Catholics, making their confession in the Sacrament of Reconciliation can be very healing and liberating.

Many people rediscover religious faith at this time, either

becoming more fervent or returning to a faith which they may have not practised even for most of their lives. A survey in Australia in 1990 found that “when faced with death” one-third of people “drew upon their *personal* histories of religious involvement... reviving lapsed practices of prayer, churchgoing and involvement with clergy.”¹⁸ It is not surprising therefore that during his own illness Philip Gould moved from “being inchoately spiritual to more emphatically religious,” finding great solace in his Anglican faith. (p. 48-49) The English Catholic bishops wisely note, “A desire to return to one’s faith or to make peace with God might be the most important thing at this point in someone’s life.” They therefore counsel those who work with people who are seriously or terminally ill to “ask about faith” and to “be sensitive to cues which might prompt offering the attendance of a chaplain.”¹⁹

A dilemma for some people at this time in their lives is that there are so many religions and they do not know which one to try. This writer is Catholic. I am more than happy to offer a personal testimony to the spiritual treasures which can be found in the Catholic way of life. But if this recommendation seems too partisan, let me offer three more general recommendations. The first is to try one of the great, long-established religions of the world. Religions which have been established only recently - perhaps in the last few hundred years – may not have had sufficient time to separate any great spiritual insights from other ideas which are less than wise. By contrast, the great, long-established religions of the world have had many centuries to eliminate ideas which are less than wise, and to express as completely as possible great spiritual insights. It is therefore better to stay with these great, long-established religions. Secondly, many people have had some contact with some church or religion at some stage in their lives. For example, they may have attended a particular church as they grew up, or there may have been a family history of connection with a particular church. My second suggestion is that people start here with the church or religion to which they are in some way already connected. My third suggestion is that people should give the church or religion which they have selected a serious try. I recently saw a gym which asked people to “take up their 6 month body challenge.” If we would contemplate spending six months at a gym, surely we should be prepared to try a church or religion for at least a year so as to really discover what it offers us. We should consider moving to another church or religion only if we are dissatisfied after having given our first choice a serious one year trial.

The Catholic Church “encourages us to prepare ourselves for the hour of our death.”²⁰ Often, however, people leave it too late. Towards the end of a terminal illness, people may lack the time or the energy to complete their life as they would like. If we face a serious illness, therefore, we should start early. We should prepare for the worst even as we hope for the best. And even if we are still young and relatively well, perhaps there are things which we can do even now.

ENDNOTES

¹ This section is inspired by Archbishop Denis Hart, "The shadow of death," *Kairos Catholic Journal* 23, no. 21 (11-24 November 2012): 2-3.

² Bruce Rumbold, "Dying as a Spiritual Quest," in *Spirituality and Palliative Care: Social and Pastoral Perspectives*, ed. Bruce Rumbold (South Melbourne: Oxford University Press, 2002), 195-218 at 196-199.

³ *Ibid.*, 198.

⁴ Peter Wilby, review of *Philip Gould: An Unfinished Life*, ed. Dennis Kavanagh, *The Guardian* (UK), <http://www.guardian.co.uk/books/2012/sep/26/philip-gould-unfinished-life-review>

⁵ Philip Gould, *Lessons from the Death Zone*, ed. Keith Blackmore (London: Little, Brown, 2012).

⁶ Adrian Steirn (Director), *When I Die: Lessons from the Death Zone*, YouTube, <http://www.youtube.com/watch?v=S2eUw0CUuMc>. In December 2012, this video had been viewed over 144,000 times.

⁷ Debra Jopson, "Wisdom in the shadow of death," 12 May 2012, *Sydney Morning Herald*, <http://www.smh.com.au/entertainment/art-and-design/wisdom-in-the-shadow-of-death-20120511-1yhv7.html>

⁸ Frank's insights are discussed in Rumbold, 199-203.

⁹ See, for example, Catholic Health Australia, *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia* (Red Hill, ACT: CHA, 2001), II.1.13-14 & II.5.9-12.

¹⁰ Thus, for example, Australian intensivist Dr Peter Saul recently observed, "I don't think that a day would go by in a large public hospital without many examples of medically ineffective treatment being carried out.... I think the doctors themselves have the major responsibility [to limit futile care]

and have failed to shoulder it." For this, see "Futile interventions question medical system's focus," *The 7.30 Report* 5 November 2012,

<http://www.youtube.com/watch?v=mliO9IW8I-I&feature=youtu.be>

¹¹ Kevin McGovern, "Ethical Challenges for Catholic Health and Aged Care," *Chisholm Health Ethics Bulletin* 17, no. 1 (Spring 2011): 6-12 at 8.

¹² Rumbold, 201.

¹³ Jenny Hockey, "Dying the Way We Live," in *Spirituality and Palliative Care: Social and Pastoral Perspectives*, 51-63 at 55-58.

¹⁴ Ron Rolheiser, "Blood and Water Poured Out!" 20 January 2008, Ron Rolheiser, <http://www.ronrolheiser.com/columnarchive/?id=391>

¹⁵ *Catechism of the Catholic Church*, #1511. "The first grace of this sacrament is one of strengthening, peace and courage to overcome the difficulties that go with the condition of illness or the frailty of old age." (#1520)

¹⁶ Rita Magris, in *A Life Well Lived: A Decade of Palliative Care at Cabrini Prahran*, ed. Amanda Place (Melbourne: Cabrini Health, 2009), 16-21 at 20.

¹⁷ *Ibid.*

¹⁸ Hockey, 58-59.

¹⁹ *A Practical Guide to the Spiritual Care of the Dying Person*, 19, Catholic Church in England and Wales, <http://www.cbcew.org.uk/document.doc?id=65>

²⁰ *Catechism of the Catholic Church*, #1014.

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