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Finding Meaning in Serious Illness and Suffering

*When we experience serious illness, one of our deepest challenges is to make sense of what is happening to us. This article considers how we might do this. It particularly explores John Paul II's *Salvifici Doloris*, which suggests that Christians might discover meaning by uniting their sufferings with the sufferings of Christ.*

Illness challenges us at every level of our being. Modern methods of pain control are extremely effective, but there can still be some residual pain, shortness of breath, discomfort and tiredness. Emotionally, there can be worry, anger, loneliness, depression, anxiety and many other difficult feelings. Socially, there are sometimes drastic changes to our plans, the difficulties of letting down both people we care about and projects we value, and at least some social isolation from the people we love. Illness also presents spiritual challenges. Almost all of us have a narrative which makes sense of our lives, a story in which we are in some sense a hero on a quest. Serious illness requires that we re-consider and revise this narrative and even our understanding of who we are. For people of religious faith, there are additional challenges in discerning the meaning of their illness for their faith and their understanding of God. Out of all this, we find ourselves asking the hard and essentially spiritual questions: *Why is this happening to me? What is the meaning of this? What is this all about?*

Here are two examples of people with fatal illnesses answering these questions. Towards the end of her twelve-year journey with breast cancer, Rita Magris wrote:

Illness brings out the best in people. They have to find courage they never knew they had.... I didn't realise how much power I had until I had to dig. Each day is urgent and important. I have fitted so much into the last 10 years.¹

Or again, a man dying of cancer in his mid-fifties said:

No, I'm not afraid of dying, though I'm finding this hard.... I have a very loving family and so many friends... but I'm deeply alone inside of this. But I'm really only afraid of one thing, of not doing this with dignity. I want to make this, the way I die, my final act of love for my family. I want to do this right!²

In answering these questions, we draw particularly on those things which have already made our lives meaningful, including our relationships, our commitments, and our understanding of who we are. People of faith also draw on their faith, on prayer, and on the rituals of their religion. For Catholics, these include the sacraments,

especially the Eucharist, Reconciliation, and the Anointing of the Sick.³ Other helpful insights may be gleaned from writings about theodicy – philosophical and theological works which consider how there can be evil and suffering in the world created by God. This article explores a significant but somewhat neglected work of theodicy, John Paul II's Apostolic Letter *On the Christian Meaning of Human Suffering (Salvifici Doloris)*.⁴ Before doing so, however, we should note the importance of this reflection on the meaning of suffering. It is important both for us as individuals and for society as a whole. For each of us as individuals, this reflection helps us make sense of our own times of suffering - and even to continue to endure them. As Viktor Frankl noted, "He [or she] who has a *why* to live for can bear with almost any *how*."⁵ As regards society as a whole, contemporary culture regards suffering as "meaningless and hence to be avoided at all costs and by all means." This is one reason why euthanasia receives "substantial popular support."⁶ So perhaps these reflections can also offer the men and women of contemporary society a more life-giving alternative than choosing to be killed.

Salvifici Doloris

In his Letter to the Colossians, St Paul wrote, "In my flesh I complete what is lacking in Christ's afflictions for the sake of his body, that is, the church." (Col 1:24) John Paul's *Salvifici Doloris* is essentially an extended commentary on this text. The pope addressed this theme earlier in his pontificate – for example, in his Address to the Sick at Czestochowa on 4 June 1979 and at Knock on 30 September 1979.⁷ Compared to these early, brief

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comments, however, the Apostolic Letter is enormously developed in both its scope and its depth. The impetus for this development was the assassination attempt on the pope on 13 May 1981. He almost died. Shot four times, John Paul suffered severe abdominal wounds, massive blood loss, and a cardiac arrest. After five hours of emergency surgery, he endured a slow recuperation with some setbacks and further surgery along the way. During this time, as most of us would, John Paul pondered the deep questions of the meaning of suffering. *Salvifici Doloris* is the beautiful fruit of this reflection.⁸

It is also clear that these insights remained with the pope for the rest of his life. In 1994, his message for the Second World Day of the Sick was about this Apostolic Letter. In the same year, when he answered a series of questions for an interview, he again returned to these insights.⁹ In his later years, John Paul experienced a great deal of physical suffering. From 1991, he suffered increasingly from the trembling hands and slurred speech of Parkinson's disease. Beginning in 1993, a series of falls resulted in broken bones, surgery, and a hip replacement. He relied increasingly on a cane and then a wheelchair. Before his death on 2 April 2005, his final illness spanned several months, and included a tracheotomy and nasogastric tube, a urinary tract infection, fever and septic shock, and ultimately kidney and heart failure. In all of this, he must surely have reflected that he continued to share in the sufferings of Christ.

Salvifici Doloris was released on 11 February 1984. It is about seventeen thousand words (including about a thousand words of footnotes). It has eight sections, which we will consider in turn:

1. Introduction (#1-4)

The pope notes that suffering is a “universal theme that accompanies man at every point on earth.” It “thus demands to be constantly reconsidered.” He adds that suffering “seems to be particularly essential to the nature of man.” Belonging to “man’s transcendence,” it is “one of those points in which man is in a certain sense ‘destined’ to go beyond himself.” (#2) He also adds that it is on the “long path of suffering” that “the church at all times... should meet man.” (#3)

2. The World of Human Suffering (#5-8)

In this section, John Paul reminds us of the vast array of human suffering. He offers many examples from the Bible and from recent world history. There is both physical suffering, and emotional or “moral” suffering.

The pope adds that people suffer when they experience any kind of evil. Such evil is essentially a “lack, limitation or distortion of the good.” Thus, “man suffers because of a good he does not share... He particularly suffers when he ‘ought’ – in the normal order of things – to have a share in this good and does not have it.” (#7)

3. The Quest for an Answer (#9-13)

One possible explanation for suffering is that it is

punishment for sin or wrongdoing. As John Paul II notes, this possible explanation is explored in the Old Testament book of Job. Job is a good man who undergoes enormous suffering. His friends – Job’s Comforters – come, and try to convince him that his great suffering must mean that he has sinned greatly. Job protests his innocence. Ultimately, God appears, confirms Job’s innocence, and rebukes Job’s friends. From the book of Job, we may conclude that “it is not true that all suffering is a consequence of a fault and has the nature of a punishment.” (#11) However, for a fuller explanation for suffering, we must turn to the New Testament and to Christ.

4. Jesus Christ: Suffering Conquered by Love (#14-18)

At the beginning of this section, the pope expands his analysis of suffering and evil. There is temporal suffering and temporal evil – that is, suffering and evil in this world. But there is also definitive suffering and definitive evil – suffering and evil in the world to come: “the loss of eternal life, being rejected by God, damnation.” (#14) Christ’s messianic or salvific mission is to overcome suffering (both temporal and definitive), as well as sin and death.

Christ’s healing miracles are therefore part of his messianic activity. But above all Christ fulfilled his mission through his suffering and death. Christians believe that Christ is both truly God and truly human. Christ’s suffering was therefore truly human suffering. But at the same time, because he is also the only-begotten Son of God, Christ was able to take on the full measure of human sin, “embracing the measure of evil contained in the sin of man: in every sin and in ‘total’ sin.”¹⁰ His suffering under the “horrible weight” of this sin was immense. (#17)

Salvation was achieved because Christ did not turn away from this intense suffering but instead through it all continued to love. “In his suffering, sins are cancelled out precisely because he alone as the only-begotten Son could take them upon himself [and] accept them with... love.” (#17) Through the passion and death of Christ, human sin and human suffering have “entered into a completely new dimension and a new order.” They have been “linked to love... to that love which created good, drawing it out by means of suffering.” (#18) In this encounter, sin is conquered, death and definitive suffering are overcome, and even temporal suffering is transformed. In the next section, John Paul will reflect further on the transformation of suffering even in this world.

5. Sharers in the Suffering of Christ (#19-24)

Four sentences from the Apostolic Letter summarise this section: “In the cross of Christ not only is the redemption accomplished through suffering, but also human suffering itself has been redeemed... In bringing about the redemption through suffering, Christ has also raised suffering to the level of redemption.” (#19) “Man,

discovering through faith the redemptive suffering of Christ, also discovers in it his own sufferings; he rediscovers them through faith, enriched with a new content and new meaning.” (#20) “Insofar as man becomes a sharer in Christ’s sufferings – in any part of the world and at any time in history – to that extent he in his own way completes the suffering through which Christ accomplished the redemption of the world.” (#24)

For Christian believers, this section presents a great challenge. If we believe that Christ brought salvation through his suffering, are we able to see our own suffering as our share in the sufferings of Christ? And are we able in this way to find meaning in our own suffering?

6. The Gospel of Suffering (#25-27)

Even as he recovered from an assassination attempt which almost killed him, John Paul did appreciate that he was sharing in the sufferings of Christ. For this reason, he is able to discuss in this section the Gospel of Suffering. As he notes, the Gospel of Suffering “signifies... the revelation of the saving power and salvific significance of suffering in Christ’s messianic mission and subsequently in the mission and vocation of the church.” (#25) This involves firstly “suffering ‘for Christ’” – “persecutions” or “tribulations experienced because of Christ.” But it also involves “all those who suffer together with Christ, uniting their human sufferings to his salvific suffering.” (#26)

As well as contributing to the salvation of the world, such suffering can transform the person suffering. For example, John Paul notes that many saints including Francis of Assisi and Ignatius of Loyola underwent profound conversion during times of illness. The pope offers at least two comments about this transformation. Firstly, it occurs through the grace of the crucified Christ and the power of the indwelling Spirit. And secondly, “it often takes time, even a long time.”¹¹ (#26)

7. The Good Samaritan (#28-30)

To this point, John Paul has considered suffering from the perspective of the sufferer. In this section, he uses the parable of the Good Samaritan to consider suffering not from the perspective of the sufferer but from the perspective of those who encounter the suffering person. Quite simply, our task in these circumstances is to be like the Good Samaritan: to notice the suffering person, to stop whatever else we are doing, to feel compassion for them, and to provide them with generous help. Thus, the pope suggests that suffering “is also present to unleash love in the human person,” and that “the world of human suffering” should summon forth “the world of human love.” (#29) This is a challenge for all of us. It is perhaps a particular challenge for those who work in health care.¹²

8. Conclusion (#31)

The Apostolic Letter’s conclusion summarises its main insights about the mystery of suffering. And we are left with much to ponder: Whether we are Christian or not, how might we find meaning in our times of suffering? If we are Christian, might we find meaning by uniting our

sufferings with the sufferings of Christ? And if we encounter people who are suffering, are we able to respond to them like the Good Samaritan?

ENDNOTES

¹ Rita Magris, in *A Life Well Lived: A Decade of Palliative Care at Cabrini Prahnan*, ed. Amanda Place (Melbourne: Cabrini Health, 2009): 16-21 at 20.

² Ron Rolheiser, “Blood and Water Poured Out!” Ron Rolheiser, http://www.ronrolheiser.com/columnarchive/archive_display.php?rec_id=391

³ For a thoughtful examination of how the prayers and sacraments of the Catholic Church help us find meaning in illness, suffering and death, see Vivian Boland, “The meaning of suffering and death in the Catholic Faith,” *European Journal of Palliative Care* 19, no. 1 (2010): 18-21.

⁴ John Paul II, *On the Christian Meaning of Suffering (Salvifici Doloris)*, Holy See, http://www.vatican.va/holy_father/john_paul_ii/apost_letters/documents/hf_jp-ii_apl_11021984_salvifici-doloris_en.html

⁵ Viktor E. Frankl, *Man’s Search for Meaning*, trans. Ilse Lasch (London: Hodder and Stoughton, 1964): 76, 106. Frankl is quoting Friedrich Nietzsche.

⁶ J. Daryl Charles, “Protestant Reflections on *Salvifici Doloris*,” *National Catholic Bioethics Quarterly* 2, no. 2 (Summer 2002): 211-220 at 212.

⁷ John Paul II, “Address to the Sick at Czestochowa” and “Address to the Sick at Knock,” Holy See, http://www.vatican.va/holy_father/john_paul_ii/speeches/1979/june/documents/hf_jp-ii_spe_19790604_polonia-jasna-gora-ammalati_en.html & http://www.vatican.va/holy_father/john_paul_ii/speeches/1979/september/documents/hf_jp-ii_spe_19790930_irlanda-knock-ammalati_en.html. Even before *Salvifici Doloris*, George Hunston Williams noted this and recognised a “very important shift of emphasis in [this] Pontiff... [Christ] is in the suffering, not the poor as such.” For this, see George Hunston Williams, *The Mind of John Paul II: Origins of his thought and action* (New York: Seabury, 1981), 295-296.

⁸ Peter J. Vaghi, “Challenge and Opportunity: John Paul II on the gift of Christian suffering,” *America* 193, no. 13 (31 October 2005): 19-21 at 20.

⁹ John Paul II, “Message for the Second World Day of the Sick,” Holy See, http://www.vatican.va/holy_father/john_paul_ii/messages/sick/documents/hf_jp-ii_mes_08121993_world-day-of-the-sick-1994_en.html; _____, *Crossing the Threshold of Hope*, ed. Vittorio Messori (New York: Alfred A. Knopf, 1994), 25.

¹⁰ In 1099, St Anselm of Canterbury wrote the enormously influential *Cur Deus Homo?* When Man sinned, Anselm argued, he incurred an infinite debt to God. Only a Man *should* pay this debt. However, only God *could* pay this *infinite* debt. Therefore, Anselm concluded, only a God-Man both could and should reconcile God and Man. John Paul’s argument here obviously has echoes of Anselm’s. However, whereas Anselm spoke of forensic debt, John Paul speaks of the existential or ontological transformation of suffering by divine love. In my opinion, this is a very significant development.

¹¹ John Paul also notes that Christ does not offer an “abstract” or theoretical explanation for suffering. (cf #26) To the contrary, suffering “always remains a mystery” and “we are conscious of the insufficiency and inadequacy of our explanations.” (#13) What Christ offers instead is not an answer made of words, but rather an answer made of life: “as the individual takes up his cross, spiritually uniting himself to the cross of Christ, the salvific meaning of suffering is revealed

before him.” (#26) John Conley notes perceptively that in this the pope “challenges the power and range of metaphysical reason.” For this, see John J. Conley, “The Limits of Metaphysical Reason: Re-reading John Paul II,” *Proceedings of the American Catholic Philosophical Association* 76 (2002): 117-123 at 117, cf 119-121.

¹² When John Paul II visited Australia in 1986, he met with sick and disabled people and their carers in Brisbane on 25 November. Significantly, he reminded “those who work with the disabled, the handicapped and the sick” that they “have chosen – either professionally or as volunteers – the life of the

Good Samaritan...” For this, see John Paul II, “Address to the Handicapped, Sick and Disabled People,” in *The Pope in Australia: Collected Homilies and Talks* (Homebush, NSW: St Paul, 1986), 32-35 at 34.

All on-line documents accessed 20 May 2010.

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Euthanasia - A Dutch Perspective

In 2002, euthanasia became legal in the Netherlands. Since then, the Groningen Protocol has been endorsed, allowing infanticide for disabled babies. More recently, a citizen's initiative is being prepared to propose to the Dutch government that people should be allowed to legally terminate their life if they consider it completed. The slippery slope in the Netherlands appears to be well lubricated.

Globally, the 1960s was a time of change, where traditional society-based religious ideals became less influential in the lives of many people. The Netherlands became a place of “controlled freedom.” It was this freedom of expression on numerous societal issues, forging further than most other Western societies, that often shapes an outsider’s opinion of the Dutch. In an evolving more democratic society, Dutch citizens expected to be listened to on issues that affected them. In 1969, Dr Jan Hendrik van den Berg, declared “the ethics of unconditional respect for human life belonged to the past.”¹

Legalised Abortion

Abortion was legalised in the Netherlands in 1984, after much public debate. However, in reality abortion had been available on request for many years. In 1970, the Stimezo Foundation was established to open a network of abortion clinics for the population, as hospital-based physicians were loath to perform abortions. No legal action was taken against the clinics and the last physician to be convicted of performing an abortion was in 1973.² Initially, the legalisation of abortion was opposed by the medical profession. Those doctors who did not support abortion consequently formed the Dutch Association of Physicians in 1972, an organisation whose activities are involved in preserving the sanctity of life. Thus, when it came to the euthanasia debate, the medical profession did not want to be left behind again.³ With the formation of the Dutch Association of Physicians over the abortion issue, there was also no longer a threat of a split in the profession.

Euthanasia debate and legislation

Euthanasia with and without patient consent had been practised in the Netherlands for many years prior to its legalisation in 2002. In 1971, Dr Postma was given a one week suspended sentence and one year probation for the “murder” of her mother. Her mother had requested her daughter end her life as she was partially paralysed and could no longer sit in her chair without being harnessed.

Many within the Dutch public argued that if a patient asked for their life to be terminated, then a physician should be able to do so. As a consequence the Right to Die Netherlands, *De Nederlandse Vereniging voor een Vrijwillig Levensinde (NVVE)* was formed in the north of the Netherlands in Friesland in 1971, emerging from a group of Dutch citizens who supported Dr Postma.⁴

Dr Postma’s actions encouraged other physicians to admit their involvement in the death of their patients. In 1973, the Royal Dutch Medical Association, *Koninklijke Nederlandsche Maatschappij tot Bevordering der Geneeskunst (KNMG)* announced that it was a court decision as to whether a physician’s involvement in the death of a terminally ill patient was warranted or if it was “a conflict of interest.” In 1982, a physician facilitated the death by lethal injection of a 95 year old lady from Alkmaar, who was experiencing rapidly declining health. In 1984, this physician was acquitted of murder. After this case, the KNMG in conjunction with the Dutch courts strove to protect physicians from prosecution if they stayed within accepted guidelines. The Medical Board became involved in the discussions on how to regulate euthanasia within the confines of good medical practice. However, they evaded becoming engaged in the ethical and legal debates about euthanasia. Their guidelines were to support physicians who were considering performing euthanasia, providing them with a framework to work within. Since 1985, euthanasia was legally accepted if the physician performing euthanasia stayed within the confines of “the requirements of careful practice.”⁵

A further watershed case in 1994 saw a physician acquitted after he assisted in the suicide of a physically healthy woman suffering unbearable emotional distress. The High Court determined that the source of the suffering was of no importance. This case clarified the circumstances a physician could base their actions on and the importance of the request from the patient.⁶

In 1998, an eighty-six year old patient who suffered from neither a serious physical or psychiatric illness but was “tired of life” took his own life utilising medications

provided to him by his family physician. Harleem courts acquitted his physician on the grounds that the patient's situation "could not expect improvement or significant change and, therefore, his situation could be considered as unbearable and hopeless." The euthanasia law of 2002 further endorsed this verdict, but several months afterwards the courts decreed that only medically determined conditions, either psychiatric or somatic, could be the rationale for a patient to seek either euthanasia or physician assisted suicide. They concluded that "suffering from life" was not a justifiable cause to terminate a life.⁷

The Remmelink Commission convened in 1990 to evaluate the practise of euthanasia in the Netherlands, discerned that 1.7% of the total deaths in 1990 were due to euthanasia, and 0.2% of total deaths were physician assisted suicides. Involuntary euthanasia, or as the Dutch state "termination of life without patient's explicit request" accounted for 0.8% of total deaths. This number of deaths from involuntary euthanasia is alarming as the Dutch law states that a physician is expected to have shown due care through set criteria and is only able to end a person's life at their request.⁸ Further studies completed in 1995, 2001 and 2005 found the rate of euthanasia increased to 2.4% in 1995 and 2.6% in 2001 with the rate in 2005 dropping back to the 1990 rate of 1.7%. Physician assisted suicide data was comparable to 1990 in 1995 and 2001 but dropped to 0.1% in 2005.⁹ Interestingly the report in 2001 indicates that there is a "growing interest in palliative care at the end of life." This was just prior to the legislation of euthanasia in the Netherlands.¹⁰ Van der Heide et al, the authors who reviewed the 2005 data encouragingly note that the declines experienced in 2005 could be attributed to an increase in other end-of-life care options.¹¹

In 1998, after several failed attempts during the 1980s to introduce a bill to legalise euthanasia another bill was introduced into Cabinet through a Private Member's Bill which gained a majority of support. This bill was approved in a modified format. In 2000, it was accepted in the Lower House and in April 2001 in the Senate. It became law on April 1, 2002.¹²

Since 2002, physicians have not been prosecuted for being involved in euthanasia if they follow six requirements for duty of care prior to the act. Euthanasia in the Netherlands encompasses both the administration of drugs by a physician to explicitly end a person's life at their request, or the provision of drugs by a physician through supply or prescription to enable the patient to end his or her life. More importantly the unbearable suffering that the patient is experiencing does not have to be due to a terminal illness. Although suffering is not explicitly defined by the act, the KNMG gives a broader understanding. Adapting Cassell's definition of suffering, euthanasia requests are considered within a holistic framework considering both the observed and hermeneutical aspect and their contribution to unbearable.¹³ "Suffering has been defined as a specific state of distress that occurs when the intactness of

integrity of the person is threatened or disrupted. It lasts until the threat is gone or integrity is restored."¹⁴

When the legislation was approved the Associate Press reported the Dutch Health Minister, Els Borst, as saying, "the next government should consider the introduction of a suicide pill for patients who are healthy but simply ready to die. In fact, a name has been invented for it, the Drion pill, after the retiring Supreme Court justice who first advocated its use 11 years ago."¹⁵ However, prior to this issue becoming the next crusade for the Dutch population, another protocol had been quietly gaining support in the northern province of Groningen.

Groningen Protocol

Before examining this protocol, it is important to note that the management of most pre-term neonates in the Netherlands is within the accepted guidelines of most Western societies.¹⁶

In 1996, two cases of infant euthanasia came before the Dutch courts, one of severe spina bifida and another of Trisomy 13. In both cases, the physician and parents deemed that the child was suffering unbearably and had not responded to treatment. Both physicians were tried in the courts and acquitted. A further twenty-two cases were examined between 1997 and 2004, with no prosecutions proceeding from the investigations. In every case the decision to terminate the infant's life was made in collaboration with approval from the infants' parents. It was found all followed "careful practice."¹⁷

In 2005, Verhagen and Sauer published an article describing the Groningen Protocol, written in 2002 by specialists at the University Medical Centre in Groningen in conjunction with the district attorney. The purpose of this protocol was to provide a framework for the assessment of whether an infant should be considered a candidate for euthanasia. The provision of the information is to avoid the attending physician being questioned by law enforcement officers. There are three categories of newborns that physicians may apply the protocol to:

1. An infant with no chance of survival
2. Those dependent on intensive care and a poor prognosis, who may survive beyond intensive care, but will experience a poor prognosis with a poor quality of life
3. Newborn not dependent on intensive medical treatment but predicted to have a poor prognosis and quality of life associate with sustained suffering¹⁸

The Dutch Association of Paediatricians ratified the Groningen Protocol and an Advisory Committee on Termination of Life in Neonates was convened to establish whether cases of infanticide are performed in accordance with the requirements of the Groningen Protocol. It does not give the paediatrician total legal protection but case law will protect physicians within the Groningen Protocol guidelines. However, paediatricians are not protected by a black-letter law, as one does not

exist in this area.¹⁹ Since the establishment of this committee in 2007, a review of the usage of the Protocol established there has only been one case reported. 15-20 cases were expected annually.²⁰ The review concluded the introduction of ultrasounds in 2006 into antenatal care to detect foetal abnormalities may have resulted in more abortions being performed to eliminate foetuses with abnormalities. This assumption is supported by an increase in the abortion ratio (number of induced abortions per 1000 newborns) over the same time period. The review also suggests that there may be reluctance to report with physicians preferring to label their care as “symptom alleviation.” Furthermore, there may have been a lack of confidence in the committee due to its lack of legal power. Buiting et al, concluded that if the Netherlands is to control the Protocol they may need to revise it.²¹

... *“The Dutch experience ... trying to open the door just a few centimetres ... finding it very difficult to prevent its being flung wide open ...”*

Within Europe, United States of America and Australia, while palliative care must always be provided, it is acceptable not to initiate life-prolonging treatment for infants in group one. Group two presents various dilemmas as judgments are made on survival and quality of life. The third group create the most dilemmas. Parents cannot request euthanasia for their child under Dutch law, as the person who wants to be euthanised must be able to request it by law. The attending physician and an independent physician examine the infant and reach a conclusion about the infant’s condition and prognosis. With the parent’s agreement, Verhagen et al states that “life ending measures can be acceptable in these cases under very strict conditions.”²² Lindemann et al state “Because parents feel that they are equal partners in the decision-making process, they seem content to let the final decision rest with the physicians who are directly responsible for their babies’ care.”²³

Completed Life Campaign

In 1991, Dr Huibert Drion wrote an essay advocating that old people who decided their life was complete, should be able to end their life at their own desire. Dr Drion died of natural causes in 2004 but his philosophy continued to gain momentum with his cause being taken up by the NVVE.²⁴

In 2004 the Royal Dutch Medical Association declared the following addressed how people felt once their life was completed. This definition was to encompass the despair and suffering that these people were expected to experience:

Suffering under the prospect of having to continue life at a profoundly diminished level of quality, which results in persistently

recurring longing for death, without being able to determine a somatic or psychological reason.²⁵

In February 2010 a campaign *Voltooid Leven* (Completed Life), was begun by the NVVE supported by the initiative group *Uit Vrije Wil* (Of Free Will) aiming to gather as many signatures as possible and thus present to the Dutch parliament a case for legalising death by euthanasia for those who felt their life was completed. Within three days of beginning their campaign on February 9th 2010, 40,000 signatures had been collected. On May 18th with 116,871 signatures on their books the *Uit Vrije Wil* campaigners took their initiative to The Hague. In the Netherlands a “citizens’ initiative” can be presented to the Dutch parliament if it is supported by at least 40,000 signatures.²⁶ The NVVE suggests that the high birth rate after the World War II which resulted in the generation known as the “baby boomers” is “more autonomous, focusing on independent choices.” This entails their control over how they live and how they die.²⁷

The elderly should be allowed to make a well thought through choice at the end of their lives and that such a choice will be entirely up to them. Of course, people are not forced to make use of assisted suicide, but they should be at liberty to resort to such, if they wish to. When human suffering can be avoided, the NVVE is of the opinion that access to assistance shouldn’t be withheld. Obviously under all circumstances all forms of due care should be practiced.²⁸

A lower limit of 70 years of age has been suggested for the NVVE campaign. They identify dying with dignity as respecting that people should be free to unshackle themselves from a life they no longer want to live. They are hoping to align dying with dignity with the unbearable suffering criteria in the present euthanasia law. Dying with dignity is naturally interpreted differently, for people are diverse in their cultural and religious beliefs. The NVVE states “for many religious people dying with dignity means trustingly enduring illness, suffering and decay.” They also acknowledge “Others reject any intervention in human life and endeavour to preserve their dignity during their natural dying process.” Furthermore, they state that dying with dignity, could be through choosing euthanasia or assisted suicide and being able to make your own decision when that moment will be.²⁹

The NVVE have determined that their initiatives are not directed towards those who have not had the means or capacity to formulate an informed choice through their own free will. Therefore their initiative is intended to address those experiencing the following aging experiences. People who may have a loss of direction or a will to live due to becoming isolated as a result of a series of non-threatening ailments including a loss of mobility which has led them to experience a lack of accessibility to social networks. People who feel they are a burden to their family due to their dependence on them for care.

Furthermore, those who feel they have no future, purpose or prospects. They stress that the decision and what is an acceptable quality of life varies from individual to individual. Nevertheless, the NVVE declare that if a person wants to avoid any of the unpleasantities that may be experienced with older age then assessing life as completed will apparently facilitate an older person in avoiding them.³⁰

Three categories of people have been targeted by the NVVE.

1. Those suffering dementia who have put in place an advanced directive
2. Psychiatric patients suffering a chronic illness who experience lucid periods
3. Those suffering from a life span incompatible with their expectations

The NVVE believe that the most common motives for writing an advance directive is the fear of loss of one's dignity. They state that "With the term irreversible loss of dignity we mean the definite loss of the value of someone's life."³¹

Three different methods of executing euthanasia for those who have completed life have been put forward by the NVVE.

1. Involvement of a physician: this allows the "due care" criteria that is utilised in the already recognised euthanasia law to be transferred to a completed life case. This would require the inclusion of loss of dignity into the law.
2. Involvement of a non-medical person: Completed life is not a medical issue but one of continued existence. Thus, a qualified person abiding by "due care" standards would be able to assist.
3. Suicide without assistance: This avenue accepts the autonomy of the person who feels that their life is completed. The argument is that people should be allowed to purchase medication from a designated outlet. If they wish to have a consultation, they can, otherwise there is no onus on the person who provides the medicine.

The above are merely proposals put forward by the NVVE, but each is plagued with their own shortcomings.³²

Conclusion

Our short synopsis of the various protocols and laws in the Netherlands is a glimpse at the progression of their society over matters which are at the heart of the integrity and sanctity of life. This article is not to condemn the Dutch but to use their experience of opening a door just a few centimetres only to find it has been very difficult to keep it in a position where it will not be flung wide open.

In the Groningen protocol, Verhagen et al state "this approach suits our legal and social culture, but it is unclear to what extent it would be transferable to other countries."³³ Chervenak et al attack the "cultural

relativism" of the Protocol, suggesting we cannot allow such actions as they are an attack on basic human rights and the ethos of the medical profession to do no harm to a patient. Infants cannot decide if their life is not worth living and the Protocol defies the basic ingredient of the Dutch euthanasia law where it is based on the patient's autonomy to be able to make a decision regarding their care.³⁴

A document published by the Netherlands as part of the European project, Assessing Needs of Care in European Nations, explains the nationwide insurance scheme available in the Netherlands which provides medical insurance to every resident to cover long term care in the event of disability or old age. The document also states that from a "social-cultural perspective, the Dutch consider the care of the elderly mainly to be the responsibility of the state." Further, the document states that "while many Dutch people partly take care of their parents, partners and others, formal care is very much accepted and the elderly might prefer to be independent and not trouble their children."³⁵

What can we take from these outlooks on life? Life is not dispensable for anyone at any stage of the life cycle. Our children are a gift and ours to cherish. We cannot and should not think of them as something to dispose of just because they are not the gift we were expecting. Parents who experience the birth of a disabled infant need time to grieve and with the support of our society we need to enable both the parents and the child to live fulfilling lives. What is fulfilling for each of us differs according to the gifts, talents and abilities that we have had bestowed upon us. The hardest part is the acceptance that life takes different turns but remembering that God walks with us on our journey of life, we should be comforted. Support and acceptance are the essential ingredients that these families need to be able to continue to survive - or have we lost our knack at caring? Society needs to aid these parents and children and this will be at an economic cost. If we dispose of these "different children" at birth, what do we do with children who although born without an apparent disability are later diagnosed with a condition that will impact on their ability to engage with the "normal" world? Each person is priceless. In the instance of the Groningen Protocol an infant loses its value and becomes a commodity. We cannot let this happen as human life is not ours to determine its worth.

The completed life campaign is one that should concern us in many aspects. There is much written on how we are not prepared for death, how we are frightened of pain, suffering, loneliness and losing our personal definition of dignity as our lives draw to a close. However as with many other chapters in our lives we can attempt to prepare and look forward to the end of our temporal life. At conception, at birth, and (for Christians) at Baptism, we were shrouded in God's love. This remains with us throughout our lives, and it does not leave us as we end our lives. Acceptance of the lack of mobility, or the pain we may experience as part of our journey with God, is not an easy task. We have never been in complete control of our life; God has, so we should not expect to be in

complete control at the end of our life. Nevertheless, society needs to more compassionate and accommodating of those who are old, unable to care for themselves, and in poor health. These people are not a burden on our society, and should not feel as such. We should not be looking at their care in economic terms, we need to show them they are a valuable component of our society and from whom we can learn much. They deserve and should receive the best quality care that we can afford them as a society. We need to assist them to avoid a feeling of negativity towards the aging experiences that the NVVE suggests could result in a person reacting as though they had completed life. An older person's acceptance and our caring will help to keep the doors shut on campaigns such as the completed life initiative.

Dr van den Berg's words "the ethics of unconditional respect for human life belonged to the past," should not be embraced now or in the future.³⁶ In 1995 John Paul II spoke of the culture of death in his Encyclical *Evangelium Vitae*. His words are a powerful reminder that the door which has been opened in The Netherlands needs to be firmly shut.

Nothing and no one can in any way permit the killing of an innocent human being, whether a foetus or an embryo, an infant or an adult, an old person, or one suffering from an incurable disease, or a person who is dying. Furthermore, no one is permitted to ask for this act of killing, either for himself or herself or for another person entrusted to his or her care, nor can he or she consent to it, either explicitly or implicitly. Nor can any authority legitimately recommend or permit such an action.³⁷

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Kerri Anne Brussen ✱

Genetic Testing and Insurance

Life, health and income insurance are very important in peoples' lives. For this reason, insurance companies should not use genetic testing to restrict access to these goods.

In some recent research into "Perceptions of genetic discrimination among people at risk for Huntington's disease: a cross sectional survey,"¹ discrimination was reported by 39%, occurring most often in insurance (29.2%), as compared with health care (8.6%).

Anyone who watches the crime shows on TV or reads the court reports in the media will be aware how often DNA testing appears now before the public's eyes.²

The Perceived Problem

If insurance companies find out the results of genetic testing, besides learning about the private areas of my life, they will have a tool to measure risk more exactly which will result in some of the following adverse effects:

Insurance companies will raise the cost of the premiums for high-risk people; they may even refuse insurance cover for certain people. Since insurance companies are basically concerned with statistics rather than with the clear risk to individual persons, someone may be caught up in statistics even when the specific risk does not apply to this person who simply comes under the general heading of genetic risk.

Part I - The Values Involved

Before going on to examine the real situation, it could be instructive to note some of the basic values involved in this question of genetic testing and insurance. Important values to consider in my view would be:

- **Health Insurance** as a social good with social responsibilities: for the insured, for business and employment;
- **Privacy** of genetic information for self, positive and negative consequences (autonomy);
- **Health and Life**;
- The **Common Good** or general social welfare of citizens (respect for equal dignity);
- Genes and the person: Are we our genes?
- General welfare and security;
- Discrimination and justice (general equality for all for basic health);

Insurance

Insurance against premature death and for financial protection in the case of illness is obviously a good thing. It is a product most people both want and are prepared to pay for. Insurance companies are also businesses that serve the public and therefore need to make a profit to continue and to remain viable. Their profit and sustainability depend on the right balance of risk in proportion to the premium demanded. To attain this goal insurance companies have to discriminate. The ethical question concerns fair and unfair discrimination. However, insurance companies as businesses are interested in statistical rather than causal relations, and this can give the impression that discrimination in a particular case is unfair.

Privacy

We all value our privacy even though in practical living there is not much we can really keep to ourselves. Anyone who has been in hospital or who works in a hospital is aware of how tenuous our privacy can be. There remain certain matters that we consider very personal and private. It seems that one of these private areas is our genetic make-up for so much can be discovered by an examination of our genes. In conjunction with privacy, we greatly value our autonomy - our perceived right to control our lives - in the face of incursions into our private affairs or attempts to diminish our independence.³

Health and Life

There is little need to expand on the values of health and life. They are generally regarded as the most basic values or assets we can have. Since the continuation and preservation of health and life depend, among other means, not only on our genes but on medical services, which are relatively costly, it is wise to insure for their adequate provision. This explains the close association between health and insurance.

The Common Good or General Social Welfare of Citizens (Respect for Equal Dignity)⁴

Allied with both health and life and personal attempts to provide insurance for oneself and family is the question of the common good of citizens, or general social welfare. This was pretty much before us as President Obama struggled to make such universal health cover the right of all citizens of the USA.

The principle of the common good aims to protect both

the individual citizen, especially the poor and high-risk people who cannot afford to insure against ill health, and the state which benefits from maintaining the health of its citizens. The social health cover or insurance that all Australians enjoy is an example of this policy. Basically, according to the principle of the common good, no one should be deprived of the goods that are vital to human welfare as a result of their genetic constitution. This is a principle of distributive justice; its opposite is nudging eugenics.

Genes and the Person: Are We Our Genes?

Radetski et al. state: “The following claim is crucial in order to understand this chapter: *a gene in itself can never give rise to the properties of an individual and can only affect an individual given an environment.*”⁵ The assertion that we are our genes is an inaccurate oversimplification that can lead to unverifiable conclusions. Genes interact with other genes and with the environment. They also mutate. This makes predicting diseases from genes less certain than one would imagine from general media reports. “Not all damage to a gene that usually causes a disease actually results in disease, since modifying genes also influence the penetrance of the damaged gene. Thus, the damaged gene gives rise only to an increased probability of becoming ill...”⁶ Nevertheless, it is almost certain that new advances in genetic science will show that genes affect many more health situations than we are aware of at present and also impinge upon life expectancy.

In discussing a broader question of anthropology, yet one allied to the question, “Are we our genes?” the German theologian Karl Rahner made the point that philosophers often used a concept of ‘nature’ (‘natural,’ ‘according to nature’) which ignores the fact that, although man has an essential nature which he must respect in all his dealings, man himself is a being who forms and moulds his own nature through culture, i.e. in this case through self-manipulation, and he may not simply presuppose his nature as a categorical, fixed quantity.⁷

Part II - The Regulation of Insurance Companies and Genetic Privacy

Privacy and autonomy are bedfellows. No matter how we guard our privacy and autonomy, the fact that we are social beings and live in community with others is going to limit both. Governments spend their days enacting new laws and regulations that will limit our individual autonomy. As a simple example, consider the road rules. The internet, Centrelink, credit card and bank information remind us how relative one’s privacy is. Is genetic information in a special category?

In certain respects genetic information is special; it is generally considered so, and there are reasons for this. First, there is the sense that this information covering many areas of our life is especially personal and intimate; people would be distressed if others knew about their genetic dispositions such as Huntington’s disease, for

example. The very predictability of a disease, the probability that it could be transmitted to offspring or what it reveals about other members of the family put genetic information in a special category.⁸ Nevertheless, some of this information can be gleaned from other sources such as family history and race.

There is no doubt that health and life insurance are important to a large percentage of the population. Since genetic information can tell us so much about our health, particularly about our future health and life expectancy, there is a reasonable fear that if insurance companies have access to this knowledge a person’s ability to take out health insurance and especially life insurance may be compromised either by exclusion or by higher premiums.

For this reason some States have legislated to provide partial or full privacy for genetic information.⁹ In reality the situation is not so simple that partial or full prohibition can solve the problem of discrimination. There are benefits and downsides to the regulation of genetic information.

Some of the benefits to the individual are obvious enough. The insurance company cannot discriminate against you as a higher risk if they cannot demand access to your genetic information, past or in the future. There are people who, through no fault of their own, have been dealt defective genes exposing them to health problems here and now or in the future. Should they be discriminated against? Since insurance is interested more in the statistical evidence in assessing premiums and issuing insurance than in what causes the actual health conditions of this particular person, who may not be adversely affected by some genetic deficiency, some may question that insurers really need to have genetic information.¹⁰ There is the fear that insurance companies will overreact through ignorance of the individual situation.

However, fear of discrimination can have an adverse effect when people avoid genetic testing which may help to prevent the onset or the treatment of an inherent disease.

At the same time, one needs to remember that insurance companies are businesses: they have to make a profit to survive and to provide a service to the population. If they cannot control the percentage of high-risk clients, they either have to raise the premiums of all those insured or go out of business. Further, they have to face the competition of other companies, especially companies with a global network which may not be subject to local regulations. In fact, companies go offshore to avoid state legislation, thus taking business and employment from the local area. A middle position could be for the state to subsidise the premiums of the higher risk people to support local business and employment. This would also seem to be a less inequitable approach for those who otherwise could not find insurance.

There is a greater need for regulation in countries where there is no system of social health insurance since the

population is totally dependent on private insurance. Where - as we have in Australia - the common good ideal prevails so that there is basic social health cover for all citizens along with the extra option of private insurance, the pressure to conceal genetic information will be lower. People can feel secure that they will have access to health services no matter what their genetic disposition. The inverse will be true where states lower the threshold of universal health cover because of increasing health costs.

Discrimination

Discrimination is generally seen as a dirty word. However, we accept discrimination in many areas of life: age, education, professions, religion/beliefs, physical functions, sexual orientation, employment contracts, to list just some. Here we need to distinguish between just and unjust discrimination, and that is difficult. On what do we base our commonly accepted anti-discrimination laws?

They seem to be based on the equal value of all people as we see in the United Nations' Universal Declaration of Human Rights. This is really a natural law philosophy by which we decry, for example, genocide, abuse of children, war crimes, much of which is now enshrined in positive law. From what has been said above about the nature of insurance based on risk, it is clear that there has to be some discrimination for insurance companies to survive and continue to serve the public. If we accept that some people have no control over their genetic disposition to disease, it would seem to be unjust to discriminate against them by not allowing them to receive adequate medical assistance if they cannot afford the higher premiums or will be excluded by insurance companies. In appealing against discrimination here, one would have to take into account such conditions as the permanent nature of the disability, its fundamental impact on health, and its inevitability. This is where overall social health cover becomes vital. It is, of course, also economically beneficial for the state to keep its citizens in good health. If one does not subscribe to the philosophy of the common good, at least political and social expediency might support universal health cover as it does for low cost housing for the disadvantaged and public education for rich and poor alike.

An option which would affect discrimination from both sides - from insurers if regulations controlling access to genetic information were repealed, and from those high-risk people seeking insurance but unable to pay the premiums - would be for the State to offer insurance to such people from a high risk pool at a lower premium. This is suggested by Radetzki et al.¹¹

Some Ethical Conclusions

To put it over-simply, the right to personal privacy over one's genetic information contrasted with the right of insurers to have access to that information has to be based on justice all round. It is a much more complicated issue when you try to put it into practice, and try to meet the demands of both commutative (between persons) and

distributive justice (the proper distribution of the goods of society amongst persons considered of equal worth).

For insurers it is fundamental that there be a proportion between the cost of insurance and the risk involved; otherwise they will go out of business and a service would be lost to society. Other factors modify this basic premise. For, as we have seen, insurance companies work on generalisations rather than exact calculations of risk and cost of premiums. They make a fairly general assessment overall mainly because it would be too expensive to assess all relevant detail. You can hear the insured saying: "Why give exact detail of your health situation against yourself, your whole genetic information, when the insurer's assessment is to a greater or lesser degree arbitrary anyway?" The argument has some value, but not totally. The importance of personal privacy, especially in the area of genetic information is another factor to be considered.

Justice implies almost intuitively a sense of overall fairness. Strictly speaking, people should pay for their high risk in health according to their ability so that they do not overburden the low risk people seeking insurance. However, this does not seem to be fair where the high risk arises from something as inevitable as one's genetic makeup. It is particularly unfair to such persons who have no means of taking out insurance.

Another factor, which may not go over-well with insurance companies, but which would apply particularly in countries where there is only private insurance and no overall social health cover, is that insurance companies like banks have social obligations as well as profit-making. Social responsibility would impinge on the claim for complete genetic information from an individual since it has consequences in the areas of both privacy and autonomy.

To achieve fairness, for justice is really a balancing of rights, privileges and obligations, well depicted by the image of the scales of justice, the values or basic considerations set out above need to be taken into account.

In the interests of fairness we seek to recognise the human dignity of every person which implies at least access to what is necessary for basic health. It is difficult to see how this can be achieved where the only possibility is to purchase private health insurance. This problem is real and so governments have had to regulate the demand for genetic testing as a prerequisite for insurance. As we noticed, for insurance companies there are ways of getting around the difficulty in the world of global business.

General public social health cover, where all pay a percentage of income, and all are covered for basic health, lessens the demand for genetic testing unless this is required for health reasons themselves. High-risk people are covered and their privacy respected as we experience in Australia. In the complex world of health and insurance, this seems to be the better option.

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⁶ Ibid, 6.

⁷ Karl Rahner, “The Experiment with Man,” in *Theological Investigations* (New York: Herder & Herder, 1972), 9:205-224 at 216.

⁸ The Human Genetics Society of Australasia, “Position Statement: Genetic Testing and Life Insurance in Australia” (www.hgsa.com.au/Index.cfm?pid=111468) states: “the issuance of a life insurance contract should not be contingent on an individual undergoing a genetic test. It is not appropriate for any individual or organisation to engage in actions which coerce individuals to undertake genetic tests against their autonomous judgement or which inhibit individuals from taking tests for fear of social or economic disadvantage... The HGSA believes an individual has the right ‘not to know’ their predictive genetic test result.” It notes that “under law, the applicant is required to disclose any information that may impact on the offer of insurance.” This refers to the *Insurance Contracts Act 1984 (Cth)*, s 21(1).

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¹⁰ An example of this approach in another area is the higher premium for car drivers under a certain age because the statistics show that this group as a whole makes more demands on insurance payouts, even though a particular driver may be the most careful on the roads.

¹¹ *Genes and Insurance*, 150.

All on-line documents accessed 20 May 2010.

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