Provision of Palliative Care in Catholic Health and Aged Care Services

Advice for staff
Acknowledgements

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Suzanne’s story

Today, many of us fear dying and death. We don’t want to think about it, and we certainly don’t want to talk about it. This means when we have to face it, most of us don’t even know where to start.

Sometimes we might have questions but we don’t know where to get the answers. If we think about death at all, we might think we want a “good death”; we don’t want to experience pain or to suffer. But we don’t think about the systems and resources necessary to make this happen, or about what we need to do ourselves to make our choices a reality.

One resource is palliative care. But most of us don’t really know what palliative care is and fear it even more than death itself. We also fear losing control.

Suzanne Reber, a teacher, spoke to Palliative Care Australia about her experience living with a terminal condition and being referred to palliative care.

Maintaining control

I had a lot of hesitation. I was diagnosed with the cancer five years ago when I was 46. So, it’s been a fairly long battle with several operations and the usual up hill and down dale in between. When it came to the realisation that outside intervention just wasn’t helping anymore, my oncologist wanted to introduce me to the palliative care team and I basically brought out the garlic and the cross, and I said no thank you very much, not for me.

My idea was that my life was going to be taken over by these hoards of people rushing into my house, basically taking control of my life.

For people in my situation, control is the only thing you’ve got left. You don’t have control of the disease, but you do have control over how you intend to live your life until the end. It’s my life and I didn’t want my home invaded and turned into a hospital – to me that was just abhorrent. But it isn’t like that. If I say don’t come, there’s no argument. If I say I don’t want something, that’s okay. It’s not foisted upon you. It’s not this heavy thing – this is what you have to do. You’re not being bullied, you’re not being controlled. They’re there, they quietly let you know they’re there, and then it’s up to you as to how much or how little you want to use them.

Aside from fears of losing control, people also fear dying in pain. Palliative care professionals have expertise in pain management. However, despite the expertise available, some people do miss out. Knowing where to go for information and help is a big part in receiving care that meets needs and expectations.
Pain

Once I hit the pain, I knew I needed help – pain management help. I had three weeks of bad pain management. I was in this vicious cycle of being very ill, very nauseous, in a very downhill spiral. Terrible side effects because I was on all the wrong medication. I ended up in hospital because I was in such a state. Mentally, it affected me greatly being in pain, you’re not normal, you can’t enjoy the company of family and friends. That’s when I met my palliative care doctor, he gave me medications nobody else seemed to be able to put their finger on. Within 48 hours, I was a human being again, a completely different person. It was amazing. He knew his business. Pain management gives you an extension of quality of life, of your normal life. It’s not a fix, no-one sells it to you as a permanent cure. All they’re trying to do is control things to make your quality of life as best as possible for as long as it is quality. It’s not we’re going to keep you alive for as long as possible, against the odds, just for the sake of watching you breathe. There are very good pain control medicines out there. With time and research it’ll get even better.

Planning for the future to ensure we receive the care we want and need when we need it is important. As consumers of the health system, we have choices but we need to make these known. Having controlled Suzanne’s pain, her doctor started talking about advance care planning.

Planning

He gave me options and asked me what I would like to do. Nothing was foisted upon me, like ‘this is what you have to do’. The choices were still left in my hands.

I told him my lines in the sand, what I wanted, I wanted to live but live while I was still me. I had my resuscitation orders and artificial feeding orders and he just looked at me and said ‘I totally agree with you’. I have his assurances that my wishes will be carried out.

But I have been one of the lucky ones who has actually seen that people can die on their own terms, it puts my mind at rest. When I saw how my Dad passed away, I knew I could wish that on my best friend. There were plans and these were followed – it was the most humane, unstressful way, not just for my Dad but for the family. Peacefully, no drama, no fuss, no histrionics. It wasn’t scary. I’ve had five years to think about a plan, so I had a plan. But there would be people who wouldn’t understand what a plan is. I’m the type of person who’ll ask questions, but there are a lot of people who don’t like to do this, who don’t have access to information.
Sometimes people need someone to open up a conversation that may go over a period of two or three sessions where you first build a rapport and then gently lead them towards information so they can make their choices.

*Having someone to talk to for emotional and spiritual support can also be important. Because we don’t like to talk about dying, death and loss, we often have misconceptions about what help is available and don’t know where to find information.*

**Emotional support**

I’ve thought a lot about dying because my Dad was living with us when he passed. We had a lot in common because we were both facing our mortality. I could talk to him about my fears and he could put things into perspective. I once said to him I was afraid of being in a dark box in the ground, and I think that’s obviously a very common thing. He said to me, you’ve got two alternatives. You either believe that there’s a spirit or a consciousness, and that consciousness leaves you when you take your last breath and it goes into a bigger something or other – so it’s not going into the ground. If that’s not what you believe, the other alternative is you’re not alive, there’s no consciousness and you won’t know where you are. So don’t worry either way. I laughed. It really made sense to me. Between my Dad’s explanation, and my doctor’s reassurance that my wishes will be carried out, and actually seeing how someone dies, it’s put my mind at rest.

There might be other people out there like me who have the wrong opinion about palliative care, and might now give it a second thought, that’s why I want to tell my story.

I have no regrets. I’m glad I took the path I took, and now I’ve had enough. I’m tired. I’ll stay home for a little longer while I’m still sort of semi-functional, because what I’m doing at home is the same I would be doing in hospital at this stage – so I might as well do it in my home.

*Palliative Care Australia thanks Suzanne Reber and her husband Brook Reber for their extraordinary generosity in sharing their experiences.*

*Suzanne passed away on 23 May 2009, shortly after telling her story.*
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**About Catholic Health Australia**

75 hospitals and 550 aged care facilities are operated by different bodies of the Catholic Church within Australia. These health and aged care services are operated in fulfilment of the mission of the Church to provide care and healing to all those who seek it. Catholic Health Australia is the peak member organisation of these health and aged care services. Further detail on Catholic Health Australia can be obtained at [www.cha.org.au](http://www.cha.org.au).

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Pope Benedict XVI writes:

“The Church wishes to support the incurably and terminally ill by calling for just social policies which can help to eliminate the causes of many diseases and by urging improved care for the dying and those for whom no medical remedy is available. There is a need to promote policies which create conditions where human beings can bear even incurable illnesses and death in a dignified manner. Here it is necessary to stress once again the need for more palliative care centres which provide integral care, offering the sick the human assistance and spiritual accompaniment they need. This is a right belonging to every human being, one which we must all be committed to defend.”

CHAPTER ONE

Introduction – A Culture of Life
In the Catholic tradition, human life is defended from conception to death. The sanctity of life is the fundamental underpinning of the Catholic Church’s understanding of human existence. All life is to be valued and nurtured until the moment of death. Even after death, a person’s life is respected, in the way that their body is treated and in preparations for their funeral, together with the way that family and loved ones are supported through their grief and loss.

Palliative care is a holistic and comprehensive form of care for people who are living with a life-limiting illness (this may also be known as a terminal illness). Palliative care is everyone’s business and as health professionals the hallmark of good palliative care is to improve the quality of life for people with a life-limiting illness, and help their loved ones in bereavement.

In the Catholic tradition, death is part of life and any act to deliberately hasten or shorten a person’s life is not supported. Palliative care is a means to promote a culture of life rather than support a culture of death. A palliative care approach does not seek to unnecessarily prolong or hasten death, but accepts a death as part of overall mystery of life.

Voluntary euthanasia or physician assisted suicide are not a part of palliative care practice. Nor are they part of the Catholic tradition of health and aged care.

As a health professional you may be asked by a patient or a family member to assist with euthanasia. In some instances the suffering from poorly managed symptoms and loss of dignity may contribute to this request, together with something more deep-seated at the spiritual level – painful loneliness, a feeling of being a burden to family and loved ones, or a feeling of losing control of one’s body and self. In this situation, palliative care and/or pastoral care could help alleviate the patient’s distress, so advice could be sought from specialist palliative care team and pastoral services teams.

The Catholic Church has always had a special place for the sick, the vulnerable and the dying and for this reason, palliative care has always held significance and meaning in the ministry of Catholic health and aged care. The Catholic Church has always endeavoured to find the meaning in suffering and death and in this way help people as they journey through this life and into the next, eternal, life.
The rituals surrounding the end of life - anointing of the sick, the vigil before the funeral and so on - are signs of a readiness to face death and dying as a necessary and normal aspect of life. Death and dying are but preludes to eternal life. What we know as life is only a phase of a journey. We are a pilgrim people - a people on the way - and that is cause for celebration. ²

1.1 Palliative Care in Catholic health care facilities

As the organisation representing Catholic health and aged care providers across Australia, Catholic Health Australia’s principles guide the healing work of the many facilities that provide Catholic health, aged, community and hospice care. These principles include:

**Dignity of the human person**

*Each person has an intrinsic value and dignity.*

In a palliative care context, this means that each person is appreciated for their individuality and uniqueness. They are cared for in a holistic way which recognises that they and their carers and families have physical, psychological, social, emotional and spiritual needs.

As death approaches, a person is likely to experience times of fear, anxiety and loneliness. It is at these times that the care provided in a Catholic facility can bring healing and comfort and a sense of meaning to this part of a person’s life. In death, Catholic facilities and their staff respect the impact on family and others in their grief. Providing an opportunity to explore this grief is a fundamental component of palliative care.

**Service**

*The provision of health care is conducted out of a spirit of service and solidarity with those in need.*

To be part of the journey of a person who needs palliative care is a privilege and an honour. It is a time when health care workers can be most connected to human frailty and vulnerability and spurs a spirit of commitment and service to ensure those in our care experience a healing presence and feel loved and supported.

² Adapted from Catholic Health Australia, *Catholic Care of the Ageing.* (Canberra: CHA, 2005), 19.
Common Good

Commitment to the dignity of every individual leads to an appreciation and dedication to the community at large.

The way in which we treat people who require palliative care is testimony to our respect for the gift of life. The gift of life is nurtured and honoured in individuals and across society at large.

There are a number of specific medical situations, particularly as the end of life draws near, in which Catholic ethics in palliative care may differ from those of other health organisations, even if they are religious-based organisations. Such situations include those where decisions need to be made about withdrawal or withholding of treatment and provision of hydration and nutrition.

The Catholic approach to palliative care is distinctive in at least two ways. Firstly, it has clear standards about treatment at the end of life. Catholics believe that we have an obligation to use those means of sustaining our lives that are effective, not overly burdensome and reasonably available. But on the other hand, Catholics believe that we have a moral right to refuse any treatment that is futile, or that we judge to be overly burdensome or morally unacceptable. Treatment is futile if it provides no benefits, such as slowing down the progress of disease, sustaining life, or relieving distress or discomfort. Treatments are burdensome when they cause distress and suffering, cause difficulties for the patient or his or her family, or are costly to obtain or provide. These clear standards help us to make wise choices as we approach the end of life.

Secondly, the Catholic approach to palliative care is distinctive in its passionate commitment to palliative care. There are at least three reasons for this. Firstly, the Catholic faith holds that each person is created in the image and likeness of God. This affirmation of the great worth and dignity of all people empowers Catholic institutions to care passionately for each and every person. Secondly, Catholic hope in the Resurrection connects death with the bright promise of eternal life. Catholic institutions are therefore comfortable with death, and also comfortable to be with people who are dying. Thirdly, Catholic reflection on the mystery of suffering reminds us that even at our very worst times there are still great possibilities. There can be special moments (even times of reconciliation) with those we love. Although many things disturb us, there can be deep peace. Even as our physical body fails, our spirit can grow. There can be hope in despair, healing in pain, light in darkness, and life in death. The distinctive Catholic approach to palliative care is coloured by all these things.
This publication is not intended to cover the very detailed specific ethical aspects of palliative or end-of-life care. Further reading on these topics can be found in the following CHA publications:

- **Book**: *The Code of Ethical Standards for Catholic Health and Aged Care Services.*
- **Brochure**: *End-of Life Issues*
- **Brochure**: *Briefing Note on the Obligation to Provide Nutrition and Hydration.*

These publications are available to order or download on the Catholic Health Australia website: [www.cha.org.au](http://www.cha.org.au).

People who know they are dying may want to live their remaining life to the full and experience every moment of love, peace and joy they can through time with loved ones, reminiscing about their life, sorting through their affairs and resolving any issues that have caused them pain and grief in the past. Having the opportunity to talk about these issues becomes paramount and often it is health care professionals who are in the position to have these conversations.

In this publication we explore the concept of palliative care with a focus on supporting life and living and supporting families following the death of a loved one.

> The events that occur in the last hours or days of a person’s life may be etched in the minds of those who are left behind – if the bereaved are witness to a good death then their journey can be more readily reconciled.
CHAPTER TWO

What is palliative care?
Many people think that palliative care is just about providing care for a person in their last few days or weeks of life. Palliative care is much more than this and can be introduced years before a person may die. As soon as a person is diagnosed with a life-limiting illness, the core principle of palliative care is practiced - focusing on quality of life, to live as full and active a life as possible. When life is clearly drawing to an end then the intent changes to facilitating a dignified death.

Palliative care can be provided in a person’s home, in residential aged care (which is also a person’s home), a hospital or hospice.

The World Health Organisation defines palliative care as:

*An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*

Palliative Care Australia adopts the World Health Organisation list of what constitutes palliative care.

**Palliative care:**

- Provides relief from pain and other distressing symptoms,
- Affirms life and regards dying as a normal process,
- Intends neither to hasten or postpone death,
- Integrates psychological and spiritual aspects of patient care,
- Offers a support system to help patients live as actively as possible until death,
- Offers a support system to help the family cope during the patient’s illness and in bereavement,
- Uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated,
- Will enhance quality of life, and may also positively influence the course of the illness, and
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

As the list suggests, palliative care encompasses many aspects of the care provided by a range of people working in Catholic health and aged care facilities.

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3 World Health Organization definition found at www.who.int/cancer/palliative/definition/en/
4 Palliative Care Australia, Standards for Providing Quality Palliative Care for all Australians. (Canberra: PCA, 2005), 10.
Palliative Care Australia’s *Palliative and End of Life Care Glossary of Terms* helps identify goals of treatment and care planning:

1. A palliative approach is taken when it is recognised that someone has a life-limiting illness. The primary goal is to promote quality of life by maximizing the person’s comfort and function and address their psychological, spiritual and social needs and support their family. A palliative approach is appropriate for patients whose needs could be met by a non palliative medicine specialist team, for example, an aged care specialist or general practitioner and a generalist community nurse or non palliative care ward nurse.

2. Specialist palliative care is provided for patients who are considered to have complex needs requiring an interdisciplinary approach from health professionals who have had specific palliative care training or a specialist in their field of palliative care. These patients are more likely to have problems associated with their disease. Specialist palliative care is appropriate when a person has complex care needs and may have been referred to a specialist palliative care team or healthcare practitioner. This does not replace a palliative approach, but enhances it for when specialist input is required.

3. End of life care is appropriate when it is recognised that a person has reached the terminal phase of life, specifically, the final days or weeks of life, indicated by: requiring more frequent interventions, being bedbound, experiencing profound weakness, loss of appetite, difficulty swallowing, dry mouth, decreased level of consciousness and ongoing deterioration that is not reversible. 

2.1 Identifying goals of treatment and care planning

The patient’s goals for care should guide the treatment and care that the patient and his or her family chooses and receives. In addition to helping to establish overall goals, palliative care teams and other health care staff can help patients and families to clarify priorities for treatments and care.

When changes occur, treatment priorities and goals should be reviewed.

Review should occur when there is:

- A significant change to health status, including life expectancy,
- Change in the setting of care, or
- Change in patient preferences.

Patient goals should be based on his or her individual values and preferences, guided by specific health status and clinical circumstances.

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Questions that can be used to help determine patients’, clients’ or residents’ values and goals for treatment include:

- What are you expecting?
- What are you hoping for?
- What do you want to accomplish?
- What is the most important thing in your life at the moment?
- What do you hope to avoid?
- What do you think will happen?
- What are you afraid will happen?  

Sometimes a health professional will not be able to support a patient’s choice, and sometimes goals are unreasonable and not achievable. If this is the case, the health professional must work with the patient and his or her family to find an alternative solution.

Supportive Care

Supportive care practices are also supported by Catholic services. Supportive care in cancer involves the prevention and management of the adverse effects of cancer and its treatment. This includes managing physical and psychological symptoms and side effects across the continuum of the cancer experience, from diagnosis, through anticancer treatment, to post-treatment care. Enhancing rehabilitation, secondary cancer prevention, survivorship and end of life care are integral to supportive care.

Supportive care primarily applies to cancer and has moved internationally into HIV services. It is hoped and expected that the application of supportive care will move into the non-malignant areas of life-limiting illnesses.

Supportive care includes self-help and support, information, psychological support, symptom control, social support, rehabilitation, spiritual support, palliative care and bereavement care.

Supportive care in cancer refers to the following five domains:

- Physical needs
- Psychological needs
- Social needs
- Information needs
- Spiritual needs

With the future expected introduction of integrated cancer care centres the profile of supportive care will grow. For example, achieving high-quality supportive care in Victoria for those affected by cancer is currently being demonstrated by an improved experience of, and satisfaction with, cancer care, access to appropriate supportive care services when required and decreased variation in supportive care provision within Victoria.
CHAPTER THREE

Essential elements in the delivery of holistic palliative care
The following diagram outlines some of the essential elements of best practice palliative care service delivery:

**Essential elements of Holistic Approach to Palliative Care:**

- **Physical Needs** (e.g. Symptoms, level of consciousness, wound care, nutrition/hydration, etc)
- **Psychological** (Emotional issues, diagnosis, fears, loss, death)
- **Social** (Welfare, cultural, family support, legal issues, guardianships, etc)
- **Spiritual** (Values, beliefs, pastoral, rituals, etc)
- **Practical** (Discharge planning, special needs, dependents, activities of daily living)
- **End of Life Care** (Pathways and protocols, needs and wishes, certification of death, funerals, bereavement support, advanced care planning, etc, education)
- **Loss & Bereavement** (Bereavement care, loss, grief, support systems)
- **Disease Management**

Catholic Health Australia believes that the special commitment to the ministry of caring for patients with a life-limiting illness and its values and ethics should make all Catholic palliative care services beacons of excellent professional practice and exceptional compassionate care. As the national body representing the interests of all Australian Catholic health and aged care providers, Catholic Health Australia actively works with other national bodies and organisations involved in ensuring the most professional approach to palliative care in Australia and in supporting measures to continuously improve service delivery and care in the field. Catholic Health Australia encourages all Catholic health services to be committed to evidence-based practice in health and to keeping up with the latest research and studies for improving palliative care.

11 Palliative Care Australia, *Standards for Providing Quality Palliative Care for all Australians*. [Canberra: PCA, 2005].
3.1 Commitment to best practice and collaboration

Catholic Health Australia works closely with Palliative Care Australia (PCA) which is the peak national organisation representing the palliative care sector across Australia [www.pallcare.org.au]. To this end Catholic Health Australia encourages all Catholic health services to support the implementation of PCA’s Standards for Providing Quality Palliative Care for all Australians as well as a number of quality improvement programs across Australia.

These programs include:

- **Program of Experience in the Palliative Approach (PEPA).** This is an initiative of the Australian Government which aims to provide flexible, experiential clinical learning experiences to improve knowledge and ability to provide care for people at the end of life. This program is available for all professionals working with people with life-threatening illnesses, eg. aged care facilities, residential facilities for the disabled, indigenous community workers, community nursing and general practice. Further information can be found at [www.pepaeducation.com](http://www.pepaeducation.com).

- **Palliative Care Outcomes Collaboration (PCOC).** This is a voluntary quality initiative which supports continuous quality improvement in palliative care service delivery, measuring the standard and quality of care and providing an opportunity for benchmarking. PCOC supports accreditation. Further information can be found at [www.chsd.uow.edu.au/pcoc](http://www.chsd.uow.edu.au/pcoc).

- **National Standards Assessment Program (NSAP).** This is a quality improvement program which will enable specialist palliative care services to undertake consistent self-assessment against the 13 “Standards for Providing Quality Palliative Care for all Australians”.


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**International Quality Improvement Initiative - Liverpool End of Life Pathway**

The Liverpool End of Life Pathway (LCP) is governed by the Marie Curie Palliative Care Institute in Liverpool. LCP prompts the healthcare team to implement 18 goals of care to ensure optimal patient comfort and family member support during the last 72 hours of life. The focus is on physical, psychological, spiritual, communication, information. Further information can be found at [www.mariecurie.org.uk/forhealthcareprofessionals/liverpoolcarepathway.htm](http://www.mariecurie.org.uk/forhealthcareprofessionals/liverpoolcarepathway.htm)
3.2 Spiritual Care

After a diagnosis of a life-limiting illness, issues around the meaning and purpose of life, faith beliefs (and doubts) and spiritual practices and rituals can become much more important and prominent. All health professionals have a role to play in ensuring the spiritual needs of their patients are met. This includes having empathy for the person and listening to their concerns. This may be as simple as acknowledging the person wants their favourite music or hymn played, someone to read them a verse or say a prayer, or having someone hold their hand for a time. These are all acts that can be done by anyone and may bring great peace and comfort when the patient needs it most.

However there will be times when referral to pastoral services is needed to assist with more in-depth spiritual guidance for the patient and their family.

Questions that can be used to understand spiritual needs

- Is there anyone that you would like to speak to about your spiritual needs?
- Do you have any spiritual practices that you would like to observe while you are with us? How could I help you with that?
- How is your family handling your illness?
- What gives you meaning or purpose in life?

Of course, any responses to these questions need to be followed up appropriately and if a person does ask for assistance or to see someone about their spiritual needs, arrangements should be made in accordance with the patient’s wishes.

3.3 Pastoral Services

Felicity, 56 years old

There was a lady who had been coming in and out of the hospital for many years. She had Multiple Sclerosis and had a major stroke which left her unresponsive. The family desperately wanted her to be a part of their lives so a PEG was inserted, enabling her to live at home. Last year she had a severe dose of pneumonia, was placed on the palliative care list and soon after died.

During all her admissions we would bring her to Mass in the bed and place a little of the wine on her lips.
It was of course the family we were supporting. They were very insistent we continue her full resuscitation orders which was pretty challenging.

In the end it was about helping the family to find peace with her death. I was present with the family when the physician spoke to them and we then organised the priest to come; she did die comfortably. When I spoke to the family afterwards and at the memorial service, they remained peaceful that everything that could have been done was done.

It is important that health professionals acknowledge religious, spiritual and cultural needs of patients and their families. This includes informing them of pastoral care and chaplaincy services, and facilitating access to these services.

This is an important aspect of our mission because “the spiritual dimension is not an optional extra, it is fundamental to a complete appreciation of being human.”

Pastoral care provides for the spiritual wellbeing of patients, families and staff, no matter what their faith might be. The special place of pastoral care in a Catholic hospital reflects the fact that it is seen as a means of giving expression to the commitment to holistic care and to a faith vision of life.

Family and loved ones may experience grief and bereavement issues as they walk the journey with someone living with a life-limiting illness. Along the journey some may grieve and mourn for their loved one. Both pastoral and spiritual care can be beneficial to families at this time and this topic is covered in more detail in the section on carer support.

From the CHA Code of Ethical Standards for Catholic Health and Aged Care Services

The work of Catholic health and aged care facilities is illuminated by hope in the Resurrection. It should, therefore, be distinguished by the quality and accessibility of the pastoral care offered to patients and their families with a life-limiting illness in a supportive context in which the person has the opportunity to find meaning and purpose from diagnoses and in some instances pending death. Healthcare practitioners should be alert to the particular religious and sacramental needs of persons with a life-limiting illness and more importantly when close to dying and be ready to link the person with his or her clergy and community.
Mark, 42 years old

Mark had a long complicated history of substance abuse. He was homeless and estranged from his family. He had a diagnosis of stomach cancer with secondary cancers in the liver and bones. His health was deteriorating and he was admitted to the hospital for symptom management and other palliative care support. He was not able to be discharged because he was homeless and the local hostels would not take him back in because of his substance abuse. During his stay in the hospital he attempted to overdose on several occasions. He stated to staff; “I have nothing to live for – I am nothing”.

He was transferred to a purpose-built palliative care service in a semi-comatose state with the prospect of just three to four days to live. Within 48 hours he started to wake up and at his bedside was a pastoral care practitioner who had spent time with him in the preceding 48 hours in the knowledge that Mark had no relatives to sit with him.

A very strong bond developed between Mark and the pastoral care practitioner in which Mark talked openly about how, in his words, he had messed up his life and the lives of those closest to him. He talked about his fear of dying alone and the reasons for his many attempts at overdosing.

Mark actually lived another 10 weeks and during that time he made peace with himself and his family. He was weaned off the narcotics he had been using and did not engage in any other form of substance abuse. He participated in creative therapy sessions, arranged the eulogy for his funeral and arranged to contribute to his funeral costs from his pension. He was baptised in the Greek Orthodox Church and lived a fulfilling final 10 weeks of his life, mostly due to the support of the pastoral care worker and volunteers.

During his baptism he stated that he “could see a very bright light and that his time on earth was nearing its end. He was ready to die in peace and with love for himself and others.”

A volunteer was at his bedside when he died. Over 20 people attended his funeral including some fellow patients and their carers whom he had come to know during his 10 weeks in the unit.
Spiritual and Pastoral Care for Catholics

The choice to receive palliative care from a Catholic facility or organisation may be a very deliberate and important decision for people of the Catholic faith, as they want to receive care in a place where they feel most spiritually at peace. Many Catholic patients who choose a Catholic facility or organisation to provide care will seek comfort and solace in the religious symbolism of a Catholic building.

Of course, not all people have the choice to attend a Catholic-run service. This is a particular issue in accessing Catholic community-based organisations, as sometimes funding is geographically determined.

It is important that Catholics in a Catholic health or aged care facility have access to all the Sacraments of the Catholic Church. Many people will want to attend a Catholic Mass or, if they are unable to come to a chapel where Mass is being celebrated, they may want someone from the Church to visit them to bring them the Eucharist (or the Sacrament of Communion). A person may wish to have a Catholic Priest visit them to celebrate the Sacrament of Reconciliation or the Sacrament of the Anointing of the Sick.

In addition to the Sacraments, Catholics may also need someone to help them to pray in the way they are most comfortable. This may be through praying the Rosary, reading the Catholic Missal or scripture, meditation, listening to sacred music and sitting for periods of time in a Catholic chapel. For Catholics, the journey to death is a sacred time, the completion of a life’s journey. The Sacraments, rituals and prayers of the Church are what sustain many people through this part of the journey.

It is this understanding of the spiritual needs of people nearing the end of their earthly life that make Catholic facilities ideally placed to provide spiritual care for people from all backgrounds and faiths.

It must also be recognised that not all Catholics with life-limiting illnesses in Catholic facilities will welcome receiving Sacraments, engaging in rituals or prayer. Members of the health care team must not assume what a person wants as they near the end of their life, particularly in relation to pastoral or spiritual care.
Maria, 41 years old

Maria came into our hospital in a desperate way. Accompanied by her husband Jeremy, she had just returned from Dubai the previous day. She had come home to die, and to be with her two sons. When we first saw Maria she was wheeled through our front door by her husband and was quite jaundiced and looked very sick. She had presented herself at the doctor’s clinic next door and they immediately referred her to our care.

Our aim was to settle her into our care and attend to her presenting needs. Her husband of four years was very anxious and her two adult sons looked grief-stricken and helpless. I noticed that Maria was Catholic; I was aware that she was deteriorating quickly so I needed to assess her religious needs, and I was wondering if she would want to be anointed. I approached her bedside, welcomed her and asked if she would like to receive communion. She appeared exhausted and unwell, I doubted if she could understand my question let alone have the energy to answer me. So I excused myself and said I would return to speak with her the next day. I had to place my trust in God that tomorrow would come for Maria.

The next day Maria was slipping in and out of consciousness, and her son was at her bedside. I asked him if he knew if his Mum would like me to call the priest, but he was anxious not to frighten her. I was wondering if he was the one who was frightened, I assured him that we would trust in the unfolding of the day and see what happened, he told me to ask her husband when he came in. I spoke to the nurse in charge and explained that I wanted to support Maria with the Sacraments if she wanted them, but also realised that she was in no state to make those decisions. The same nurse rang me later to tell me that she had noticed a picture of the Sacred Heart near her bed and a brown scapular next to it. We both knew that someone must have placed them there and that this was telling us something.

When Jeremy came in I asked him the question and he assured me that Maria would want to be anointed. It was at that time that I heard a familiar voice in the next room, and I realised that our Catholic Chaplain was anointing another patient, so I waited for him to come out and told him the story about Maria. He went straight into the room and anointed her with the family present.

One of Maria’s sons asked me to assist him in making plans for her funeral, he did not know where to start and wanted to be prepared. We talked about the possibilities and he talked about his grief and sadness and the suddenness of his mother’s deterioration. Time was running out and he did not have enough time to be with her; both he and his brother were in shock and disbelief.
Mid-morning the next day Maria died. Her husband was with her and her sons were coming in. This was also the Mass day at Prahran so the priest was expected at any minute. I went into the room to comfort Jeremy who was in total shock; he asked me to meet Maria’s sons as they did not know that she had died. I stood near the front door and waited, and as each son came in I told them what had happened. Within the next few minutes the priest came to pray with them.

During the next few hours my colleague and I helped the family in their grief and assisted them in making some decisions. It was decided that the funeral would be held at the church across the road and celebrated by our chaplain who was most supportive to the family.

As we reflected on Maria’s short stay with us, we marvelled at the wonderful work of God. Here was a young woman who died within two days of coming into our care, and the priest who anointed her was also at her deathbed and then celebrated her funeral service. All of this happened without us really getting to know Maria, yet there was a deeper knowing that was infinitely more important. The Cabrini sisters have a special devotion to the Sacred Heart, and obviously Maria had the same devotion, and it was the Sacred Heart that helped us in an uncertain time.

Staff need to remember that some people come to a Catholic facility by means of purely geographical location and the role of the Catholic provider, in these instances, is to respect an individual’s spiritual needs.

Jim, 60 years old

There was a gentleman who had no religious belief; in fact described himself as an atheist. His wife had died under our care four years earlier and subsequently he had ‘gone bush’, roaming around Australia. The wife’s ashes had been scattered at the beach and every so often he would return and visit this place.

When he was diagnosed he was devastated and we had many conversations about leaving his wife here when he died.

He also did some preparation for his two sons and grandchild. He didn’t have much but bought a piece of jewellery for each and a little gift for the baby he was sure his son would have after he died. He visited the son and his family up in the remote far north. His other son returned here to care for his dad.

The son told me how he himself had gone off the rails after his mum’s death and been heavily involved in drugs and had left here to get away from the company. He was doing ok so far and believed he was strong enough to cope after his dad’s death.
The gentleman had numerous visits for respite in the unit until his last admission, when it was obvious he was going to die.

We talked of his leaving his wife here and the boys and he was now absolutely sure he would see his beloved wife after he died.

He was content that he had done all he wanted to do for his boys and grandchildren.

The son was present when his dad died and managed well immediately after his death with no use of drugs. He returned north, near to where his brother lived.

3.4 Carer Support

Part of good palliative care is offering a support system to the family and loved ones of someone with a life-limiting illness to help them cope during the patient’s illness and in bereavement. Providing support to carers and loved ones is a hallmark of Catholic health and aged care. Health care workers and pastoral care workers need to ensure that carers have the support and space to be able to talk about their feelings, what is happening to their loved one and how this is impacting on their own life.

Carers generally want to know factual information about the illness, pain management, and treatment options, as well as practical care such as financial management. They may want to know about signs of impending decline or death and what to do when the person does die. Where appropriate the professional may be required to consult with a more specialised practitioner.

Carers may need help in planning practical matters such as respite care, wills, sorting out financial matters to include access to a Carer’s payments and planning for an eventual funeral. In some instances the person with diagnosis of a life-limiting illness may have been the main breadwinner, resulting in the family experiencing significant financial hardship. Hence it is important that an in-depth assessment of the family’s social needs is undertaken early in the disease trajectory. This may require the support of a social worker or other allied health worker.

Sometimes the person being cared for and their carers and loved ones have different attitudes and wishes about end of life care and treatment options. At these times health care workers need to be sensitive to such conflicts and stay compassionate and factual. Working within a multi-disciplinary team will help health care professionals work through any difficult issues faced by patients and their carers.

Family meetings are an important time for members of the multi-disciplinary team, the person with a life-limiting illness and family members or significant others, to come together to discuss the physical, psychological, and spiritual aspects of care. It is essential
that a family meeting is facilitated by experienced health professionals and provides a safe space in which to foster open communication. Family meetings are often appreciated by patients and their families and provide an opportunity for family members and patients to receive the same information at the same time. Members of the multi-disciplinary team should be aware that adequate preparation and consent, and skilled facilitation, improve the effectiveness of family meetings while maintaining the patient’s sense of autonomy.

Young Woman with ten year old twins

A young woman with 10 year old twins was admitted to a palliative care unit for end of life palliative care. Her former husband lived overseas and had been denied access to the children by the courts. During the course of her admission to the unit it became obvious to one of the nursing staff that the twins were not coping with the situation, and contact was made with the twins’ school by the social worker. The school confirmed the social worker’s observations and concerns. The issue of guardianship had not been addressed but in subsequent discussions, the woman requested that her mother become the sole carer of the twins. However, it soon became evident to staff that the woman’s mother had health issues and did not want to accept responsibility for the twins. Further, the relationship between the woman and her mother did not appear to be a healthy one. A series of family meetings took place including involvement of the guardianship board to work through this very delicate scenario. The end result was that the children were put in the care of a family friend.

Bereavement Care for Carers

An earlier Catholic Health Australia publication has defined some of the terms associated with bereavement:

> Grief is the personal feeling of loss and involves the realisation that what we maintain about treating people as individuals has a truth in the finality of death, that we are irreplaceable. Mourning on the other hand, is the public face we give to our grieving. In bereavement companioning there must be room for both grief and mourning.  

One of the most important ways that Catholic facilities provide support to carers is through bereavement and grief support while the person is still alive and of course after the person has died.

Even where death has been expected, when it actually occurs the finality can come as a shock and lead to a greater sense of loss and grief.

15 Catholic Health Australia, Catholic Care of the Ageing. (Canberra: CHA, 2005), 19.
Where a patient has died in a facility that is not their home it is important that staff allow the family members and significant others to spend time in a very close relational way with the deceased, in a way that allows them to connect with their loved one’s life.

Health care professionals are not expected to have the answers to inevitable questioning that some loved ones will undertake when a person dies. Health care professionals are not expected to have solutions that will allay anxiety or take away someone’s feelings of loss and grief. What health care professionals can do is be aware of some of the expected (and potentially unexpected) experiences of grief and be available to provide the support and space to loved ones so that they feel accepted and able to show their grief in their own way. A Catholic facility should always be a place where people are free to show their emotions and receive a compassionate response and a listening ear.

People experiencing grief will feel a range of different emotions, some at the same time. They may feel numb, shocked, angry and guilty. They may feel confused and unable to function normally. They may feel deeply lonely and abandoned. For someone who has seen a loved one live through life-limiting illness, there can be an enormous sense of relief and with this relief may come guilt that they can feel this way.

The pastoral care, bereavement team or chaplains in a Catholic facility should provide advice about - or be available to deliver themselves - grief counselling for family members and loved ones. They should also be able to point to services and rituals that the carers or family members can perform through the Catholic facility, or in their own homes, in accordance with the loved one’s wishes and religious beliefs.

Many Catholic facilities hold regular memorial services so that family and loved ones of people who have been cared for by a Catholic facility can return to receive ongoing support and remembering in their bereavement. These are held with respect to the values of the Catholic tradition in a format that meets the needs of the local community.

**Supporting Families**

There was an Italian lady with whom we spent a lot of time. She was elderly and language was limited so we arranged for a volunteer to visit her with Communion every fortnight and I visited the other fortnight. The volunteer was Italian and they developed a close relationship. Whenever she came into the unit the priest visited and she received the Sacrament of the sick regularly. Since her death we have seen the family often. They drop in and also they have celebrated her anniversary and birthday Masses here with us at our Thursday Mass.
3.5 Conversations about Death and Dying

For many people, talking about death and dying is difficult. It can be uncomfortable to admit that we and the people we love will die, possibly after a period of illness. On the other hand, the fact that we are all vulnerable in illness and we will all die is a fact that links all of humanity.

Many people may not bring up the topic of preparing for death because they feel that others are uncomfortable talking about the topic. Yet, many people, particularly those who are ageing and those living with life-limiting illness, may feel the urgent need to openly talk about their options for care, ways to get their affairs in order and how to prepare for a ‘good death’.

Not all health professionals will be required to give a person the diagnosis of a life-limiting illness or to tell a person how long they are expected to live. Yet, most health professionals will be required to work alongside someone who has a life-limiting illness at some point in their careers. There may be times when a person or their family is just at the point where they want to discuss some issues about their prognosis and future and are looking for an opening to talk about the topics of concern to them. It is important therefore that health professionals listen to the cues given by patients, their families and loved ones. If there is not enough time, ensure a time is made to continue the discussion as soon as possible after the conversation has been initiated or refer to another service, such as pastoral care, to enable an open and honest conversation that is not rushed.

Of course some people may not be able to confront their own mortality (or that of their loved one) and may not wish to enter into conversations about death and dying. This is their choice and preference and should be respected. However, it is much better to give a person the option to discuss issues if they wish to. If they are not willing to discuss issues, it may be worth gently trying again at a later date.

Simple questions are easier for the patient and family member to answer. Some possible conversation starters for health care workers to provide an opening for a patient or their loved ones to talk about their future include:

- Is there anything you are worried about at the moment that you would like to talk about?
- Are you worried about......?
- How are you managing the things you are worried about at the moment?
- What questions come to your mind and how could I help to answer them?
- What are your hopes for the future?
- Do you have any questions about the future?
- What is your biggest concern at the present time?
- As you think about the future, are there any aspects in your life that you would like to attend to? Can I help in anyway?
- What are things you still want to achieve in your life?
- What are your thoughts about where you would like to be cared for if you get sicker with this illness?
- How do you think [the patient] is coping with the illness?
- What information would be helpful to get you through this time?
- What additional support we can offer you at this time?

Maria, 44 years old

Maria was married with four young children. Maria was admitted to hospital following a fall whilst playing tennis. Maria had fractured the neck of one femur and during surgery extensive cancer of the bone was discovered. Whilst in recovery Maria had a seizure and during the next 24 hours in the intensive care unit she had two more seizures. It was discovered that Maria had a brain tumour and the bone cancer was a secondary cancer. Maria’s prognosis was very bleak. The oncologist asked the palliative care specialist to meet with Maria and her husband. Maria was unable to walk and needed to have her pain managed. Maria wanted to go home but this was going to be difficult as her home was four hours from the nearest hospital.

The palliative care specialist and the clinical nurse consultant broke the devastating news to Maria and her husband that she was likely to live only another six months. Maria responded, “What about my kids? I need to live for my kids. I don’t want to spend my remaining months in hospital. I have to be with my kids and if I am going to die, I want to die at home”.

Extensive discharge planning arrangements were put in place to facilitate Maria and her husband’s desire for her to go home. Given her limited life expectancy, these arrangements needed to take effect as soon as possible. Collaborative relationships were established with Maria’s local church, the children’s school, including arranging counselling for the children, the local community and Maria’s general practitioner. Maria’s husband was given training to administer pain relief and attend to her dressings which enabled Maria to spend each Friday to Monday at home with her family until she died.
3.6. Needs of specific groups

**Palliative Care and Children**

While it is hard to see any person we love and care for experience the journey of a life-limiting illness, when this person is a child or an adolescent, the feelings are magnified. Half of all children who require palliative care have some form of cancer, whilst the other half experience a range of other illnesses including neurological or metabolic illness. To see a young person suffering or having their life cut short can bring such profound sorrow and suffering to family, carers and anyone who allows themselves to feel the pain of others.

It is important to reflect on some of the additional needs of children and adolescents who have life-limiting conditions and the needs of their families. Palliative Care Australia has described some of the unique aspects of palliative care as it applies to children. It is important to provide care for children and adolescents that:

- Fully embraces the whole family as well as the child,
- Involves health professionals with specialised skills in the care for children who may not be able to communicate their wishes clearly,
- Takes account of the child’s developmental needs,
- Supports families as they care for their sick child and their other children,
- Offers palliative care and cure oriented treatment at the same time,
- Adapts to the child’s changing needs, for example, a child may ‘graduate’ from palliative care should curative treatment be successful (e.g. transplant patients), and
- Understands the different responses by children to both symptoms and their treatments.16

Children who need palliative care are also developing in other ways even as their disease progresses. Like any child, they are developing cognitively, emotionally and physically alongside the development of an understanding about the disease they have and what will happen to them. They often recognise and understand their illness and the progression far more readily than many realise. Special sensitivity and professional expertise is necessary to help provide palliative care services for children and their families. Children can respond very differently to medications and have very different symptoms to adults. Specialist paediatric palliative care services should be part of any palliative care for children where appropriate.

It is important that the emotional and spiritual needs of children are acknowledged and addressed and sometimes this may be separate to those of their parents. Children are often wise beyond their years and have a clear idea of what they require for their own

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16 Palliative Care Australia, *Journeys: Palliative Care for Children and Teenagers.* (Canberra: PCA, 2005), 2:3-4.
care. It is important this is woven into the approach to care, ensuring children are not left isolated with their thoughts. It is not unusual for a child to protect his/her parents by not talking to them.

Families of a child who needs palliative care have additional needs and require compassion and support. Coming to terms with a child with a life-limiting illness will always be very emotionally difficult for any parent. Palliative care for children may extend over many years depending on the disease and treatment possibilities. When a child dies, the death gives a sense of being unnatural and unexpected even where death has been predicted as a likely outcome.

In addition to the emotional and practical support that should be offered to parents and families, it is important to remember that parents have legal and moral responsibilities for children (in ways that family members tend not to have for adults) and they need to be included in care planning and significant decision making about a child’s care and treatment. Children should be involved in their care plan where intellectually possible. It is important to recognise the level of responsibility parents experience in making decisions about their child’s care.

Community often offers significant benefits in supporting the child with palliative care needs and their family, and it is important to consider the role the school, local clubs or special interest groups can play in supporting the family during the illness and in bereavement.

The Culturally and Linguistically Diverse

People from a culturally and linguistically diverse (CALD) background are traditionally known as people who were born overseas in a country whose first language is not English, or in the case of children born in Australia, if their parents speak a language at home other than English.

There are people however from the United States of America, United Kingdom and New Zealand who would also be considered to belong within the CALD group. Cultural diversity refers to more than ethnic diversity: age, gender, sexual preference, capabilities, education, place of residence, and occupation (including the health professions) contribute to diversity of culture. 17

People from CALD communities experience considerable barriers to accessing universal health services. The cultural competency of health providers impacts on the capacity to overcome these barriers to access.

There is often a lack of appropriate information for CALD groups about palliative care and the CALD populations often have difficulty in accessing CALD specific palliative care services.

Catholic facilities have a strong commitment to servicing the under-served, and to providing adequate, timely health care for all. Catholic services recognise the cultural and linguistic diversity of the population in their service provision and planning.

Palliative care services should ideally ensure that there is:

- A general understanding among staff and volunteers of the concept of cultural awareness and diversity, including multiculturalism,
- Access to information about specific cultural rituals in relation to health, illness and dying and death for CALD populations,
- Appropriate information for CALD groups about palliative care and the services available within their local area, so that family and carers can make informed decisions about care,
- Access to and availability of interpreters when deemed appropriate by patient/family and or health professionals working with the family,
- Data collection that effectively identifies persons from CALD backgrounds, and
- Effective networks between palliative care services, general practitioners and other community services for people from a CALD background.

The most recent literature dealing with the general Australian context of cultural competence and awareness in palliative care lists the following issues as being generic to all settings where cultural competence at the end of life is necessary:

- **Communication issues**, including disclosure and consent,
- **Modes of decision making**: how or when the patient, family or community representatives become involved,
- **Concepts of disease**, meaning of pain and other symptoms,
- **Ways of conceptualising death**, burial or cremation, and bereavement,
- **Attitudes to medication** (especially opioids drugs and sedatives) and to nutrition,
- **Privacy issues**, and
- **Spiritual matters**, as well as religious issues, including rituals.

It seems that health care providers must recognise that the basic values, principles, and assumptions of western medicine and bioethics are themselves historically situated and culturally determined – there is a wide variation of beliefs and behaviours within any culturally diverse group.

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Aboriginal and Torres Strait Islander People

It is also important to recognise the cultural dimension in service delivery to Aboriginal and Torres Strait Islander citizens at their end of life. All Aboriginal and Torres Strait Islander communities in Australia have a common heritage of loss, and it is well recognised that Indigenous Australians use mainstream health services reluctantly and palliative care services very rarely.

There are a number of specific cultural considerations that must be respected when providing palliative care services for Aboriginal and Torres Strait Islanders including an understanding of causes of disease, attributions of blame for sickness, the performance of ceremonies before and after death and the importance of dying on traditional lands. There are several Catholic facilities that provide outreach to Aboriginal and Torres Strait Islander communities and the inclusion in a palliative care team of an Indigenous health worker is of great value in facilitating team and personal interactions with Indigenous people.

Implications for palliative care

- When an Indigenous person dies away from the homeland the body needs to be escorted back to the homeland,
- It is culturally appropriate to allow the “smoking” of a room in which a patient has died, even a hospital ward, and
- It is important that all parts of a body be sent back: amputated limbs or fingers, hair that has been removed and clothes worn at death or worn in hospital are deemed important parts of the person. Such items need to be collected and stored appropriately.

Aboriginal woman from remote Australia

An Aboriginal woman from a remote area was in the last few days of life in a city palliative care unit. The family members had come to the city to be with her. As death approached, the family requested that her bed be moved so that she could not see a tall tree which was outside her room. The family explained to the staff that they believed the tree was full of bad spirits that would prevent her from leaving this world and going to the next. The family also created a chain of spirit angels made from paper which they put around the room in a circle including the doorway to protect the woman from the evil spirits from the tree. The family explained that it was important that the chain not be broken until the woman had died. Staff in the hospital respected the family’s wishes and the woman died very peacefully.

20 Op cit
3.7 Advance Care Planning

Advance care planning is a process whereby someone with a life-limiting illness has the opportunity to think about, discuss and record their wishes and preferences for their care in the future. Advance care planning is appropriate for all people including those with a chronic illness such as heart failure or severe lung disease.

Advance care planning can be a useful tool for individuals, their families and health care professionals to engage in ongoing conversations about the future so that as much as possible families and health care professionals know the preferences and wishes of the person. If in the future the person has limited capacity to make decisions, previous discussions about health care treatment options will guide health care professionals and help a person’s family to make decisions about the person’s ongoing care and treatment.

If these preferences and wishes have been recorded, it is often in a document known as an Advance Care Directive, also known as a Living Will.

In Australia, advance care planning and advance care directives have legal status. Some aspects of advance care planning are covered by common law and other aspects are covered by statutory law which is determined at the state and territory level. There are some common principles for all advance care planning but in some difficult situations, legal advice will be necessary to determine how individual cases are affected by legislation.

In general, advance care planning can be helpful for the simple reason that it gives patients some reassurance that their needs and preferences have been heard and will be respected. However, advance care planning can never cover all situations and eventualities. The nature of a person’s illness may change over time and their wishes for future treatment may change accordingly, without the change in preferences being recorded.

It may seem like a difficult area to navigate, however, health care professionals can follow some general principles including:

- Decisions need to be made in the patient’s best interests, keeping in mind their known fears and wishes,
- Encourage people with a life-limiting illness to discuss and document their wishes,
- Where a person has lost capacity to make their own decisions, efforts must be made to determine whether the person has undertaken any advance care planning and if so to obtain a copy of any outcomes or written Advance Care Directives,
- Be aware of the legal and statutory obligations of implementing Advance Care Directives,
- Where a health care professional or health or aged care institution first begins to care for someone who has an existing future health care plan (or Advance Care Directive), the documentation should be reviewed. Health care professionals should assess the applicability of the plan in the actual circumstances, and judge whether any requests made can be met in keeping with responsible medical practice, individual professional conscience and the values of the institution.21

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• Where there is difficulty interpreting an Advance Care Directive in a given situation, collaboration is required between health care professionals, family members and patient representatives to determine and agree on the best treatment or care options,

• Where there are difficult issues to resolve, the advice of a specialist palliative care practitioner should be sought as they will have considerable experience in matching patients’ best interests with advance care planning requests, and

• If in any situation, a health care professional feels their ethics or the ethics of the Catholic facility are compromised by implementing an Advance Care Directive, “the health care professional or institution may choose to decline to be involved further in the care of the person or resident, provided that no one is endangered by that decision”.22

A person may choose not to have an Advance Care Directive, but rather appoint a trusted person to be their representative in the event that they become incapacitated. The person must be confident their representative is able to make decisions in accordance with their wishes, hence a family member may not always be the best choice. There are three ways in which someone may become a person’s representative:

• The representative was appointed previously by the person,

• The representative was appointed by a court or tribunal after the person became incapable of making decisions about his or her own medical treatment, or

• The representative has legal authority automatically, as the person’s spouse, carer, other next of kin or close friend.23

A patient representative should make health decisions based on the patient’s previous advice and values together with input from health professionals and their own judgement.

Health care professionals are likely to come across patients who will at some point lose the capacity to make decisions about their own care. Where it is known that the person has not undertaken any form of future care planning, it may be helpful to promote a conversation about the options they could consider.

Questions may include:

• Is there anything you would like to write down about your care and treatment preferences for the future? For example, advance care planning or living wills?

• What thoughts have you had about who would make decisions on your behalf if you were unable to make decisions yourself? Is there anyone else you would like to nominate to make these decisions?”

• Have you thought about where you would most like to be cared for if you require more assistance?

• Who have you nominated to make decisions for you should that be necessary in the future, and would you like us to include them in our discussions?

22 Ibid.

23 Ibid.
Catholic Health Australia has produced *A Guide for Health Care Professionals Implementing a Future Health Care Plan* and this provides a comprehensive summary of some of the issues associated with advance care planning/advance care directives. A copy of these Guidelines has been attached as an Appendix to this publication.

**Sylvie, 88 years old**

Sylvie is an Italian widow who lived in the residential aged care facility for five years. Her primary diagnosis was that of Advanced Dementia, accompanied by severe renal failure.

She experienced an acute episode of delirium, and was transferred to hospital, for IV antibiotics. Sylvie could no longer communicate verbally and her family was very distressed by her stay in the hospital. On discharge, a case conference was held to develop Sylvie’s plan of care for a palliative approach. Sylvie’s GP (via teleconference), a representative of the catering staff, her sons and their wives, the facility’s Spiritual Care Coordinator, an RN and an Assistant in Nursing all attended the meeting.

Sylvie’s condition was reviewed. Her prognosis was very poor, but uncertain. Her appetite fluctuated, she was bed or chairbound and required two people and a lifter to transfer, and was doubly incontinent.

Her family was adamant that she should not return to hospital again as they felt that Sylvie was much more comfortable in the facility with familiar staff and surroundings.

Sylvie’s pain and symptom assessments were presented and addressed and her long list of medications was reviewed, and only the medications that promoted her comfort remained. Her oral analgesia was converted to a transdermal route so that if she wasn’t swallowing, she would still receive analgesic benefits. Decreasing oral intake in advanced dementia was discussed and it was decided to concentrate efforts on ensuring that Sylvie’s mouth was clean and moist at all times, rather than focussing on her calorie intake. A list of all her favourite foods was given to the catering staff so that they were readily available for her in small quantities, to match her small appetite.

As her condition deteriorated, nursing and care staff were comfortable in the knowledge that Sylvie was receiving care that reflected her stage in life. The spiritual care coordinator arranged for the local Catholic Minister to provide ongoing spiritual support for Sylvie and her extended family.

Sylvie died in her own room six and a half months later, with her family by her side.
3.8 Interdisciplinary approach

As this publication has highlighted, there are many aspects to providing palliative care including meeting the physical, psychological and spiritual needs of patients and their families, to name a few. Having a life-limiting illness affects every aspect of a person’s life and the lives of their loved ones. No single care professional can meet all these needs. To provide holistic care therefore means having a care team from a range of disciplines who work together and come together to provide optimal and comprehensive care.

Depending on the person’s individual needs, an interdisciplinary team might include:

- Volunteers
- Psychiatrists
- Chaplains
- Community Workers
- Dieticians
- GPs
- Paediatric specialists for children
- Pharmacists
- Pastoral Care Workers
- Palliative Care Specialists
- Nurses
- Divisional Therapists
- Psychologists
- Surgeons
- Music Therapists
- Care Assistants
- Physiotherapists
- Occupational Therapists
- Art Therapists

Of course not every person will have an interdisciplinary team involved in their care with members from all of the professions listed. However, holistic palliative care should cross over several disciplines and the members of the care team should reflect the interdisciplinary nature of good palliative care. It is important to identify one or two key people with whom communication can be coordinated. A person’s home will, of course, not be visited by the whole team - appropriate members will be introduced if and when required.

Families, carers and community members (e.g. colleagues, friends from church or clubs) should be considered as part of the care team. They are often the people who know the person most intimately and can recognise their care needs, especially if they have been caring for them at home. Where it is possible and appropriate, families and carers form
part of the interdisciplinary team. In the case of children, this is even more important as parents maintain legal and moral responsibility for their children while they are receiving palliative care.

Volunteers make an extraordinary contribution to Australian society. The contribution of volunteers within a palliative care context is one that is rich, rewarding and often a challenging personal experience for the volunteer. As such volunteers require appropriate support and supervision.

### Volunteers are Angels

The volunteers are truly angels. They bring a sense of normality to the unit. They are always on hand to prop up my pillows, pour me a drink, sit with me and give me a massage. My wife and I are truly indebted to them for making our wedding day such a special day. We had planned to get married in Bali but my condition deteriorated and the volunteers went out of their way to create a Bali-like scene with frangipanis and they became the ushers and waitresses. It was like paradise!

### Caring for Staff

It is important that healthcare workers acknowledge that providing palliative care can be emotionally challenging and the importance of discussing openly these challenges.

Healthcare providers should be aware of the impact that caring has on their staff and have in place suitable support structures.

The interdisciplinary team is a great source and opportunity for healthcare workers to debrief and review the clinical management of patients.

Many healthcare workers obtain great benefit from professional or personal supervision as well as mentoring and mentored roles. The same should be available for volunteers working closely with families and patients.

### 3.9 Symptom Management

Minimising and preferably alleviating symptoms is a fundamental goal of palliative care. A range of symptoms can be caused by a number of factors including physical, psychological, and spiritual factors.

The palliative care team or health professional must liaise and communicate with the patient, resident or client as well as significant others, including those involved in treatment, to manage pain and symptoms in a coordinated way.
Types of symptoms include:

- Pain
- Fatigue
- Frustration
- Difficulty breathing
- Difficulty swallowing
- Lack of appetite
- Constipation
- Hopelessness
- Confusion
- Psychological distress
- Terminal restlessness
- Hypercalcaemia

There are a number of medical emergencies that occur in palliative care and these may be completely unexpected. However in some instances these can be predicted from the nature and location of the disease, for example, haemorrhage in patients where tumours have encroached on large blood vessels.

Rapid recognition and response is essential to avoid unnecessary suffering and it is important that at all times communication channels are kept open to ensure the needs and wishes of patients and their families are acknowledged.

Examples of some specific emergencies include:

- Spinal cord compression
- Bowel obstruction
- Airway obstruction
- Haemorrhage

Further resources for staff on the management of symptoms

There are numerous resources available to help staff address the management of symptoms. The Palliative Care Victoria website is one such resource where hands on information can be found and useful information for carers and health professionals.


Palliative Care Australia provides specific training resources for the management of symptoms in the palliative phase of ageing. Symptoms covered include nausea and vomiting, bowel care, nutrition and hydration.


Staff may find additional support for managing symptoms in *Therapeutic Guidelines - Palliative Care - Version 2 – 2005*, Published by Therapeutic Guidelines Limited Victoria.
Finally, Care Search, the palliative care knowledge network, is an online resource of palliative care information and evidence. All materials included in this website are reviewed for quality and relevance. The website has been funded by the Australian Government as part of the National Palliative Care Program.


Assessment is the Key

Effective symptom management requires an understanding of the cause of the symptom to enable the provision of appropriate treatment.

It is essential in effective symptom management to complete a detailed clinical assessment, actively questioning about symptoms to obtain a full picture and to continually assess the clinical situation in the face of constant change. There is no substitute for taking a detailed medical history.

When completing a detailed clinical assessment consider the following as the guide to management:

- Why is the patient complaining of constipation – have they been prescribed a laxative when commenced opiates?
- Patient/client complaining of insomnia – contributing factors could be pain or nausea and also steroids, for example dexamethasone.
- Swollen ankles, nausea and vomiting, abdominal discomfort, diaphragmatic pleuritic pain may be signs of liver involvement with cancer.
- Bone metastases may cause pain and risk of pathological fractures
- How often is the patient nauseated: is it after eating; is it all the time; is it only at the smell of food or does the patient vomit with no preceding nausea?
- What type of pain is patient/client complaining of? The literature talks about two broad groups of pain which are:
  - **Nociceptive pain** [stimuli from somatic and visceral pain for example pressure sores, liver capsule pain, stomatitis, or where the patient or client sometimes refers to pain as burning or dull aching pain]
  - **Neuropathic pain** [results from injury to the nervous system, for example nerve pain, chest wall invasion, spinal cord compression, sometimes symptoms referred to by patient/client are a shooting/burning pain and/or pins and needles]24

24 Guidelines for a Palliative Approach in Residential Aged Care – 2006, Australian Palliative Residential Aged Care (APRAC) project team, approved by the National Health and Medical Research Council, Australian Government.
Case Study 1

David a 47 year old man, was diagnosed with malignant melanoma with extensive bony metastases. He was complaining of pain in his lower abdomen and despite analgesia the pain worsened. He did not mention to the nurse that he had not passed urine for 24 hours and the nurse did not ask this question as part of her assessment.

A scan of his bladder was undertaken by another nurse using a bladder scanner and he was noted to have an enlarged bladder. A catheter was inserted and a large volume of urine was drained and David’s pain subsided.

Case Study 2

Maria a 63 year old lady, was diagnosed with breast cancer with extensive bony metastases. She was admitted to a ward for management of her pain. During her admission she complained one morning to the nurse that she had extensive numbness in her feet and weakness in her legs. The nurse immediately contacted the medical practitioner as she suspected a diagnosis of spinal cord compression. MRI scan was ordered immediately and diagnosis confirmed and treatment with opiates and steroids commenced. Prompt action by the nurse prevented further loss of function and paralysis occurring.
A guide for people considering their future health care

Foreword

Recently, Catholic Health Australia has been approached for guidance over the issue of advance care planning for patients and residents in Catholic health and aged care services.

Since a variety of approaches already exists in the wider community, Catholic Health Australia thought that prospective patients and residents of Catholic facilities, and the health professionals who take care of them there, would appreciate guidance that is consistent with Catholic, and indeed with good secular, ethics.

To that end, a drafting group comprising Bishop Anthony Fisher OP, Rev Dr Gerald Gleeson, Dr Elizabeth Hepburn IBVM, Dr Bernadette Tobin and Dr Nicholas Tonti-Filippini was asked to prepare a first draft of guidelines for patients and residents and for health care professionals. These drafts were circulated for comment by doctors, nurses and other health professionals, managers, patients and the general public.

Responses received in that consultation process then informed the writing of this guide for people considering their future health care needs, and the accompanying guide for health care professionals.

Both documents have now been approved for use in Catholic health and aged care services by the Committee for Doctrine and Morals of the Australian Catholic Bishops’ Conference and by the Stewardship Board of Catholic Health Australia. We thank all those who contributed to their preparation.

We now commend these guidelines to Catholics, and indeed to all Australians, who are considering their future health care.

George Cardinal Pell
Chairman, ACBC Committee for Doctrine and Morals

Sr Therese Carroll RSJ
Chairperson, CHA Stewardship Board
1 Introduction

1 This guide is written for people who are considering their health care needs and treatment preferences in future cases where they may be unable to do so. Its purpose is to:
   • help people nominate a representative to make health care decisions based on their wishes and values;
   • help people provide reasonable and adequate guidance for their representative; and
   • recognise the issues that need to be taken into account to achieve this.

2 This guide is intended to supplement the Code of Ethical Standards for Catholic Health and Aged Care Services in Australia (approved by the Australian Bishops and published by Catholic Health Australia in 2001, and hereafter referred to as 'the Code') and aims to help people prepare for illness and death. It is issued in response to proposals for 'advance directives' or 'living wills', which are documents that detail a person's wishes about specific medical treatment in case an illness or accident leaves him or her unable to communicate. In addition to this guide, there is a corresponding document for health professionals, called A Guide for Health Care Professionals Implementing a Future Health Care Plan.

3 In a truly democratic society, the life of every member is respected and protected, and each member is provided with the basic necessities for life and health, no matter how frail or disabled he or she is. In addition, for believers, God is the author of life and we belong to Him and thus have stewardship, not ownership, of our own lives. We care for our life and health, and seek assistance from others, especially when we are sick. In illness, we face the reality of our mortality and the limitations of health care. If approached well, the days leading up to death can have a positive meaning for many people.

4 Because we know that a time may come when we are unable to make decisions about our own care, it is a good idea to ensure that someone we trust will be in a position to make such decisions for us. For the same reason, it can be sensible to let trusted people know our values and our wishes for medical treatment, to help guide them to make such decisions.

5 No one, however, should be compelled to issue instructions about future care, nor should any guidance we leave be too prescriptive. Disability and dependence may be unavoidable in our later years, and we should not expect to control the dying process fully. We should leave those entrusted with our care free to respond to the course of illness as it unfolds in the mystery of our lives. Like Jesus at Gethsemane, believers strive to place their trust in God's will.

Key point 1

Though illness can be unpredictable, we may choose to offer those entrusted with our care some guidance about our wishes for our future health care.

2 Planning future health care

1 People often need time and assistance to reflect on the meaning of death in their lives — to face and resolve personal differences within families, and to minimise future conflict between family members.

2 You can guide your future medical treatment in different ways; it is not necessary to leave written instructions. Many people trust their families and their health care professionals to know and do what is best for them. In some cultures and ethnic groups, this is the normal way in which health care decisions are made.

3 Talking to your family and your health care professional is important. It is best if you seek out a personal doctor with whom you can develop a good, continuing relationship. As trust and understanding between you and your health care professional develop, it becomes easier to communicate your fears, hopes and desires.

4 Patients need their health care professionals to explain the likely course of an illness, the various treatment options available, and their benefits and side effects.

5 Health care professionals need to hear from patients about their hopes and goals in life, their relationships with their families and communities, their tolerance of treatment side effects, their religious commitments, and what will be important to them as death approaches.

1 Available at http://www.cha.org.au
6 The best way to establish this communication is through conversations over the years with your family, friends and health care professionals. If you gradually and gently introduce conversations about these matters, then it will be easier to discuss specific and immediate questions relating to a terminal illness, should it arise. In addition, new opportunities for conversation may occur if an illness or disability changes your life situation.

Key point 2
Planning future health care relies on good, long-term communication between you and your family, friends and health care professional.

3 Appointing a representative
1 Illness and disability may change your life situation, affecting your independence and relationships with the people around you. How you endure, and the new relationships that form through illness and dependency, are an important part of your journey that continues until death. These relationships continue even when your own ability to communicate is diminished. For Christians, in becoming more dependent on others, there is an opportunity to share in the suffering of Christ.

2 If you become unable to make decisions for your own medical treatment, there are three ways in which someone may be or become your representative:
   • you have appointed someone previously;
   • a court or tribunal appoints someone after you become unable to do so; or
   • your spouse, carer, other next of kin, or close friend, according to law, may have that authority automatically.

3 If you do not have confidence in the person(s) who would automatically become your representative, then you need to appoint someone specifically. There are legal processes for doing this.

4 Your representative will need to make decisions about your medical treatments if you become unable to do so. The representative will need to assess what a particular treatment may achieve and what difficulties it may cause.

5 To fulfil this role, your representative needs to know about your current health issues and what may be involved in your future health care.

6 The person you choose as your representative should:
   • be able to make good judgements in what may be difficult and painful circumstances;
   • know you and know your values and wishes; and
   • be available to be your representative if you need one in the future.

7 The advantage of appointing such a person is that he or she is able to respond, on your behalf, to the changing circumstances in which treatment decisions may be needed. Your representative's formal role is to make decisions on your behalf and to communicate with the treatment team. However, he or she might also have a less formal role in coordinating discussion among your family, where this is desirable and practicable.

Key point 3
A representative can make health decisions on your behalf, based on your advice, the advice of your health care professionals, and your representative's own good judgement. These health decisions have the advantage of being flexible in response to changing circumstances.

4 Guiding your representative
1 You may wish to give your representative some guidance about how you want decisions made for you. You may simply be happy to discuss what may happen, or you may want to provide something in writing as a reminder for that person, when the time comes.
2 You can record your values and wishes in several ways:

a) Your health care professional may (and usually should) keep his or her own notes of what you have said and review them regularly in the light of changing circumstances.

b) You may prepare a statement of general principles about what you would like done in the future.

c) You may prepare a specific plan for your care in the immediate circumstances of a degenerative illness about which you have been well informed. When you prepare this plan, it is important that you communicate with your health care professional as much as possible, because usually only a medical practitioner has the expertise and experience to inform people of their prognosis and of the treatment options. Guidance from other health care professionals, pastoral carers, ministers of religion, or community elders may also be helpful.

d) In some jurisdictions, advance directives or advance care plans have been given a legal status. However, these plans are likely to be inflexible and their legal status may prevent health care professionals from changing your care to suit changes in the circumstances. Such directives may also suggest wordings that refuse care that should be provided, or insist on inappropriate treatment.

3 It is best to avoid documents that attempt to be too directive. Rather, your written wishes should guide what happens, while being flexible enough to allow your representative to respect your values as he or she adjusts to new situations on the advice of health care professionals.

Key point 4
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.

5 Understanding responsibilities and rights

1 By giving guidance to others, such as your representative, about your future treatment and care, you may relieve the anxiety and burden of decision making for them. However, the guidance that you give should respect their moral responsibility to value and care for you until death intervenes. The person who accepts the role of representative takes on the same responsibility that each of us has to protect and sustain our own life.

2 You can help your representative and health care professionals by considering the possible course of your illness and indicating your priorities. We have a moral responsibility to use those means of sustaining our lives that are effective, not overly burdensome and reasonably available. (Such means are referred to in the Catholic tradition as 'ordinary' or 'proportionate'.) You or your representative have a moral right to refuse any treatment that is futile, or that you judge to be overly burdensome or morally unacceptable (referred to in the Catholic tradition as 'extraordinary' or 'disproportionate'). Such refusals must also be respected by health care professionals.

4 Treatments are futile if they provide no benefit to a particular patient. Assessing the benefits of a treatment includes judging whether the intervention corresponds to the real situation of the person before and after the intervention. The benefits of treatment include:

- slowing down the progress of disease;
- sustaining the patient's life; or
- relieving the patient's distress or discomfort.

5 Treatments are burdensome when they cause distress and suffering to you, cause difficulties for you or your family (or the community), or are costly to obtain or provide. For example, if you were suffering from a degenerative disease with a predictable course (eg renal failure, cardiac disease, cancer or dementia), you should be informed of the likely progress of the disease, and of the likely benefits and burdens of treatment options — especially in the later stages.
It may be helpful to others for you to think about the circumstances in which you would regard some intrusive life-sustaining interventions (such as cardiopulmonary resuscitation, renal dialysis or mechanical ventilation) as overly burdensome.

6 Alternatively, you may wish to guide your treatment and care in the foreseeable circumstances of a life-threatening situation (e.g., a stroke, heart failure or accident). In such a case, you can give only general guidance about the treatments you would want and the kind of benefits and burdens of treatment that you would judge reasonable. For example, a frail, elderly person might consider resuscitation (including intubation, cardiac massage and defibrillation) after a heart attack as overly burdensome. However, that person might want other care to continue in the meantime, such as antibiotics for infection or assistance with feeding.

7 If the time comes when you cannot feed yourself, others would be expected to provide you with food and water as part of the normal obligation to sustain you. If you have swallowing difficulties, tube feeding is appropriate if it nourishes you and/or alleviates your suffering, unless it would be overly burdensome. As death approaches, your body may not be able to digest food, feeding may overload a failing system, or the burdens associated with tube feeding (e.g., discomfort or the risk of choking) may make it overly burdensome.

8 Given the continuing debates over euthanasia and the withdrawal of medical treatment, it is important to state explicitly that you do want life-sustaining treatment that is reasonable to be provided unless it becomes futile or is overly burdensome.

9 In addition, when planning your future health care, you need to realize that there are ethical and legal limits to what can be requested of your representative or health professional.

Key point 5
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.

6 Summary
1 Planning your future health care requires good communication between you and your family, friends and health care professional. It is also based on careful consideration of the benefits and burdens of treatment options, including what can reasonably be expected of the person(s) chosen to be your representative, as well as your health care professional.

2 A good future health care plan should also take into account the ethical and legal responsibilities of your health care professional and representative, and aim to provide them with clear guidance for providing you with the best and most appropriate health care, which can also be adapted according to changing circumstances.

7 A model statement
1 The 'model statement for future health care', which is found over the page, contains some suggestions about the kinds of things you might like to think about, and perhaps to record, to guide your future medical treatment.
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:

Alternatively:
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 treatments 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 effect 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 teachings 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
A guide for health care professionals implementing a future health care plan

Foreword

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George Cardinal Pell
Chairman, ACBC Committee for Doctrine and Morals

Sr Therese Carroll RSJ
Chairperson, CHA Stewardship Board
1 Introduction

1 This guide is written for health care professionals who are involved with people considering their future health care needs and wishing to give advice about their values and wishes. Its purpose is to:

- inform health care professionals about the role of a patient representative;
- identify professional and ethical responsibilities associated with implementing future health care plans; and
- identify the responsibilities of people involved in a person's future health care plan.

2 This guide is intended to supplement the Code of Ethical Standards for Catholic Health and Aged Care Services in Australia (approved by the Australian Bishops and published by Catholic Health Australia in 2001), and hereafter referred to as 'the Code'). Also, it is intended to be read in conjunction with A Guide for People Considering their Future Health Care.

3 The principles in this guide apply also to 'advance directives' or 'living wills' — documents that detail people's wishes about medical treatment in case an illness or accident leaves them unable to communicate.

2 Using a future care plan

1 People often need time and assistance to reflect on the meaning of death in their lives — to face and resolve personal differences within families, and to minimise future conflict between family members. When considering their values and wishes for their future health care, many people trust their families and health care professionals to know and do what is best for them; others prefer to provide specific guidance for their treatment in the form of a health care plan.

2 People can express their future health care wishes in several ways. However, the legal status of these expressions may vary depending on the jurisdiction; therefore, legal advice relevant to the jurisdiction should be sought.

3 When a person becomes incompetent, he or she is no longer able to respond to the current circumstances. There is always a moral responsibility to provide reasonable care, and the progress of illness can be uncertain. Thus, an incompetent person's earlier wishes and values should guide, rather than direct, the specific treatment and care decisions to be made in the actual circumstances that later arise. Although the earlier expression provides evidence of the person's past wishes, the health care professional must still make responsible decisions in the actual circumstances with the guidance of the person's representative.

4 Accordingly, when a health care professional or health or aged care institution first begins to care for someone who has an existing future care plan, the documentation should be reviewed. Health care professionals should assess the applicability of the plan in the actual circumstances, and judge whether any requests made can be met in keeping with responsible medical practice, individual professional conscience and the values of the institution.

5 Usually, collaborative discussion with the person or representative leads to agreement about a revised future care plan. There may sometimes be an unresolved difference, especially if the person or the person's representative insists on elements in the health care plan that require the health care professional or institution to act unethically. In such cases, the health care professional or institution may have to decline to be involved further in the care of the person or resident, provided that no one is endangered by that decision.

Key point 1

The health care professional's role is to be familiar with the person's values and earlier wishes, to review his or her wishes with the person's representative in light of any changes in the current situation, and to resolve differences, where possible, according to his or her individual professional conscience and professional and institutional codes of ethics.

3 The role of the patient representative

1 The most helpful part of future health care planning is the fact that someone is able to speak on behalf of the person when that person is unable to do so. A patient representative is responsible for being adequately informed about the circumstances and the treatment options, as well as about the person's values and previous wishes. The fact that someone has been appointed as the patient's representative

1 Available at http://www.cha.org.au
should not lead to the exclusion of other people who are close to the patient. Usually, the representative should inform and consult those who are professionally or emotionally close to the patient, so that they can provide relevant information, and can understand and be part of the process of caring for the person.

2 There are three ways in which someone may become a representative:
   
   • the representative was appointed previously by the person;
   
   • the representative was appointed by a court or tribunal after the person became incapable of making decisions about his or her own medical treatment; or
   
   • the representative has legal authority automatically, as the person’s spouse, carer, other next of kin or close friend.

3 To lessen uncertainty about these issues, continuity of care and carers is highly desirable.

Key point 2

A person’s representative makes health decisions for the patient, based on the patient’s previous advice and the patient’s own values, input from the health care professional and their own good judgement.

4 Interpreting a future health care plan

1 Interpreting a future health care plan is not always straightforward. Even when a patient has a progressive illness with a predictable course, unanticipated circumstances may arise. Similarly, a life-threatening event may occur when there are no nursing or medical personnel familiar with the person or the patient’s medical record (e.g. in a residential care facility), in which case the nursing or medical personnel cannot consider the applicability of a future care plan.

2 To pre-empt problems arising from unexpected circumstances, the patient’s family, representative, primary care givers and those involved as health professionals need to address the following questions:

   a) Do the present circumstances correspond to the situation that the patient imagined when he or she recorded his or her values and wishes?

   b) Do the treatment and care options available correspond to those of the patient’s future health care plan?

3 Do the effects of implementing the patient’s values and wishes correspond to the effects that the person understood would be their consequence?

4 Are there new or changed factors in the present circumstances that the patient may not have taken into account but might have wanted to be considered in the present circumstances?

5 Understanding responsibilities and rights

1 The person who accepts the role of a patient’s representative takes on the same moral responsibility that each of us has to sustain our own life. In addition, the guidance provided by the patient about his or her values and wishes should respect the health care professional’s moral responsibility to value and care for the patient until death intervenes.

2 Patients or their representatives have a moral right to refuse any treatment that is futile, or that they judge to be overly burdensome or morally unacceptable (referred to in the Catholic tradition as ‘extraordinary’ or ‘disproportionate’). Such refusals must also be respected by health care professionals.

3 Treatments are futile if they provide no benefit to a particular patient. Assessing the benefits of a treatment includes judging whether the intervention corresponds to the real situation of the person before and after the intervention. The benefits of treatment include:

   • slowing down the progression of disease;
   
   • sustaining the patient’s life; or
   
   • relieving the patient’s distress or discomfort.

4 Treatments are burdensome when they cause distress or suffering, cause difficulties for the patient or the family (or the community), or are costly to obtain or provide.
5 Those responsible for the patient (eg health care professionals, family members and representatives) need to judge whether the patient’s future health care plan, applied in the actual circumstances, is in accord with the patient’s values and represents what the patient would have wanted. They also need to establish that acting on those wishes is ethical and lawful, given both the patient’s and their own moral responsibilities.

6 The right to refuse treatment is not unlimited, and there are ethical and legal limits to what may be requested of a health professional or any other person, even by a competent person or representative. For instance, there is an ethical obligation to prevent suicide when this is possible and in most jurisdictions the law allows one to do so. A health care professional cannot be expected to act upon a future health care plan that expresses a suicidal or homicidal intention.

Key point 4
Health care professionals need to assess the relative benefits and burdens of treatment, taking into account the person’s values and previously expressed wishes and advice from the representative. However, health care professionals also need to be aware of their own ethical and legal responsibilities.

6 Recognising the responsibilities of representatives

1 Usually, representatives have the same moral responsibilities to request or refuse treatment as the patient had while competent. However, in some circumstances, the rights of the patient and the rights of his or her representative are not identical. For example, people are permitted to act generously by placing themselves in some danger for the sake of others (eg to donate tissues or to lessen a burden on their family), whereas their representatives are not free to make a similar choice for them. 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.

2 In addition, while respecting the patient’s wishes, a representative making a decision for a person who cannot make his or her own decision is always obliged to act in the best interests (respecting life and health) of that patient. The representative is also constrained by objective moral principles and his or her own conscientious judgments.

3 To become a person’s representative for medical treatment decisions is to assume a publicly accountable responsibility. Health professionals and other concerned people need to ensure that such representation is reviewed by the appropriate legal authority if a representative does not appear to be fulfilling the role adequately.

Key point 5
When making decisions about treatments, the rights of representatives may differ from those of the person. A representative must act in the best interests of the person, and health care professionals should ensure that this occurs.

7 Summary

1 Developing and implementing a successful future health care plan depends on good, long-term communication between the health care professional, the person and the person’s representative, family and friends.

2 In addition, planning for unexpected events requires health care professionals — together with representatives, friends and family — to consider the consequences of potential changes and how these differ from the person’s values and original wishes.

3 Above all, when implementing a future health care plan, health care professionals must comply with their personal, professional and institutional ethical responsibilities, while ensuring that they provide appropriate care.

4 This guide for health care professionals is intended to be read in conjunction with the guide for patients, A Guide for People Considering Their Future Health Care. More information about people considering their future health care needs and treatment preferences can be found in this latter document.

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2 See the Code of Ethical Standards for Catholic Health and Aged Care Services in Australia, section 1.17 (available at http://www.cha.org.au)

3 See the Code of Ethical Standards for Catholic Health and Aged Care Services in Australia, section 1.16 (available at http://www.cha.org.au)

4 See the Code of Ethical Standards for Catholic Health and Aged Care Services in Australia, section 1.21 (available at http://www.cha.org.au)