Emotional, spiritual and ethical end-of-life issues

An information booklet for clergy, health professionals and those facing end-of-life issues
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We thank UnitingCare Queensland for their encouragement to produce this valuable resource for clergy, health professionals and those facing end-of-life issues.

Our thanks also go to the Uniting Church Foundation which provided financial assistance for the publication of this booklet.

Rev Brian Gilbert
Chairperson, Queensland Synod Bioethics Committee
Emotional, spiritual and ethical end-of-life issues

An information booklet for clergy, health professionals and those facing end-of-life issues
There is no script for dying or for caring for a loved one. This book invites people to put aside the “should” and “ought to” voices and to listen to each other through the experience of terminal illness.

This book is a tool for clergy, carers and individuals as they navigate a way through difficult times. It features the stories of real people facing death, and their carers and families.

Their experiences illustrate in a poignant and meaningful way that each person’s experience is unique. The quotes, which are interspersed throughout each chapter, sharpen the reader’s understanding and provide insight into how a person can be involved in making informed choices about how they want to be treated and supported as they prepare to die.

Clergy will find this helpful as they seek to provide comfort and spiritual support. Whether or not a person practises a religion, clergy can be important companions and can help to make sense of the meaning and purpose of life. Carers and close friends or family members also may need to talk about their grief, fears and hopes. This book may help clergy put some shape into their own reflections on the pastoral engagement.

Healthcare professionals may appreciate these insights to enhance their endeavour to provide holistic care.

I congratulate the researchers and the writers for gathering these stories and translating them into a valuable resource. My thanks to the members of the Queensland Synod Bioethics Committee for persisting until the project was completed.

Rev Kaye Ronalds
Moderator, The Uniting Church in Australia, Queensland Synod
This booklet incorporates the findings of a research project conducted by the Uniting Church Queensland Synod Bioethics Committee.

The purpose of this study was to understand more fully the experiences of hospital end-of-life care from the perspective of patients, family and caregivers.

The findings highlight important issues in the delivery of care and support, and provide insight into the deeply personal experiences of those facing death or the loss of a loved one.
Introduction

The aim of this booklet is to provide a practical resource to assist clergy, family members, volunteers and health-care providers to support people in terminal care.

The main focus is to highlight issues identified by patients and family members as significant in end-of-life care, particularly in relation to emotional, spiritual and ethical matters.

Of key concern is the importance of helping people to articulate their needs, and listening to their concerns. Good communication skills that facilitate helpful conversations are essential to the provision of quality end-of-life care.

This booklet may assist in the development of end-of-life support systems and resources for patients and their families whether they are in hospital or at home.

Short quotes suitable for reflections are included at the end of each chapter.
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Communication about end-of-life care may involve difficult conversations for patients and family members as well as clergy and health professionals.

The challenges of communication, and the need to provide holistic end-of-life care, were particularly emphasised in this research project. All of the participants expressed some concern around issues such as the quality and effectiveness of communication with health professionals.

This concern highlights the necessity for full disclosure and consistency of information between different health professionals. Good communication is important in preparing the patient and family for death as well as minimising the impact of grief during the bereavement phase.

**Patients**

For patients, the ability to communicate choices to health professionals and family members is an important factor in end-of-life care.

Inadequate information and a lack of understanding may mean that the patient does not have the opportunity to make choices and to have an active involvement in their own health care plan. This may result in a loss of dignity for the patient and additional stress for family members.
For some patients in the study, verbal communication was extremely difficult; therefore there was a need to provide alternative ways of communicating.

One respondent said:

_We bought her a little white board. She liked that because she could not talk because she had a tracheostomy and the ventilator. She said, ‘I don’t want this [medical intervention]. Take all this machinery off me’._

**Carers**

For families, being invited to participate in the care and decision-making process may provide a sense of purpose as well as closeness to the patient. Generally, it is the patient who determines who else is involved and consulted regarding treatment plans and care.

It became clear in the study that most family caregivers believed that the amount of information they received from health professionals was insufficient for them to provide adequate support.

This was explicitly mentioned by a carer:

_I can only say that the doctors assumed that because Mum knew [her prognosis and choices] that was as far as they needed to share information._

_For us, it would have been helpful to have had some more information earlier about how exactly she was going and what the options were. Not that we wanted to make any decisions on her behalf, but just so that we knew where we stood._

End-of-life discussions with health professionals can provide an opportunity for the appropriate sharing of information with family caregivers, and these were generally considered a positive experience by most of our participants.
The following two statements indicate that the opportunities to take part in these discussions varied between the different participants:

He [the doctor] is very informative. He knows that I would like to know, and my children usually request a visit with him each time I go in and want to be updated. He very generously gives of his time and comes to talk to them.

I would have preferred a conversation that said that [explained side effects of operation] and if there were going to be implications, but they don’t do it.

Other participants spoke of the difficulty of health professionals not being direct or open in their provision of information:

They don’t want to give you the full hard whole facts as they are.

Ineffective communication impacted on the ability of end-of-life care to be consistent with the wishes of this patient and her family:

They prescribed anti-depressants ... and that made her really angry that they weren’t listening to her, they didn’t listen to what she was trying to say, that she didn’t want all this.

Some family members, not knowing what was happening, or what treatment was being offered, felt isolated and even more distressed.

Family conferences

End-of-life family conferences are aimed at improving communication with relatives of dying patients and easing the burden that weighs on the family.

In our study, family conferences were found to be of great benefit, as they helped everyone to become more aware of treatment choices and the implications of treatment.
One respondent commented:

*When we finally had the family conference... I found that helpful because the doctor told us. He just said, ‘going home is not an option’.*

Both patients and families should be recipients of care, and both sets of needs must be considered by health professionals.

Some advantages of family conferences are:

- They provide an opportunity to discuss difficult matters openly with medical staff.
- They allow for consensus decision making by families, and can support them to identify realistic goals of care whilst assisting them to deal with their own distress.
- The patient is not left with the responsibility of passing on information that may be difficult for family members to accept or understand.

People are different, and some may want to remain private and keep information to themselves. Sometimes this is done out of fear or because it may be too emotionally difficult to talk about dying. It may well be that some patients would be more comfortable with their family members talking to health professionals about their prognosis.

Certain sensitivities to cultural values and personal experience may affect what patients want to hear or talk about. For example, some people consider talking about death to be unwise, unlucky, or a violation of their spiritual beliefs.

It is important to respect each person’s individual choice; and it is equally important to give them an opportunity to share their concerns. It may be that they need someone outside the family to gently initiate the conversation.
Life support

The decision about when to withdraw life support is an area that involves some difficult ethical decisions. The goal of end-of-life care is to maintain quality of life while neither hastening nor postponing death.

Families are often faced with the decision to withhold or withdraw life support. If a patient is legally competent it is possible to refuse treatment including ventilation as long as enough information is made available. It is important to take into consideration quality of life, comfort and dignity.

Reflection

The light of God surrounds us
The love of God enfolds us
The power of God protects us
The presence of God watches over us
Where ever we are, God is!
And all is well!

James Dillet Freeman

Hear my prayer, O God;
Give ear to the words of my mouth.

Psalm 54:2
Experiencing terminal illness

Each individual has different needs which are based on their past experiences, personality and occupation.

Health professionals and family members need to treat each person as an individual, respecting their choices and unique way of dealing with situations.

It is imperative that family members understand the aspects of care that are important to the patient. This will help to reduce stress, anxiety and the emotional burden for the family as well as enhancing the relationship with the patient.

Loss of identity

Terminal illness can bring about a change in roles and the loss of identity due to the impact of an overwhelming treatment regime.

It is important for the patient to continue to lead as normal a life as possible, rather than taking on the “sick” role.

This participant discussed the importance of being perceived and treated as a person:

*We don’t want to be treated as different, we want most of all to be normal and to be treated as normally as possible.*
Another person articulated their frustration:

_I am going nuts. I cannot go anywhere anymore. I can’t shop anymore; I can’t play my Bridge anymore. I can’t go and visit my friends anymore. I live in these four walls and I am going crazy._

Losing control of the things that provide purpose and meaning in their lives is a crucial issue for people. It is therefore important to continue to involve the sick person as much as possible in day-to-day decision making.

Each person responds differently to situations encountered during treatment and end-of-life care.

The importance of being treated as an individual following the loss of her hair as a result of treatment was expressed by one person in this statement:

_A lot of people say … you are making a fuss about it. It is an individual thing and each person feels it in their own way. Some women suffer badly as I did and are extremely embarrassed._

_Holistic care_

Holistic care involves seeing the person for who they are rather than as their illness or bed number.

The importance of assisting health professionals and visitors to enter into the life and interests of the patient is highlighted in this statement:

_We went and got pictures of her when she was a young woman and we put cards and emails from the grandchildren and made a whole storybook of her life._
Losing the capacity to act independently, and losing control over the body, may be experienced as a fundamental loss of dignity and identity.

For many people, there is a strong link between independence and status as a person, and thus disease and the dying process may threaten an individual’s sense of self-worth.

There is a clear link between the provision of care which enhances the dignity of patients, and the quality of life which they experience during the dying process.

**Reflection**

Lord and giver of all life, help us to value each person, created in love by you.

In your mercy, guide and assist our efforts to promote the dignity and value of all human life

Amen

He turned to me and heard my cry.

**Psalm 40:1**
Working with health professionals

Many aspects of end-of-life care are highly dependent on the quality of the health care services.

Honest communication between the patient, family and health professionals helps the care team to achieve effective coordinated care which meets the complex needs of patients and their families. Talking openly can lead to a better understanding of any needs or concerns.

What’s going on?

Those who participated in this project indicated some concerns about the quality and consistency of information given to them by health professionals.

It was their opinion that it would be helpful for the doctor to bring up common difficulties that are experienced by patients and their families during the end-of-life period.

Actually making times with the family to sit down and explain and answer questions face to face ... that would have been good ... but it wasn’t so.

Having an opportunity to discuss end-of-life issues with a health professional in an open and honest manner is beneficial for both family members and patients. Arranging a family meeting with the relevant professionals can provide an opportunity to discuss
treatment options, advance care plans and to ensure that the wishes of the patient are considered.

Advance care planning

Advance care planning is the process of documenting a person’s wishes while they are able to articulate their choices. It increases the chance of these wishes being respected and avoids unnecessary suffering and distress. These plans will help family and friends make decisions when the person is no longer able to do so.

It is important to feel free to discuss any of these matters with health professionals. Research indicates that the earlier the patients’ wishes are discussed, the more positive the end-of-life experience will be.

Delivering compassionate care

Those who participated in the study valued staff who spent quality time discussing issues with the patient and family, and indicated that this is a vital aspect of end-of-life care.

_The really important thing was that the staff talked to you, they were kind, and they understood what was going on._

One participant made the comment that he felt his wife was “being cared for, not treated” when she was in the palliative care environment.

Health professionals were assessed by the participants on their level of care and kindness rather than their clinical skills. One allied staff member was described as “a hand reaching out in the darkness”.

Within the hospital setting, multidisciplinary care sometimes introduced additional stress due to the lack of communication between health professionals working independently.
There was this total loss of control that suddenly your life isn't your own. You are being tossed around by different medical groups, all exploring possibilities independently of each other.

This may cause unnecessary distress and confusion to both the patient and the family. It was suggested that a case manager would limit the discrepancies in information and provide a point of contact in regard to any concerns.

**Choosing where to receive care**

End-of-life care can be provided at home, in hospital or in a hospice.

As far as possible, the person and their family choose where the care is given.

Most people spend the majority of their time at home and are admitted to hospital for particular treatments, symptom management and pain relief. Some people choose to die in hospital and others choose to die at home.

There may be times when circumstances prevent people from dying in the environment of their choice.

**Effective communication with professional staff**

It is important for patients and families to have the opportunity to speak easily with those providing health care services at all stages of care.

A few suggestions for effective communication are listed below:

- Prepare a list of questions before appointments.
- Invite a family member or close friend for support.
• Take notes or ask if the visit can be recorded.
• If a concern is not addressed, ask the question in a different way.
• If you are unclear about an answer, ask for clarification.
• Be honest with the doctor about how you are coping emotionally.
• Don’t be afraid to ask questions about end-of-life treatment and medical decisions.
• Let the doctor know how much information you want to receive about the illness, prognosis and care options.
• If you think of extra questions after your appointment, ask to see the health professional again.
• Don’t be afraid to ask for another opinion if you are not satisfied with the information you are given.

Reflection

Grant me to recognise in others, Lord
God, the radiance of your own face.

Teilhard de Chardin, SJ

Hear me, O Lord, as your loving kindness
is good: Turn to me, as your compassion
is great.

Psalm 69:17
Family members usually play a significant role in end-of-life care and are a major source of support for the dying person.

Early involvement in care and decision making is important in preparing people psychologically and spiritually for the death of their loved one.

For the patient, family support is usually a key factor in their end-of-life experience.

*Lucky I had my sister, she was with me every minute of every day just about, and she was my strength ... brought me a great deal of comfort.*

**Changing roles**

When a person is diagnosed with a terminal illness their role in life changes as they try to make adjustments within their family situation. The role of family members also changes as they do their best to provide support for their loved one.

One family member highlighted this:

*He took on the role of caring for her for two years and his world shrunk hugely because she hardly left the house. She was really housebound and he basically dropped a lot...*
of things; but he did it and learnt to do all
the domestic stuff and drove her to every
appointment and we did not share the load
of that.

Some family members will find themselves doing a
juggling act as they try to continue normal life as well
as care for their loved one.

Many family members discussed the importance of
supportive care to assist them in the role as caregiver.

This family member described what might have been
helpful:

I would have been quite happy for it to be
someone else [other than the doctor] that
sat down and said, ‘What about you? Is
there anything about her that you would
like to ask?’

The health care system is becoming increasingly
complex and information regarding treatment and
care plans can be quite confusing for patients and
families.

Dealing with conflict

There may be times when family circumstances
make communication difficult. Conflict may arise
when family members have different views or beliefs
regarding end-of-life care.

A family member faced with this dilemma stated:

I wanted to take her home and look after
her at home. My mother had a sister and
I said, ‘let’s take her out of here and take
her home and look after her’. She [sister] said, ‘you can’t do that, that’s murder.’
You see she wanted her in that hospital
environment with all the machinery and all
the technology and everything. She couldn’t
imagine, you know, just nursing her.
It is normal to disagree with each other from time to time, especially in these circumstances. Communicating in a positive way can help reduce conflict so that family members can reach a peaceful resolution.

Sometimes strong emotions, or the power imbalances that can be present in relationships, are difficult to resolve. In these situations it may be helpful to engage the support of a counsellor or chaplain.

**Supporting the patient**

Patients who were interviewed described how their family members provided support emotionally and physically, as well as assisting with decision making. They expressed their appreciation for the constant support and said that they experienced “a great sense of comfort” and “strength”.

During the end-of-life period relationships changed, and there was a strengthening of bonds between family members. There was acknowledgement by patients of the long hours devoted to care, and the way that family members put their own lives on hold to provide that level of support.

**Supporting families**

End-of-life care involves care of the patient and the family. The family should be provided with honest communication, practical, psychosocial and spiritual support as well as support during the bereavement phase.

No matter where the family chooses to care for their loved one, health care professionals need to provide the family with clear, honest answers to questions about medication, symptoms, comfort, and concerns about the imminence of death.

The family may need someone to listen to their fears and provide compassionate and supportive care. Sometimes family members can become depressed.
and may need to be referred to professionals who can provide counselling.

Children in the family have special needs when coping with the illness or death of a loved one. They need added comfort, support and reassurance to cope with changes in routines affected by the care of their family member. Their questions should be answered honestly and in an age-appropriate way and they should be included wherever possible.

Family members may need help with practical issues such as Advance Care Plans, Enduring Powers of Attorney, wills, and funeral arrangements.

A few suggestions for families are listed below:

- Pay attention to your own health and plan some activities for personal recreation.
- Don’t be afraid to ask for, or to, accept help.
- Support each other: assistance with simple tasks like mowing the lawn, preparing meals, or assisting with transport can ease the load.
- It may be helpful to have someone stay with your loved one for a short time. This will give you an opportunity for some respite.
- Remember, allowing others to help gives them an opportunity to share the journey.

**Reflection**

*Lord, you are closer to me than my own breathing, nearer than my hands and feet.*

_**St Teresa of Avila**_

*O give thanks to the Lord, for he is good: For his loving mercy is forever.*

_**Psalm 107:1**_
Spirituality

The World Health Organisation recognises spiritual care as an essential element which should be offered to all those who approach end-of-life.

Spiritual care can play a significant role when cure is not possible, especially when people begin to question the meaning and purpose of life.

Defining the spiritual dimension to life can be a considerable challenge.

Ruth Tanyi defines spirituality “as an inherent component of being human, [and is] subjective, intangible, and multidimensional. Spirituality and religion are often used interchangeably, but the two concepts are different. Spirituality involves humans’ search for meaning in life, while religion involves an organised entity with rituals and practices about a higher power or God. Spirituality may be related to religion for certain individuals, but for others, such as an atheist, it may not be.” (Journal of Advanced Nursing Vol. 39, Issue 5, 2002)

Finding purpose and meaning

Spirituality is that which drives human beings to find purpose and meaning in their lives regardless of whether they believe in a God or not.
The search for meaning, purpose, wholeness, and integration is a never-ending task.

One patient acknowledged the difficulty in being able to adopt new and meaningful roles during times when she felt reasonably well. She would have liked to volunteer her time in helping people who had cancer:

*I just want to help and give something back for all the help that I had been given ... No avenue, and they deny you that right unless you were cured.*

The uniqueness of each end-of-life situation demonstrates that, along with individual preferences for care and communication, there are also individual preferences in spiritual needs.

**Spiritual distress**

Patients and their families often experience spiritual distress when they are trying to come to terms with a life-threatening illness.

Spiritual distress could be described as “the impaired ability to experience and integrate meaning and purpose in life through connectedness with self, others, art, music, literature, nature, or a power greater than oneself.” *(The North American Nursing Diagnosis Association International Nursing Diagnosis, Definitions and Classifications, 2005-2006 Philadelphia)*

Some of the symptoms of spiritual distress are:

- sorrow and grief
- withdrawal and isolation
- meaninglessness and emptiness
- fear and avoidance of the future
- hopelessness and despair
- anger and bitterness towards God, fear of God/punishment/judgement
• loss of meaning and hope
• loss of identity
• conflict with family members, friends or support staff
• depression, fear or dread.

Research indicates that honest discussions with patients and caregivers assist them to prepare emotionally and spiritually for death. Studies have also found that caregivers who have been able to engage in end-of-life discussions are not as likely to experience depression in bereavement.

Withholding information to promote false hope was not seen as an acceptable approach.

Acceptance of death varied amongst those who participated in the study, and was determined by factors such as how the family was dealing with the situation, the patient’s ability to discuss dying and their own personal experiences of death.

**The role of faith**

Some family members were able to accept and come to terms with what was happening because of a strong faith.

_We had all these other people that prayed for Mum. It made a big difference and of course it makes a huge difference when you know that someone is going to a wonderful place and not just going off forever to nowhere and nothing; it is a very different experience to say goodbye for a while to someone as opposed to forever._

One patient was able to let go of fear because she believed in eternal life. This gave her hope that loved ones would be waiting for her when she died.

_What is there to be afraid of? If you have got people like that [family members] waiting for you?_
Others were inspired by the faith of their loved one:

*She was just so peaceful; she had no fear of dying. Her faith was very strong; she was quite a witness I think to people.*

*She is approaching now a state of peace. The final stage of peace which I was praying and praying for, even though I don’t pray.*

Adequate preparation for death and the role of faith can aid in the reduction of fear and the overall acceptance of death. Some participants in our study were able to acknowledge the importance of their faith and how it assisted in their acceptance of dying and reduced their fear.

Spirituality, faith and religion come under the category of mystery – that which cannot be proven or understood.

*If we are talking about spirituality my mother who never went to church and I was packing up all her stuff... she had an angel in every room of that house. Isn’t that interesting? She had a little angel. She was quite spiritual but it was not something that she spoke about.*

**Providing religious comfort**

As people grapple with the mystery of life and death and the unknown, spiritual care brings a quality of presence in the midst of their suffering.

Many patients do not expect a solution to their spiritual questions, only an opportunity to explore and discuss these issues.

When asked how your faith helps you, this patient responded by saying:
Well it is something that I never think about. I would think that it probably doesn’t pay a big part in my life at all but I think it does. In one way I would say I am not religious at all and in other ways I would say well that is the only way to go.

A few suggestions on how to address spiritual distress or provide religious comfort are listed below:

- be present and listen carefully
- offer companionship
- provide opportunities for expression of beliefs, fears and hopes
- answer questions honestly without pushing your own beliefs
- provide access to spiritual and religious support for patients and families to explore their faith
- respect and provide opportunities for patients and families to practise spiritual or religious rituals and sacraments.
- provide appropriate resources such as reading material or music
- remember that the emphasis is on being (with), not doing; you don’t have to fix things, or to have the answers.

Reflection

O God, teach me to breathe deeply in faith.

Søren Kierkegaard

O let me hear of your merciful kindness in the morning,
for my trust is in you:
show me the way that I should go,
for you are my hope.

Psalm 143:8
Preparing for death

When a person approaches death they will experience a variety of changes.

They will have less energy and tire more easily, often eating and drinking less and spending more time resting or sleeping. There can be a feeling of detachment from the physical world and a loss of interest in things formerly found pleasurable.

Some people will want to know what will happen physically to their body, and this knowledge can help to reduce anxiety and fear. Being prepared can help a person feel more in control.

For others, having too much information means more things to worry about.

Remaining alert and being able to communicate will be important for some people, and others may wish to be a little more sedated.

Each person’s death is individual, just as their life has been, and it is important to respect individual needs and choices.

The final stages of life can be marked by change and growth when there is a supportive community and good care.
Journeying together

When a person agrees to accompany someone who is dying, they enter into a covenant relationship with that person. They agree to journey with them.

They listen to their stories, discern their needs and provide a safe and sacred space for them to express their anger, sadness, guilt, shame or doubt as well as joy, hope and acceptance. They seek to answer their questions honestly, to love them unconditionally and to guide them where appropriate.

Provision of this type of care provided growth for this person’s loved one:

\[
\text{Just accepting her as a person as she is, as a valuable human being. She is only just beginning to realise this after all these people have come to visit her. She is just beginning to realise that people love her. She has felt unloved all her life ... so sad.}
\]

The hardest part of dealing with end-of-life issues may be starting the conversation. Some people wait for the dying person to bring it up, while the dying person may wait for their family members to talk about it. In either case, important decisions are put on hold while people wait for someone else to start the conversation.

Many people believe that talking about end-of-life issues means they are giving up hope.

Hope is a complex issue and is usually wrapped up in hope for a cure. Hope changes over time and with the approach of death it is more likely to focus on quality of life issues.

Many people are surprised to find that a dying person wants to talk about what’s happening to them. Talking
about it can be therapeutic and healing for the dying person as well as their family and friends.

One of our participants stated:

_The hardest thing I find is people’s acceptance of the fact that you are dying. Because you want to talk about it but no one wanted to._

**Fear of death and dying**

The thought of dying can evoke fear and apprehension. The fear of death is common and many fear the death of their loved ones. It’s very normal to experience these feelings, and primarily what is feared is the unknown.

A family member found that both she and her loved one were still afraid of death even though most of the time they were peaceful and calm.

_She has told me that she is terrified of dying and doesn’t want to go._

_No matter what happened I knew that one night I would come and she would have died. I dreaded that._

For some, the fear of death is more focused on the act of dying. Some people are more afraid of what it will feel like to die rather than the idea of ceasing to exist. They may worry that they will feel pain or fear when they die.

Some may feel afraid of losing dignity and quality of life or of living too long.

Dying people can feel ostracised from society, even avoided by close friends and family. One patient reported feeling isolated and alone.

_It’s exceedingly lonely. You know, there were what I thought were very good friends. You don’t see them, you don’t hear from them._
The role of family

Being surrounded by friends and loved ones is how the majority of people would choose to spend their last months or days. There may be times when families feel that they need to protect or shield the dying person; however this may isolate them even more.

End-of-life care often provides more opportunities for families to spend time together, appreciate each other and not take each other for granted.

Families who have been used to concealing their innermost emotions often turn around and start saying “I love you” more often, and telling one another how they feel.

This was certainly true for these family members who recognised the value in the time they spent together.

“Yes, great respect for each other and to see the other side of each other. We are so lucky to have had that. It has just made all the difference in the world that they have bought that time for us with their care.

I have to say it has been the most beautiful time of my life. I told her that and it has been. It has been such a privilege and I am so grateful I had it.”

Acceptance

Coming to terms with the end of your life is not easy. Acceptance doesn’t mean that a patient likes what is going on, and it doesn’t mean that a patient has no hope – it just means that they are being realistic about the situation. Some people do this more easily than others and it often depends on the particular situation or context as to how a person adjusts.
One patient reflected:

_I adjusted well. Yes I was accepting. As I say, I don’t like to think I am throwing in the towel. I think I am accepting of the fact and acknowledging that I have had a long life._

Sometimes it is more difficult for family members to imagine a world without their loved one. Caring has been such a major focus of their life that their imagined new world without their loved one seems fruitless and empty.

_Leaving B. It is something we have joked about all our lives because our lives are so entwined._

Witnessing the death of a loved one proved to be beneficial for understanding and acceptance for this family member:

_Afterwards I thought, I am not afraid to die, watching her. You know, that last look, it was so peaceful._

As life ends, we want to know that we will be remembered and that our life has had value and meaning. Many people approaching death find it helpful to reflect on their lives. This can help bring closure and a sense of fulfillment.

It may be useful to think about creating a variety of memories for your loved ones such as:

- keeping a journal
- collating photo albums and memory boxes
- Making video/audio recordings
- compiling a life history
- writing letters to special people.
Reflection

The words of Khalil Gibran are simple, yet profound, and there is room to interpret them and hear them according to your own spiritual journey.

You would know the secret of death. But how shall you find it unless you seek it in the heart of life? The owl whose night-bound eyes are blind unto the day cannot unveil the mystery of light. If you would indeed behold the spirit of death, open your heart wide unto the body of life. For life and death are one, even as the river and sea are one.

The Prophet

You have turned my mourning into dancing;
You have taken off my sackcloth and clothed me with joy,
so that my soul may praise you and not be silent.

O Lord my God, I will give thanks to you forever.

Psalm 30:11-120
Booklist

Klein, A 1998 *The Courage To Laugh* Jeremy P. Tarcher/Putnam
Albom, M 1997 *Tuesdays With Morrie* Sphere
MacPherson, M 1999 *She Came To Live Out Loud* Scribner
Morgan, JD 1999 *Death and Spirituality* Doka KJ (ed.) Baywood Publishing Company
Reyes, BF 1986 *Conscious Dying World* University of America
McFarlane, R & Bashe, P 1998 *The Complete Bedside Companion* Simon & Schuster
Ainsworth-Smith, I & Speck, P 1999 *Letting Go: Caring for the Dying and Bereaved* SPCK
Bausch, WJ 1984 *Storytelling: Imagination and Faith* Twenty-Third Publications/Bayard
Quinlan, J 1996 *Loved and Lost: Journey through Dying, Death and Bereavement* Columba
Alexander, H (ed) 1990 *Living with Dying* BBC
Buckman, R 1996 *I Don’t Know what to Say* Pan
Callanan, P & Kelley, P 1994 *Final Gifts - Understanding and Helping the Dying* Hodder & Stoughton
Copperman, H 1983 *Dying at Home* Scutari
Green, J & Green, M 1991 *Dealing with Death: Practices & Procedures* Singular
Bolby, J 1986 *Loss: Sadness and Depression* Basic Books
Schaefer, D & Lyons, C 1993 *How Do We Tell The Children?* Newmarket Press
Doka, KJ (ed.) 1995 *Children Mourning, Mourning Children Hospice* Foundation of America


“Do You Remember When…?”
(Creative Memories Project UQ OT students and Mater Adult Occupational Therapy Department)
Available from Occupational Therapy Department, Mater Misericordiae Health Services $60, or from Trinity Theological Library library@ucaqld.com.au.

Useful organisations in Queensland

Palliative Care Queensland: Freecall 1800 660 055 palliativecareqld.org.au

Palliative Care Information Service: 1800 772 273 pcis.org.au

Caresth: caresearch.com.au

Carers Queensland: 1800 059 059 carersqld.asn.au

Cancer Council Queensland: Helpline 131120 cancerqld.org.au

Leukaemia Foundation of Queensland: 33184418 leukaemia.org.au

Commonwealth Carer Resource Centre: 1800 242 636

Motor Neurone Disease Association of Queensland: 07 3372 9004 mndaq.asn.au

Karuna Hospice: 3632 8300 karuna.org.au