We will die one day, yet this is not a subject upon which we like to dwell. Many will not face up to this reality until forced to, either through our own illness or when someone close to us is sick or suffering from a chronic or terminal illness. It can be very confronting to watch someone close to us pass from a strong, fit and active healthy person, into someone suffering and in pain. Some may wish that they didn’t have to experience this, or that they didn’t have to watch them enduring such a disease. Some of us may wonder why a God of love allows this to happen; why there is so much suffering in the world; why does it have to be this way?

Many people have concerns about issues around dying, advanced care directives, refusal of treatment, euthanasia and end of life care. A few people argue that we should allow euthanasia for those who are dying in pain. Often this view is underlined by a fear of being “over treated” and kept alive “hooked up to a machine”. Others can fear that they will be “under treated” and abandoned when they are old and sick. We can worry that we may not be cared for as we would wish and we may fear approaching healthcare professionals as we get older. Most of us fear dying and being in pain. We might fear being a burden to others and wonder what does a good death really mean?
ADVANCE CARE DIRECTIVES?

In many hospitals and aged care facilities patients are being asked to sign advanced care directives or a living will, in case an illness or accident leaves them unable to communicate their wishes about medical treatment. We should be cautious in signing these sorts of documents. Advance care directives or plans can be too inflexible and in jurisdictions where they have been given a legal status, this could mean that health care professionals are prevented from acting in our best interests and changing our care to suit changing circumstances. The wording of these documents can be misleading, with the result that appropriate care is refused or inappropriate treatment given. Advance directives are often issued without full information because illness is unpredictable. They are thus not informed consent.

It is best to avoid documents that attempt to be too directive. A better alternative is to appoint someone to act as a representative. Written wishes may be produced to guide what happens, while being flexible enough to allow our representative to respect the patient’s values as the representative adjusts to new situations on the advice of health care professionals. When appointing someone it is important to discuss with them our values and beliefs, and which things we would consider to be burdensome. (Unless we appoint a representative, the law defaults to the senior available next of kin to make decisions for us.)

LEGITIMATE REFUSAL OF TREATMENT

The Catholic position on end of life care is often misunderstood. The Church does not hold a literalist position which requires us to fight death at all costs to the bitter end. Rather, we are obliged to be good stewards, caring for our health and life but accepting death when it comes. We are not obliged to use overly burdensome means to prolong life.

We can refuse medical treatment in instances where the treatment has become overly burdensome or disproportionate – where it is no longer providing any benefit to the patient, where it has become painful, frightening, repugnant, “overzealous” or even dangerous, or where it has become an excessive burden, on the patient and his or her family, or the hospital. This is also referred to as “refusing extraordinary treatment.”

We should be careful not to confuse refusing burdensome treatment with euthanasia. Euthanasia is defined as the deliberate ending of a life by active means (eg fatal injection) or by omission (withholding reasonable, non-burdensome care) in order to end suffering. Euthanasia is a grave violation of the law of God, since it is the deliberate and morally unacceptable killing of a human person.

Euthanasia crosses a line; its focus is on ending the life, rather than ending pain. Refusing extraordinary treatment is very different from euthanasia. The focus is not on hastening death or killing, but accepting that a treatment is no longer effective or reasonable, and that natural death is inevitable. John Paul II says that “in such situations, when death is clearly imminent and inevitable, one can in conscience refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted.”

We cannot legitimately refuse ordinary care. Ordinary care means care that offers a reasonable hope of benefit and can be obtained and used without excessive pain or other inconvenience.

Decisions to refuse burdensome medical treatment should be made where possible by the patient if he or she is competent. If the patient is no longer able to make the decisions, then such decisions should be made by those legally entitled to act for the patient, and who are required to act in the patient’s best interests. This includes someone appointed by the patient to be a medical power of attorney, the senior available next of kin, or a guardian appointed by a court or tribunal.

SICKNESS DOES NOT ROB US OF OUR DIGNITY

Every human being has a special dignity regardless of age, sickness, disability, or our inability to communicate. Our dignity lies in our being, our existing. We possess dignity not because we can think, or make or do but simply because we are human.

TUESDAYS WITH MORRIE

An old man, a young man and life’s greatest lesson

When Mitch Albom hears his old professor has amyotrophic lateral sclerosis (ALS) he decides to look him up. Their story becomes an international best seller and helps to pay Morrie’s medical bills.

His death sentence came in the summer of 1994. Looking back, Morrie knew something bad was coming long before that. Morrie’s doctors guessed he had two years left. Morrie knew it was less.

But my old professor had a profound decision, one he began to construct the day he came out of the doctor’s office with a sword hanging over his head. Do I wither up and disappear, or do I make the best of my time left? He had asked himself. He would not wither. He would not be ashamed of dying. Instead, he would make death his final project, the centre point of his days. Since everyone was going to die, he could be of great value, right? He could be research. A human textbook. Study me in my slow and patient demise. Watch what happens to me. Learn with me. Morrie would walk that final bridge between life and death, and narrate the trip. You know Mitch, now that I’m dying, I’ve become much more interesting to people.

“We’re Tuesday people,” he said. Tuesday people, I repeated. Morrie smiled. “Mitch, you asked about caring for people I don’t even know. But can I tell you the thing I’m learning most with this disease? What’s that? The most important thing in life is to learn how to give our love, and to let it come in. His voice dropped to a whisper. Let it come in. We don’t think we deserve love, we think if we let it in we’ll become too soft. But a wise man named Levine said it right. He said, “Love is the only rational act.” He repeated it carefully pausing for effect. “Love is the only rational act.”

*Ref. 9*
We share this dignity with every human being, because we have been created out of love by God and intended for eternity. Every human being is therefore a “someone” and not a “something”.

The very best human societies work together to ensure that everyone has the basic necessities, care and support when they most need it. They seek to protect and respect the dignity of each unique human person no matter how old, frail, sick or weak they may be.

WHAT IS THE POINT OF SUFFERING?

It is hard to watch someone we love suffer and often we can feel helpless, and frustrated.

There may be a tendency to want to control death and to think that suffering results in life that no longer has any meaning. This can be exacerbated when people lose contact or feel abandoned by their own families.

However, suffering is not pointless. Pope John Paul II reminded us that God is always on the side of those who are suffering and that the Cross gives new meaning to suffering. Jesus, he says, freely accepted His suffering, although He could have chosen not to do so, but He stayed on the Cross until the end, in order to reveal His complete Love. Christ is the one who loved … to the end.17

John Paul II further explains that “To the end” means to the last breath … it is the revelation of that Love which endures all things. It is the revelation that God is Love and the One who pours out love into our hearts through the Holy Spirit.18

We have a natural tendency to abhor death, to want to fight the destruction which it brings, John Paul II explains that it is because we bear within ourselves an eternal seed which cannot be reduced to mere matter. It is in the face of death that this riddle of human existence is heightened. Through his Cross and resurrection, Jesus has defeated death, He has liberated us, and given us the hope of resurrection and at the same time cast new light on the mystery of suffering and death.

Belief in the resurrection humanises the dying process by giving us hope. Life and death have new meaning. Life is in transition, dying becomes the way through, as we are called home to be with God. John Paul II encouraged us by reminding us that in the “new Jerusalem,” that new world towards which human history is travelling death shall be no more, neither shall there be mourning or crying nor pain any more, for the former things have passed away.”19

When confronted with suffering and dying, Christians are called to follow the way of love and true mercy, and not to abandon the person but to respond with companionship, sympathy and support, empathy and love. We are called to hope when all human hopes fall.20 The experience of suffering can be a factor in personal growth as we find that our love of others increases our capacity to suffer and that love responds effectively to suffering through empathy.21

ROLE OF HOPE

There is some evidence that people5 suffer from a condition that researchers have called existential suffering or hopelessness, which simply means that they have nothing to look forward to that day, or the next day. The remedy can be as simple as a visit from a loved one or seeing the sun rise the next morning. We can all play a role in bringing hope and like Mitch (see text box story) we may discover that we receive more than we could have imagined in return.

A GUIDE FOR PEOPLE CONSIDERING THEIR FUTURE HEALTH CARE

Catholic Health Australia with the Committee for Doctrine and Morals of the Australian Catholic Bishops’ Conference has produced guidelines to assist patients, and their families, ‘A guide for people considering their future health care.’ (In addition they produced a second document for health care professionals.)

The guide helps people prepare for illness and death and for the instance where they may not be able to communicate their wishes. It encourages them to consider their health care needs and treatment preferences and to discuss their wishes with their family members. It also has a form that can be completed to explain what we would want.

The guide aims to help people:

- nominate a representative to make health care decisions based on their wishes and values;
- provide reasonable and adequate guidance for their representatives; and
- recognise the issues that need to be taken into account to achieve this.

They point out that:

- Though illness can be unpredictable, we may choose to offer those entrusted with our care some guidelines about our wishes for our future health care
- Planning future health care relies on good, long term communication between you and your family, friends and health care professional.
- A representative can make health decisions on your behalf, based on your advice, the advice of your health care professionals, and your representatives own good judgement. These health decisions have the advantage of being flexible in response to changing circumstances.
- You can allow your representative to make health decisions for you, or you can provide that person with specific advice, verbally or in writing, or by having it recorded in your doctor’s records.
- You may wish to clarify the burdens that you would find acceptable, for example, by requesting that you be given only the kind of treatment or care that can be provided in your home, without the need for prolonged hospital care.

‘Given the continuing debate over euthanasia and the withdrawal of medical treatment, it is important to state explicitly that you do want life sustaining treatment provided that is reasonable unless it becomes futile or is overly burdensome.’22 ACBC 5, 8

The guidelines also provide an example of a model statement.

www.cha.org.au or www.lnf.cam.org.au

Continued page 4
WHAT IS PALLIATIVE CARE?

Modern palliative care and support recognises the unique needs of a person with an incurable condition and their family and carers. It is about allowing the person to live as well as they can for as long as they have, whether it is days, weeks or months, or even years left to live. It is whole of life care attending to their distress, relieving the pain where necessary, as well as attending to their psychological, social, emotional, cultural and spiritual needs. It provides support to help the family cope during their loved one's illness and death. It aims to help people live as fully as possible during the dying process.

Like the Good Samaritan, Catholics have a long tradition of caring for the sick and the dying. Today Catholic hospital and aged care facilities provide 55 per cent of palliative care in Australia. Staff work to uphold the dignity of the human person. In the provision of health and aged care, patients, residents, practitioners, family and carers become a small community united in working for a person's good. The Order of Malta has a biography project in which people are trained to sit with a dying person and record their life story in order to give it to the family. This greatly enriches the dying process.

PRAYING AND PREPARING FOR A GOOD DEATH

From the beginning Catholics have prayed for a “good death” through prayers such as the Hail Mary. The last stage of our life can be a special, grace-filled time of preparing for death, of reflecting on, of forgiving and being forgiven, and of giving and receiving love. It can be a time to say thank you, a time to pray and be prepared for, time to say goodbye, and a time of preparing to meet God. Willingness to accept the care of family and friends can be a source of love and hope. And as St Paul (Romans 14:7) reminded us, the lives of each of us have their influence on others. We pray that when our time comes we too can love ... to the end.

Prayer for Life

Heavenly Father,
We pray that you might awaken in us a new respect for every human person, especially those who are sick, suffering and dying, that we might remain close to them and be able to love ... to the end. Amen.

ENDNOTES

3. John Paul II. Evangelium Vitae: The Gospel of Life (Sydney: St Paul's, 1995). No. 16. 6
5. 5y of the Gospel, p.143
6. And p.420
9. pp 48-50
10. pp 41-42
11. pp 42-44
12. Benedictine nun, Br. Mary, who wrote: “Journey, appreciate and suffering from Largo Culligan Disease (which is on the x-axis that Marie has)”. Margaret Farnese. The Medical Century (Melbourne: 2004) p.178
16. pp 45
17. pp 44
18. pp 42

JOHN PAUL II’S PERSONAL WITNESS

Throughout his long life Pope John Paul II travelled the world proclaiming the sacredness of every human life. He reminded us of all that we are to be: a young, healthy, that aging and suffering are a natural part of life.

Pope John Paul II suffered from the debilitating effects of Parkinson’s disease in his last years. As he used the gift of his illness, he used the gift of his illness, his Pope John Paul II lived his mission until the very end, accepting being absent from the Holy Week services of that year and not concealing his physical weakness. On Easter Sunday (27 March 2005) when his body lay in state in the Gemelli Polyclinic and a trainee, he tried, as we all remember, to take his own pulse, but the only clear thing was the gesture of the Blessing. He used his example, the late Pope taught us how to walk the path which leads us to the mystery that awaits us when each of us is given the gates of eternity will be opened.

Hospices and Palliative Care Services

For a complete list see www.cha.org.au or call (02) 6203 2777
Cabram Health
(03) 9596 2583
Calvary Healthcare Bethlehem
(03) 9596 2583 or www.bethlehem.org.au
Mercy Hospice
(03) 9364 9777 or mwps@mercy.com.au
St Vincent’s Health: Sisters of Charity
www.cha.vic.edu.au

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