Euthanasia and the Fragility of Living a Burdensome Life

NICHOLAS TONTI-FILIPPINI
John Paul II Institute for Marriage and Family
Melbourne, Australia

A Personal Perspective

IN several Australian jurisdictions there are proposals to permit mercy killing or assisted suicide. This article began as a letter I wrote to members of Parliament, as a person whose protected status would be likely to be affected were the law to permit euthanasia.

I am dealing with my own terminal illness (combination of renal failure, advanced ischaemic heart disease and rheumatoid auto-immune disease) and am dependant on haemodialysis and palliative care. I have undergone fifteen angioplasty procedures and the placement of eight stents to attempt to recover some blood flow after the failure of coronary bypass surgery. The last such procedure was unsuccessful, as the blocked artery could not be accessed. The rheumatoid disease causes chronic pleuropericarditis. I mention these matters only to establish that I am no stranger to suffering and disability and am well aware of the limitations of palliative care. It is particularly difficult to control chronic pain because the effectiveness of most forms of pain relief is of limited duration, given the development of therapeutic tolerance. I have reached the limits of what palliative care can offer.

I cannot speak for all people who suffer from illness and disability, but think I can speak more credibly about suffering, illness, and disability than those people who advocate for euthanasia and present an ideological view of suffering and disability. Facing illness and disability takes courage, and we do not need those euthanasia advocates telling us that we are so lacking dignity and have such a poor quality of life that our lives are not worth living.

Professionally, I have been involved with issues to do with the care of the terminally ill for many years, having been Australia's first hospital

ethicist, twenty-nine years ago, at St. Vincent's Hospital, Melbourne, where I was also Director of Bioethics for a period of eight years. Since then I have been a consultant ethicist in private practice and have taught ethics in the medical faculties of the University of Melbourne and Monash University, before taking my current position at the John Paul II Institute. The Institute is associated with the Lateran University in Rome and is a registered Higher Education Provider in Australia, offering accredited specialist graduate courses in Bioethics and in Theological Studies in Marriage and Family.

Also relevant is that recently I had the experience of chairing a Working Committee of the Australian National Health and Medical Research Council (NHMRC), which prepared guidelines for the care of people in an unresponsive state or a minimally responsive state, and of receiving a large number of public submissions on that topic. The topic is closely related to this issue. The strength of submissions from people who care daily for Australia's most dependent and needy individuals was overwhelming, and I highly recommend reading the public submissions on the NHMRC's website or at least the NHMRC's *Ethical Guidelines for the Care of People in an Unresponsive State or a Minimally Responsive State (2008)*. Importantly, the guidelines provide a careful analysis of the way in which care decisions may be made so as to preserve respect for the dignity and worth of people who are so profoundly disabled and to provide care for the families and others who care for people with post coma unresponsiveness (PCU) or minimally responsive state (MRS). Note that PCU is the preferred term and more accurate than "permanent vegetative state" (PVS) because the reality is, all that we can observe is unresponsiveness and we do not know what level of brain activity may occur in that state.

I have also had a long-term association with a home hospice service that serves the eastern area of Melbourne. I would like to record my own view that it would not benefit seriously ill people, particularly those who are terminally ill and suffering intractably, if the current law that prohibits euthanasia were rescinded. The current legal situation, while not perfect, does provide a measure of protection against the terminally ill being regarded as a burden. As a chronically ill person, I know well what it is to feel that one is a burden to others, to both family and community, how isolating illness and disability can be, and how difficult it is to maintain hope in the circumstances of illness, disability, and severe pain, especially chronic pain.

For several years, until I objected, I received from my health insurer an annual letter informing me how much it costs the fund to maintain my health care. I dreaded receiving that letter and the psychological reason-

ing that would seem to have motivated it. Each year I was reminded how much of a burden I am to my community.

The Dignity of the Chronically Ill

The fear of being a burden is a major risk to the survival of those who are chronically ill. If euthanasia were lawful, that sense of burden would be greatly increased, for there would be even greater moral pressure to relinquish one's hold on a burdensome life. Seriously ill people do not need euthanasia. We need better provision of palliative care services aimed at managing symptoms and maximizing function, especially as we approach death. The dignity of people who are chronically or terminally ill would be better protected and supported if, rather than being assisted to die, people were given more help in their attempt to live more fully with the dying process.

If euthanasia or assisted suicide were to become a legitimate option with a determined structure, such as was the case in the Australian Northern Territory for a brief period and is the situation in Switzerland, Belgium, the Netherlands, and Oregon, then life for the chronically seriously ill would become contingent upon maintaining a desire to continue in the face of being classified as a burden to others. Essentially such legislation or guidelines involve isolating a category for people whose lives may be deliberately ended. Their protected status as a member of their communities depends on a contingency. Passage of such legislation would imply that our community considers that our continued survival depends on us not succumbing to the effects of pain and suffering, depends on us not losing hope.

Chronically ill people need the unequivocal protection of their lives. We need protection and encouragement from our community; we do not need this form of discrimination. Far from protecting the dignity of those who are seriously ill and suffering, a law to facilitate euthanasia would undermine dignity by undermining our sense of individual worth as a person, no matter our suffering and disability.

It should be noted that of the seven deaths that happened under the terms of the Rights of the Terminally Ill Act in the Northern Territory of Australia—which, before it was overridden by Commonwealth legislation, permitted euthanasia—four did not actually meet the criteria.[1] The legislation was manifestly unsafe, and I would argue that legislation that permits euthanasia could never be made safe for those of us who

[1] David W. Kissane, Annette Street, and Philip Nitschke, "Seven Deaths in Darwin: Case Studies under the Rights of the Terminally Ill Act, Northern Territory, Australia," *The Lancet* 352 (1998): 1097–1102.

have serious chronic illnesses, because the essence of such legislation is to make respect for our lives contingent upon the strength of our will to survive. Such legislation depends on each of us, who have a serious illness and are suffering, not losing hope. If euthanasia is lawful, then the question about whether our lives are overly burdensome will be in not only our minds, but the minds of those health professionals and those family members on whose support and encouragement we depend. The mere existence of the option will affect attitudes to our care, and hence our own willingness to continue.

That desire to live is often tenuous in the face of suffering and in the face of the burden our illnesses impose on others, our families and the wider community. Politicians would gain nothing worthwhile for us by supporting the legalization of deliberately ending the life of those who request death. Such requests warrant a response in solidarity from our community, a response that seeks to give us more support and better care, rather than termination of both life and care. Further, if euthanasia were lawful, then health professionals would be obliged to mention the possibility, and that would dramatically change their vocational role in which they encourage us to live as well as we can with our illnesses.

Christian Care of the Dying

The unqualified protection of their lives is important for people who are chronically ill. However it is also important there be an acceptance of the human condition and our mortality so that the chronically ill are not subjected to inappropriate efforts to prolong life.

When a person is considered to be in the last phase of life, then more than ever, it seems, issues to do with the meaning of life and the purpose for our existence become evident. Dying is a most important phase of a person's life, as we are led through growing disability to surrender the things of this life and to prepare for the life to come. Christians believe that it is not an end but a transition to a new beginning.

In the dying process, not only the dying person but those around them become acutely aware of the human condition. Christians believe that we are made in the image and likeness of God, for the purpose of communion with him, and we have free will. We accept the biblical story of mankind which tells us that we are affected by sin and that that fallen nature is characterized by suffering, war, oppression, poverty, vain striving, disappointment, and death. Death is part of the human condition: we are born dying—"the wages of sin" (Rom 6:23; cf. Gn 2:17). At the same time, however, we believe that we are redeemed by Christ's life, death, and resurrection and are called to communion with Him.

That belief in resurrection humanizes the dying process by giving us hope. It humanizes the dying process by allowing us to accept that life is in transition, that we are called to be with God, and therefore death is both tragedy and gain. Before us we have Christ's example, in which, at Gethsemane and in prospect of his own death, he expressed his complete and free submission to the will of the Father. His death transformed us through the sacrifice he made for our sins. For us, then, death is the end of our earthly pilgrimage; through death, we look forward to life in complete communion with Him. For that reason, we are not obliged to use every possible means to prolong life but can accepts death's inevitability in prospect of the life to come.

Christ's suffering, death, and resurrection also provide insight into the mystery of suffering. We know from experience and from the biblical account of the Fall that suffering is an inescapable burden of human existence. Christ has also shown that suffering in others provides the opportunity to love as he did in response to those he encountered. Christ's own suffering also shows us how best to respond in acceptance of the divine will for us. His suffering, especially his cry of abandonment on the Cross, also indicates the human reality of extreme suffering both in its effect on us (as it disables rational function) and in our need for the support of others. Empathy diminishes suffering.

The experience of suffering is for us thus a factor of personal growth, as we find that our love of others increases our capacity to suffer and, further, that love responds effectively to suffering through empathy. We also come to realize that though suffering dehumanizes, love humanizes, both the victim and those who love him. N·V