
BIOETHICS OUTLOOK

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Illness, ageing and bioethics

David Langsford

In this issue

In the first article David Langsford reflects on the nature of suffering in the context of those chronic illnesses which mark the modern trajectory towards death. He argues that suffering should be distinguished from the experience of symptoms of illness and ageing, that it should be understood rather as a diminution of the self in its attitude to the world, and that this understanding of suffering should shape both the doctor's medication plan and the health care administrator's allocation of resources.

In the second article, Bernadette Tobin recommends *Catholic Health Australia's* two new sets of ethical guidelines: *A guide for people considering their future health care* and *A guide for health care professionals implementing a future health care plan*.

Medicine has become very adept at treating and managing infections, trauma and childbirth. Indeed, medicine's success in curing cases that killed people 100 years ago may now be taken for granted in some cases, in other cases successful cure or treatment is still heroic. Nonetheless, the rapid advances in medical science and clinical practice have altered the trajectory of dying for us in Western societies. Fewer of us die of acute events, more of us live with chronic diseases (the leading chronic diseases being arthritis, asthma and diabetes) and more of us die from a chronic disease (coronary heart disease, stroke, lung cancer, chronic obstructive pulmonary disease) that progressively become more disabling as we edge towards death (AIHW, 2005).

It ought not to be a surprise, therefore, that the trajectory towards death has significantly altered its shape from one hundred years ago. Death does not commonly follow a period of rapid deterioration (except in some cancers). Rather, patients live with these diseases for some period of time, live with increasing debilitation and die at a time that is not predictable: for example, a patient with advanced chronic heart failure disease in the USA has at the time of death a 50-50 chance

of living six months (Lynn and Cretin, 2000). These patients' gradual decline is interspersed with bouts of marked decline and hospitalisation and commonly one of these hospitalisations occasions the patient's death. Death is not commonly sudden and does not commonly come to those of us who are healthy. Rather, commonly we live with the illness from which will we die for a significant period of time before death. We may experience a rapid deterioration as death nears (as in some cancers) or we may experience a gradual decline marked by many intermittent acute exacerbations that are not predictable. In fact, this second trajectory description is more common than the cancer trajectory (especially in the elderly). In her testimony to the USA Senate's Special Committee on Ageing, Joanne Lynn said:

Most of us will not die this way [the lung cancer trajectory]. Instead, we will be disabled by diseases such as heart disease, emphysema, stroke, dementia, and even cancers like breast and prostate cancer. Along the way, we will have episodes of serious complications. Any of these episodes can cause death, and one of them will - but we will not know which one until it is upon us. In other words, most people die of a serious chronic disease, in a week that started just like many other weeks. People now die 'suddenly' of long-established illness. (Lynn, July 2000)

Suffering and Chronic Illness

There are many avenues for inquiry with regard to how adequately health systems have adapted themselves to managing this modern trajectory towards death. There are questions about the appropriate medical interventions, about resources, about the functions of hospitals, hospices and nursing homes, the role of GPs, about the training of clinicians (both medical and adjunct professionals), about the needs and requirements for wills and advanced directives. While it is a false claim that medicine has been interested only in acute events (e.g., medicine has long been interested

in managing syphilis, tuberculosis etc., before the advent of antibiotics), it may be that Western health systems are nonetheless geared more towards treating acute events. As such, it would not be surprising if patients with chronic illnesses found themselves and their illnesses being moulded to fit the acute event framework of a health system: being treated when there is an acute exacerbation and otherwise having treatments routinely monitored. If so, then some or all of the above questions, which address many facets of a health system, are important if a health system is also to be geared towards managing the common modern trajectory towards death.

Nonetheless, answering the above questions would not be adequate for addressing the ethical issues raised by the modern trajectory towards death. Any such inquiry ought to commence from the resolution that medicine's calling is to relieve suffering, and from there reflect upon the nature of suffering that is inherent in chronic illness, particularly that illness unto death. Regardless of the response to the clinical and political issues implicated in reorientating many resources of a health system, it would be quite uncritical and ethically unsatisfactory to mould the perspectives of suffering from a chronic illness unto death by way of an understanding of suffering weighed down by the history of medicine's encounters with the acute event.

This is not at all to claim that the medical world is unaware or unconcerned about the nature and management of chronic disease; rather, at stake is the degree to which the nature of the experience of chronic illness is understood. A paper such as this ought not to pretend that such questions can be answered a priori and cannot, therefore, ignore the descriptions of experienced physicians. However, it is curious that in recent writings on chronic illness the descriptions of the correct response to patients with cardiovascular, respiratory diseases or cancer often do not involve attention to issues that can broadly be construed as ethical, from the practical concerns of wills to the spiritual concerns of dying. Consider:

However, they [patients older than 65 with chronic cardiac, respiratory diseases and cancer] live with the constant threat of exacerbation and associated visits to hospital, and uncertainty about their life expectancy. Our challenge with these patients is to ameliorate distressing symptoms, halt progression of the disease, and prevent complications and unnecessary hospital admissions. (Gray and Scott, 2003)

This is not the forum to argue whether these objectives are correct, although at face value one tends to accept that they are. However, this is the forum to speculate whether such objectives constitute a sufficient response to chronic illness, whether in fact reflection upon the experience of suffering a chronic illness unto death teaches us that there are more objectives than those set out above.

Chronic and Acute Illness

It may be thought that one of the most useful tools for elucidating the nature of suffering in chronic illness is via a comparison with acute illness. Indeed, I will later return to this contrast. However, the difficulty with the recognition of there being a distinction between acute and chronic illness is the theoretical manner in which the distinction is drawn. My claim that there needs to be a distinct ethical approach to chronic illness does not rest on concepts of pathology providing the justification for a clinical and ethical distinction between acute and chronic illness as these pathological concepts are not sufficient to capture the difference between suffering in acute and chronic illness. For instance, the disease model of illness directs us towards the patient's acute illness being directly and proportionately related to an underlying organic injury that medicine can resolve and by doing so relieve the patient's suffering. The disease model, however, is not adequate to all cases of acute care. For example, an old man presents with pneumonia. Is the cause of his illness the multiplying bacteria, the malnutrition allowing for the bacterial invasion and survival, the grief over the death of his wife, or poverty or loneliness leading to the

malnutrition (adapted from Cassell, 1991). Here, we encounter the beginnings of the bio-psycho-social model of illness. Importantly, both theories give us a way of thinking about the cause/s of the patient's malaise; but neither theory instructs us as to the nature of the experience of the patient's suffering. Indeed, as distinct as both theories are, they share a common assumption, bred out of the reductive materialist assumptions of the successful clinical sciences. They are reductive as each allows that the locus of suffering is the organic. While the theories provide different accounts of the causes of suffering and emphasise different management options, neither instruct us as to the experience of suffering and thus cannot instruct us as to the ethical response to suffering, in acute or chronic illness.

Suffering and the experience of symptoms

The experience of suffering is to be distinguished from having clinically significant symptoms of illness. I propose to make this distinction by suggesting that suffering is an experience initiated by symptoms, be they varieties of pain, breathlessness, wasting, weakness, fatigue, anorexia, anaemia, cognitive dysfunction, etc. To describe suffering in this manner is to describe suffering as a state that pertains to the self that is at the centre of experience. Here I need to say a few words about the conception of experience that I have in mind.

I have drawn this conception from several important conclusions in the philosophical work of Edmund Husserl (see Husserl, 1982). The first important conclusion is that the idea that there is any distinction between the self and the body is an abstraction from an initial unity. Furthermore, the body, if described as that which is the object of medical concern and as that which is the location of sense organs, is insufficiently described. A sufficient description must acknowledge that the body places me at the centre of a surrounding world, full of objects and people with all their material, aesthetic and moral qualities.

Moreover, the body is me and the scientific description and investigation of the body overlooks (perhaps necessarily) that the body is the 'living body'; in other words, the self is necessarily embodied and embodiment implicates the self, and all its attitudes and concepts, as necessary to the structure of experience. Husserl's lengthy analyses bring us then to the question of the relationship between the self and the world it experiences. The self, he reminds us, experiences the world through the living body. That is, experience is always structured by the attitudes and concepts of the self (which Husserl describes under the heading of intentionality). The important point is that experience of the world is necessarily structured by the attitudes that are available to the self to take up with regard to the world. Another way of putting this point is: the world is not a substrate that we impose meaning on, but is primarily meaningful because we are capable of the act of meaning.

Suffering and the Self

This brings us to the crucial point for providing an understanding of suffering. The self resides in the living body that is composed (at least in part) of moving, sensing, remembering, of moods, emotions, needs and desires, and reflection and contemplation. If any of the living manners in which I can take up a meaningful perspective on the world are restricted or lost (from senses to memory to desires and emotions) then the world that I can experience may be narrowed. Many organic dysfunctions can result in the restriction or loss of the living ways in which I can 'mean' and thus have experience of the world; that is, the symptoms of organic dysfunctions, be they pain, malaise, cognitive deficits, etc, can restrict the world that I experience and correlatively alter the shape of the self that can be disclosed in that world.

This provides a way to describe the nature of suffering. Suffering is a privation initiated by symptoms. Suffering is a diminution of the ability of the self to continue to take up attitudes to the world and thus, correlatively, also a loss of certain experiences of the world.

The idea that suffering could be understood as a loss of world and self is not a new idea. We can find formulations of it in such work as Elaine Scarry's *The Body in Pain* (1985). Her chapters on torture's aims and consequences are rich with insights into the experience of suffering. In her accounts suffering is the result of intense physical pain that may be attended with psychological torment. When she deals with the question of the betraying 'confession' made by the tortured prisoner, she finds that no moral culpability can be attached to this act, for no-one is betrayed. Her conclusion is not reached by a naive appeal to duress, but by an analysis of the nature of the duress of the tortured prisoner. Her analysis reveals that "intense pain is world-destroying" (Scarry, 1985, 29). Without a world there is no possibility of relationships such as friendship, family, political and citizenship and so forth, and therefore there is no possibility of betrayal. There are two reasons for this: if there is no world, therefore there are no 'people' who meaningfully populate the world with whom to form relationships. Secondly, the possibility of such relationships is itself grounded in the self. Given the intimacy between the self and world, the destruction of the world is also the destruction of the self and as such the destruction of the possibility of relationships that demand moral attention. While Scarry herself focuses on pain, she acknowledges that other aspects of ageing (which is commonly associated with chronic illnesses) can narrow the world and self:

As the body breaks down, it becomes increasingly the object of attention, usurping the place of all other objects, so that finally, in very very old and sick people, the world may exist only in a circle two feet out from themselves; the exclusive content of perception and speech may become what was eaten, the problems of excreting, the progress of pains, the comfort or discomfort of a particular chair or bed. (Scarry, 1985, 32-3)

While it may be thought that such a person's suffering is describable in terms of their difficult bowel habits, their poor appetite and poor sleep, I argue that this confounds

underlying causes and the nature of experience of suffering itself. Such a person's suffering takes the form of the world existing, "only in a circle two feet out from themselves". As a result, it may be that their ability to take up an attitude of love, or take up an attitude of desiring a meal for the pleasure it brings, has diminished. Pleasurable meals and pleasurable company no longer hold the significance that they once did for the person, not because nothing pleasurable comes their way, but because the ability of the self to be so disposed has been lost, and so, correlatively, pleasure in the world diminishes. I contend that the experience of suffering has this form: the shape and extent of the world and self diminish.

Suffering in Chronic Illness

This description of suffering is not the complete picture of suffering from a chronic illness. To complete that picture we need to distinguish the experience of acute illness from the experience of chronic illness. An example of an acute illness is a normally healthy young person being struck down with pneumonia and hospitalised. It is possible to conceptualise this event as though something alien to the person has invaded and it must be defeated, i.e. cured. While the patient suffers organically (fever, fatigue, shortness of breath, cough), because they recover without developing any complications that are a threat to them, their suffering is limited to that period of disease and can be described in terms of that disease (Jennings et al, Feb-March 1988). However, the otherwise healthy person who develops severe meningococcal meningitis and as a result undergoes an amputation has, as a consequence, a sequelae of an acute disease that cannot be treated merely as something alien to the patient to be defeated. Instead, the results of the amputation must be incorporated into the patient's understanding of themselves. If the patient was a right handed fanatical golfer who lost his right arm then the personal and social world of the patient has changed and so too, correlatively, must his self. The breach of the body can be managed, but this does not thereby restore the

patient to themselves and the world of coherent meaning they knew 'before'. For as long as the self and its intimate relation, the world, are restricted, or even struggle to cohere, then there is suffering. The suffering is alleviated by restoring the world and the self. Sometimes it may not be possible to restore the world and self to their former shapes, but only to a 'new' state in which 'they make sense'. To restore is to ensure that the world is a field in which the person can disclose themselves, and speak of a plot that is coherent. In the case of the patient with meningococcal meningitis, there has indeed been a breach of this patient's integrity, a breach that is sustained beyond the period of disease. This patient's suffering, therefore, is not limited to that period of disease. The suffering during the period of disease (something alien has invaded) and the suffering following the period of disease (a loss of world and self) are qualitatively different.

Finally, with regard to chronic illness, it is important to recall that I have argued that suffering cannot be exhaustively described in terms of the disease or by an organic description. Suffering, as a loss of world and the intimately intertwined self, may take the shape of psychological, social, spiritual concerns, the meanings of which the self can no longer find forums for expression of, or make sense of in terms of that coherent meaningful plot of a life. These concerns are commonly encountered in the patient with chronic illness. Recognition of this ought then to lead us to conclude that to suffer a chronic illness is not to suffer merely because of an acute exacerbation of the symptoms, it is to suffer also in those periods when the symptoms appear managed and to suffer in a way that may not be connected to the underlying dysfunction, both in terms of timing and experience. A patient with chronic illness can suffer in those times of relative clinical health, not just because of the symptoms (and, indeed, their management, such as haemodialysis) but because of the consequences of the symptoms for the scope and shape of their world and their self. We cannot predict the nature of suffering in any one case but we can predict that the suffering cannot be described in terms of the clinical

disease. Thus, ethically it is insufficient to treat a chronically ill suffering patient merely upon the terms of their disease; their suffering is not their disease but is their loss of world and self.

As a result, the earlier cited comment from the *Medical Journal of Australia* falls short of the mark for expressing what lies in the challenge posed by chronic illness. It is, of course, important that symptoms be managed, complications reduced, hospitalisations prevented - all of these factors ought to lead to a reduction in suffering.

However, if we are alert to the possibility that a patient whose symptoms appear well-managed and who has no recent hospitalisations could, nonetheless, be suffering, then we must recognise that our challenge is greater than we first acknowledged. Nonetheless, not all patients with a chronic illness must suffer - how, then, may we identify who is suffering and what may be done about it?

At this point I draw briefly on the philosophy of Emmanuel Levinas. In his work, *Totality and Infinity* (1969), he opposes the thought that needs and desires are a privation in life and a source of displeasure and pain. Instead, he argues, needs and desires are the source of enjoyment of the living body, indeed, of life. To have needs that are satiated, such as to be warmed in the sun, to enjoy a meal and a drink, brings vitality to living. To be suffering a chronic illness, to have one's world shrinking to within two feet of one's chair, is to suffer a diminishing of the attitudes of needs and desires that had, for so long, sustained the vitality of life.

The relevant thought of Levinas does not cease with a consideration of the vitality of life. His most important (and controversial) contribution is to argue that source of moral concerns is to be found in the possibility of the vitality of life and its insecurity. Precisely because I have no natural right to my place in the sun to the exclusion of others, we encounter, he argues, the origins of morality.

The concern with being moral is not established by reason or religion, but rather is intrinsic to the nature of the enjoyment of having needs and desires. Thus, to lose one's needs and desires is also to be partly separated from that which has constituted for the individual a human life: the ability to express values, to recognise moral duties, to belong to a moral community and participate in the relationships such a community makes possible. This is consistent with the thought of Scarry above; that suffering consists in destruction of the world such that morality ceases to have currency. Such a patient is not only organically vulnerable, but existentially vulnerable: it is not only their body that is threatened and the continuation of living into the future, but the moral significance of their own past and present life. To respond ethically to such a patient must then be to restore them to their needs and desires, to restore them to the vitality of life and thus also to restore them to moral agency. Or, negatively expressed, the ethical response to suffering patients whose world and moral agency are diminishing is to ensure that diseases, symptoms, institutions and treatments (and even the patients themselves) do not enhance the deterioration of the patient's needs, desires and vitality: that moral agency is not unwittingly abrogated.

An Ethical Response to Suffering

To draw the conclusion that the ethical response to suffering in chronic illness is restoration of world and self does not imply that the physician must acquire further skills, such as in psychology or spiritual counselling. However, it is to conclude that the clinician ought not to administer a treatment that hastens or enhances the narrowing of world or self, and one of the touchstones for this would be to ensure as far as possible that the patient can find expression for their values and tenure of their needs. This may require the physician to modify the administration of particular medications with side effects that undermine the patient's vitality; or it may require a physician to be a witness to a patient's suffering, when the institutional or management causes of suffering cannot be

avoided. To be sure, it may require that the physician consults others in order to alleviate the patient's suffering: family, friends, religious ministers or psychologists or psychotherapists whose skills can aid them to find ways to restore the patient's world and self, and maintain them along the trajectory of chronic illness unto death. Indeed, it may be, given the modern trajectories towards death often involve chronic illnesses far more so than in the past, that not only is there a social responsibility to attend to re-orientating the health system and its resources appropriately, there is also a social responsibility to foster the training of professionals who with medical and psychotherapeutic training can alleviate the suffering that many of us will be exposed to in the final years of our life.

This conclusion is not as fanciful as perhaps it seems. There is growing interest in the use of multidisciplinary care teams for the management of chronic terminal diseases, such as chronic renal failure, heart failure and chronic airways limitation. Such teams aim to achieve an improvement in factors that can be measured, such as re-hospitalisation rates and mortality. These factors are themselves clearly important outcomes to improve in this patient population; however, they are not the sole aims of these teams. While community nurses work to ensure patient treatment compliance and good symptom management, others such as social workers, psychologists and chaplains concern themselves with the psychological and existential aspects of the patient's suffering. In summary, medicine's ethical responsibilities to patients with terminal chronic illnesses extend beyond the management of acute exacerbations and prevention of re-hospitalisation. Given that the chronic illness trajectory towards death is more common than it ever has been as a result of our ageing population, it is imperative that the orientation of modern health systems includes a means to ameliorate the suffering of terminal chronic illness. The amelioration cannot take the sole form of symptom management, but rather must also involve the maintenance of the patient's self, world, moral agency.

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Future Care Planning

Two new sets of guidelines: for people considering their future health care and for professionals looking after them

Bernadette Tobin

At its Annual Conference in August, *Catholic Health Australia* launched its two new sets of ethical guidelines: *A guide for people considering their future health care* and *A guide for health care professionals implementing a future health care plan*. These are now available to both members of the public and to health care professionals.

The guidelines, which come with a warm recommendation from the Committee for Doctrine and Morals of the Australian Catholic Bishops' Conference, were prepared by a small group after extensive consultation with health care professionals both in Australia and overseas. The drafting group comprised Bishop Anthony Fisher OP, Rev Dr Gerald Gleeson, Dr Elizabeth Hepburn IBVM, Dr Nicholas Tonti-Filippini and myself. An order form for the guidelines is on the opposite page. What follows is no more than a brief summary of the main features of the guidelines: nothing replaces a close and careful reading of them in full!

Background

Three quite distinct social challenges - and the opportunity to respond to each of them - motivated the preparation of the guidelines. First, it is now possible for medical technology to be used to keep people alive in circumstances in which they would not want

their lives prolonged: measures to minimise that possibility becoming an actuality are thus needed. Secondly, a 'qualitarian' ethic about the significance of human life would have us believe that illness can so reduce the 'quality' of a life that it is no longer 'worth living': we need to resist that view, particularly when it issues in backdoor (and even frontdoor!) approaches to legalising euthanasia and assisted suicide. Thirdly, the various approaches to 'advance care planning' or 'future care planning' which are now available are of mixed quality: we need to ensure that people thinking about the medical treatment they would wish to receive when they are no longer able to make decisions about that (together with health care professionals who look after them) have the best possible assistance: guidelines that are true to medicine's own internal ethic, to good secular ethics, and to Catholic teaching about life, dying and death.

Think and talk about future medical treatment

The guidelines encourage people to think about the meaning of death in their own lives, to face and resolve personal differences within the family, to realise the desirability of leaving others with some guide to future medical treatment. They encourage people to talk about their hopes and fears, their goals in life, the kinds of treatment they would (and would

not) tolerate. They encourage people to initiate the relevant conversations not only with their own doctor but also with members of their family, and to do so over the years: if these matters are introduced early and gradually, it will then be easier to discuss specific and immediate issues relating to a terminal illness. Planning relies on good, long-term communication between the person, the family, friends, and health care professionals.

Consider appointing a representative

The guidelines encourage people to consider appointing someone to represent them should a circumstance arise in which they are no longer able to speak for themselves. They clearly recommend this approach to future care planning over that of filling out an 'advance directive'. The advantage of appointing a personal representative is that he or she will be able to respond to the changing circumstances in which treatment decisions need to be made. The representative's role will be to make decisions and communicate with a treatment team or nursing home manager, and possibly also to coordinate discussion among the family. (In a useful aside, the guidelines explain a number of different ways in which someone may become a representative, noting that this may happen quite automatically in some parts of Australia!)

Give guidance to the representative

The guidelines encourage people to provide their representative with some guidance about how they would like decisions to be made, some 'evidence of their past wishes'. That can be done by conversation and by the preparation of a statement or record of one's wishes: in fact the guidelines provide a useful model of such a statement, a model which can

be adapted by individuals for their own personal use. This 'model' is reprinted on page 12.

In another useful aside, the guidelines point out just how unhelpful so-called 'advance directives' may be. 'Advance directives' may be written in such a way that they actually prevent health care professionals from changing care to suit changing circumstances. They may be used to reject care that ought to be provided. They may be used to insist on treatment that is inappropriate. And, in some jurisdiction, their legal status may compound all these problems. That is why these guidelines recommend that people do not fill out any piece of paper that is called an 'advance directive'; rather if people wish to give written guidance to others about the forms of treatment and care they would and would not accept, they should make a statement of their values and wishes, a statement which can subsequently be used to inform, but not direct, their representative and the relevant health care professional.

Understand responsibilities and rights

The guidelines clarify the individual person's moral responsibilities with respect to medical treatment and care: that is, to use those means of sustaining one's life that are effective, not overly-burdensome and reasonably available. They clarify the individual's moral rights with respect to medical treatment and care: that is, to refuse any treatment that is futile or that is overly-burdensome or morally unacceptable. The guidelines then explain each of these key terms using the language of ordinary secular morality, and connecting that language with the corresponding language of the Catholic theological tradition. (Indeed, since the guidelines are intended to be useful for both believers and non-believers, there is only passing reference to a religious sense of the significance of life and death.)

Understand distinctive responsibilities of representatives

The guidelines for health care professionals point out something that is often missed in the literature on 'advance care planning': in some circumstances the rights of the patient and rights of his or her representative are not the same. Usually, of course, they are the same: a representative has the same moral rights and responsibilities to request or refuse treatment as the patient had while competent. However in some circumstances this is not the case. For example, individual people may well act generously and place themselves in some danger for the sake of others (for example, to donate tissue or organs or to lessen a burden on others). But a representative should only allow a patient to be endangered if 'the course of action would have been morally permissible for the patient while competent, and provided it is explicitly in accord with the patient's earlier clearly expressed wishes'.

There is much else in the guidelines. For instance, in the 'for people' guide, there is advice about how to plan for treatment and care in circumstances in which one is not able to feed oneself, and it is pointed out that it may be just as important to state what treatment and care one *would* want as it is to specify what treatment and care one would find overly-burdensome. And in the 'for health care professionals' guide, clear and action-guiding advice is offered about how to interpret an advance care plan in circumstances in which its applicability is not clear.

Bernadette Tobin is the Director of the Plunkett Centre for Ethics

Dear Associate Members,

Please find enclosed, as a loose sheet, the 2007 renewal of subscription form.

This form is made as a tax invoice especially for institutions who require an invoice for payment purposes.

May I take this opportunity also to remind you of the increase in subscription rate of which we advised you in June this year.

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May I wish you all a joyous christmas, and a very peaceful new year.

Linda Purves

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Catholic Health Australia

A model statement for future health care

I (name)
of (address)

ask that this document be used to inform decisions about my health care, in the event that I am not able to communicate my wishes. This statement is intended to guide but not direct my representative.

Person(s) appointed

Name(s):.....

Contact Details:.....

Statement of my wishes for my future health care

1. I wish to be given appropriate care to sustain my life, to cure disease, or to reduce deterioration in any physical or medical condition that I suffer.
2. I know that death need not be resisted by every possible means. I ask that I not be given any treatment that would not sustain me, or give me comfort or relieve a condition that I have, or would be overly burdensome to me or to others.
3. I ask that I be given adequate palliative treatment to manage uncomfortable or distressing symptoms, while maintaining as much function as possible, especially lucidity, during the dying process. If the only way to manage my distress is with treatments that have the side effects of reducing lucidity or even shortening life, then I am prepared to accept these consequences.
4. I wish to be provided with food and fluid, and with other basic means of sustaining my life and making me comfortable, for as long as I need them. This may need to be done by tube, unless or until such methods of treatment and care are ineffective or are overly burdensome.
5. I do not want my life to be ended, or my death to be hastened, by any act or omission that is intended to cause my death.
6. When it is thought that I am in the final stages of terminal illness or injury, or that my death is imminent, I ask that all reasonable steps are taken to allow me to be with my family and be reconciled to anyone from whom I may have become estranged, and if it is practicable, that I be allowed to die at home or at least in a home-like hospice or other institution.
7. (Strike out, if not applicable) In my medical care, I wish to follow the rites and teaching of my religion _____ (insert the name/denomination of your religion). I ask that I receive pastoral care and the appropriate ministry, both early in the course of my illness and again when death approaches.
8. (Strike out, if not applicable) I ask that those looking after me observe the *Code of Ethical Standards for Catholic Health and Aged Care Services* in Australia (CHA 2001) and subsequent Catholic Church documents.
9. (Strike out, if not applicable) I am suffering from the following degenerative illness:

In the following circumstances:

I would want effective, non-burdensome treatment and care that is reasonably available to be continued, but would consider the following to be overly burdensome:

I would also want the following:

Signature

Date

Witnesses