A guide for family and friends with loved ones in aged care
ACKNOWLEDGEMENTS

Many people and organisations have collaboratively contributed to the development of this booklet. It is based on the expertise of leaders in the field, multidisciplinary partners as well as family representatives.

DRAFTING OF CONTENT
- Associate Professor Rosalie Hudson, consultant
- Robyn Allan, consultant

PROJECT MANAGEMENT
- Francis Icasiano, Mercy Health

REVIEW AND DEVELOPMENT OF CONTENT
- Mercy Health
- Mercy Palliative Care
- North West Aged Person’s Mental Health
- Centre for Ageing and Pastoral Studies

ENDORSEMENT OF CONTENT
- Palliative Care Victoria
- Aged and Community Care Victoria
- Centre for Cultural Diversity in Ageing

EDITING AND ART DIRECTION
- Jaclyn Bond, Mercy Health

This booklet was funded through the Department of Health and Ageing (DoHA), Local Palliative Care Grant Round 5.

We would like to give special thanks to everyone who provided invaluable insights and reviewed drafts in the development of this resource.
WHAT IS A PALLIATIVE APPROACH?

A GUIDE FOR FAMILY AND FRIENDS WITH LOVED ONES IN AGED CARE
# CONTENTS

## AIM OF THIS BOOKLET 06

## INTRODUCTION 07

### CHAPTER 1: PARTNERSHIP IN CARE 08
- What care can I expect my relative to receive? 08
- Decisions about care 08
- What does partnership in care mean? 09
- How will I know what is happening? 10
- Key messages 11

### CHAPTER 2: WHAT IS PALLIATIVE CARE? 12
- Common life threatening, incurable conditions 13
- What is a palliative approach? 14
- What does “specialist palliative care” mean? 17
- What can we expect at the end? 18
- What do I do at the time of death? 22
- Reactions to death 22
- Key messages 23

### CHAPTER 3: PALLIATIVE APPROACH AND DEMENTIA 24
- What is dementia? 25
- Key messages 27

### CHAPTER 4: WILL MY RELATIVE BE IN PAIN? 28
- Pain management and drugs 30
- Non drug measures 32
- What other comfort care is available? 32
- Key messages 33

### CHAPTER 5: GRIEF, LOSS AND DEPRESSION 34
- What is loss? 34
- What is grief? 34
- Helping your relative through grief and loss 36
- Is grief the same as depression? 36
- What is depression? 36
- How do you know if an older person is depressed and not just sad? 37
- What makes an older person more at risk of depression? 39
How can depression be treated? 39
Helping an older person with depression 40
Key messages 41

CHAPTER 6: ADVANCE CARE PLANNING (ACP) 42
ACP: Who decides? 42
How does ACP work? 43
What if I don’t want to talk about death and dying? 43
Summary of ACP 44
Key messages 45

CHAPTER 7: CULTURAL CONSIDERATIONS 46
Interpreter services 46
Key messages 49

CHAPTER 8: SPIRITUAL CONSIDERATIONS 50
Key messages 53

CHAPTER 9: WHAT CAN I EXPECT TO FEEL? 54
Different visiting patterns 58
When you don’t feel like visiting 59
Looking after yourself 59
How will I feel after the death? 60
Key messages 61

FINALLY 62

GLOSSARY 64

REFERENCES 66

YOUR FEEDBACK IS VALUABLE 67

Interpreters are available if you require assistance in another language.
AIM OF THIS BOOKLET

This booklet aims to provide information that will enable you to understand the palliative approach provided in residential aged care and to encourage your partnership in this care.

The contents of this book are based on The Guidelines for a Palliative Approach in Residential Aged Care, published by the Commonwealth Government in 2004 and endorsed by the National Health & Medical Research Council in 2006. All aged care homes in Australia have access to these guidelines which are the first guidelines in the world to combine aged care and palliative care. They are based on the best evidence available, so they can be used with confidence. You can download your own copy at: www.palliativecare.org.au.
You may find that when your relative is admitted to residential aged care you enter a strange, new and different world. You will already have loads of information and forms to fill in, all of which can be quite overwhelming. You may be wondering why you need additional information about a palliative approach.

Whilst we generally don’t like to talk or think about it, aged care homes are the place where people spend the final chapter of their life. People come into care because they are no longer able to look after themselves and most will have chronic illness alongside ageing. The focus of care in aged care facilities is to help people live well with their illness and frailty during their time spent there. This focus on living well is the essence of the “palliative approach to care”.

This book is intended for you, a relative, or friend, so you have the most up-to-date information about a palliative approach in residential aged care. This change in aged care only came about in 2004, so for many people it will be new. The book is divided into chapters so you can select what is most important to you. You may also find that different chapters will be helpful at different times. You may also use the book to help you know what questions to ask, or if you are unsure about different aspects of your relative’s care.

You may find the written information in this book is sufficient for your needs or you may require further discussion and explanation. For many, conversations about the content will be far more important.

We hope you will read it at your leisure. Please request a meeting with staff if you would like more discussion about any of the content at any time. You may find that, as you accompany your relative on this journey through residential aged care, you will have different questions at different stages. As we explain throughout the book, it is important to discuss these issues early; otherwise, you and your relative may miss out on all the advantages of the palliative approach.

As no two residents are the same, no two relatives are the same. We appreciate you will have your own unique contribution to your relative’s care as well as your own particular questions. We welcome an ongoing conversation.

A word of explanation about the term “relative”. We know some carers are not relatives of the resident in care; you may be a close friend or partner or guardian. We hope you’ll feel included if we use the term “relative” throughout the book to mean the person who has been (or is likely to be) the main carer.
WHAT CARE CAN I EXPECT MY RELATIVE TO RECEIVE?

It can be difficult when your relative is admitted to residential care with all the meanings and feelings associated with the admission. It is often a difficult time leading up to the admission, either because the waiting time is too long or too short. It can be unfamiliar territory and families and residents can have many questions and concerns particularly about the care they will receive. People are admitted to residential aged care because they are no longer able to independently care for themselves. Most will have one or more serious illnesses or health conditions as well as the frailty often associated with ageing. This period is often made more difficult when the person is mentally frail (such as in dementia) or when the person is not aware of what is happening and is unable to understand the most careful and repeated explanations.

No matter how frail your relative is, mentally or physically or both, you can expect that all care will be given according to the guidelines and standards for aged care and palliative care.

You don’t stop caring just because you no longer do the physical task of caring.

DECISIONS ABOUT CARE

The best person to decide what care is needed is the person requiring the care. However, partnership in care means that we all need someone to help us at various times in our lives. If your relative cannot express their own wishes or preferences, then the person who knows them best can speak for them. A good question to ask yourself is, “If my relative could speak for themselves right now, what would they wish for?” That way, when you speak for them you will be acting, as far as possible, in good faith.

The most important person to decide on care decisions and planning is the resident. They should be asked their own preferences for care before anyone else offers an opinion.
WHAT DOES PARTNERSHIP IN CARE MEAN?

Aged care staff have a duty to provide care based on the latest evidence and informed by the guidelines quoted at the beginning of this booklet. While family members have a role as partners in care, your role is also to respect the professional knowledge of the aged care staff. The best partnership occurs when you and the staff meet regularly to discuss issues that affect your relative’s care. You may have vital information that the staff do not have.

“I think to myself, ‘Even though you’re the professional, I shouldn’t be afraid to say something about my mum’s care. Our input is just as important as the professional.’” – Daughter

Likewise, staff may have vital information to share with you. Your relative is the most important person in this partnership.

Partnership in care means that care is individualised to meet the needs of the resident, family and friends; staff, residents, families and friends work together to meet these needs; and there is good communication and an understanding of the resident’s life history as well as how they are now.

(Alzheimer’s Australia, 2005)

If your relative is unable to make their preferences known, then whoever speaks for them must act in their best interests.
HOW WILL I KNOW WHAT IS HAPPENING?

Depending on how often you visit, you will probably notice any changes in your relative’s condition as soon as they happen. If you have questions about these changes it’s best to ask the person in charge on that day as not all aged care staff have the same knowledge and skills in the palliative approach. The person in charge will let you know the best times to ask questions either in person or by phone. As you develop a relationship of trust with staff they will get to know your preferred communication pattern. For example, some relatives want to know about changes in medication, others are more interested in their relative’s diet or mood changes. You should feel free to ask about any aspect of your relative’s care.

You will be invited to discuss your relative’s “care plan” from time to time and to contribute your own comments as the care plan is updated regularly. If you’re not sure what’s happening at any stage, you may ask the person in charge for a meeting to discuss issues on your mind.

Palliative care regards the patient and the family as partners in the care. You are, therefore, part of the team.
• You don’t stop caring just because you no longer do the physical task of caring

• The most important person to decide the matters that affect your relative’s care is your relative. They should be asked their own preferences for care before anyone else offers an opinion.

• Partnership in care means that care is individualised, everyone works together and there is good communication and an understanding of the resident’s life history as well as how they are now

• If your relative is unable to make their preferences known, then whoever speaks for them must act in their best interests
Palliative care refers to the goal of care. It means that the focus of care changes from cure to care. This includes relieving any distressing symptoms, promoting the best quality of life and providing support for families. When cure of the underlying illness is not possible, there is much more that can be done to help the person live well until they die (and this may sometimes be years).

Palliative care is no longer confined to people with cancer. It now includes people with other life threatening, incurable conditions. Palliative care is no longer confined to the last days or weeks of life. That is why a palliative approach applies to all people in residential aged care who have illnesses that are not curable. Palliative care is about getting to know the person and their family and to plan what support is needed throughout the whole journey. That’s why the palliative approach to care begins early.

The goal is “care” rather than “cure” in palliative care.
COMMON LIFE THREATENING, INCURABLE CONDITIONS

Common diseases of older people requiring residential care include stroke, heart disease, lung disease, diabetes, Parkinson’s disease, cancer and other neurological diseases (such as multiple sclerosis and motor neuron disease) and dementia. There is currently no cure for any of these diseases so the goal is to care for the resident by providing the best possible treatment for distressing symptoms and to promote their overall comfort and wellbeing.
WHAT IS A PALLIATIVE APPROACH?

A palliative approach is a type of palliative care and recognises that death is inevitable for all of us; however, for older people admitted to residential care, this is often the last chapter in their lives. For some it will be a short chapter and for others it will be a longer chapter.

When a resident has one or more conditions that cannot be cured, a palliative approach is offered. The goal is care rather than cure. The goal of a palliative approach is to improve the resident’s level of comfort and function and to offer appropriate treatment for any distressing symptoms such as pain. A palliative approach also addresses the resident’s psychological, spiritual, social, emotional and cultural needs. Families are welcomed as partners in this approach.

Q: Which residents should be offered a palliative approach?
A: Every resident who has one or more life threatening (incurable) diseases and for whom the focus is total active care rather than curative treatment for a disease.

Q: Does this mean that the person no longer receives medical treatment/interventions?
A: Definitely not. Medical treatment to manage symptoms goes alongside comfort care and could include chemotherapy, surgery or medications.

Q: When should the palliative approach begin?
A: Because it is so difficult to know how long the "last chapter" will be, it is better to begin as soon as possible after admission. In other words "at the beginning of the chapter". When a resident has been thoroughly assessed for all their needs a discussion about the palliative approach should be offered. When a resident and their family have been given accurate information about the goal being care rather than cure, then the palliative approach has begun.

Q: But isn’t this too soon to be talking about death and dying?
A: The focus of a palliative approach is on living. That is why staff will want to have a discussion with you and your relative to set goals and to plan for how the person wants to live the rest of their life. To give the best holistic care possible, discussion should begin early in the last chapter about what this means for you and your relative. We cannot predict when death will occur, so it’s best to concentrate on the best quality of life and to plan for changes that may occur.

Q: How can families be involved?
A: By open discussion about the palliative approach and the goals of care for your relative, and by communicating clearly and receiving ongoing information and support.
Q: Why is communication about the palliative approach so important?
A: Open communication between families and staff makes sure that realistic expectations can be set and families are better able to plan their lives. One relative said,

“I was told mum had some old age problems and that she should be in an aged care residence. Nobody told me what was wrong with her and that she wouldn’t get better. I thought she’d come home again.”

Another relative said,

“I had no idea my brother could get this kind of care here. I didn’t think he could stay here until the end. I thought I’d have to take him to hospital if he got any worse.”

Often things go wrong because of poor communication. Here are some examples showing the benefits of an early meeting with family, soon after admission.

Example 1: Mr C had been cared for at home by his wife for 10 years before he was admitted to residential aged care. Mrs C hoped he would live for many more years as she did not want to be parted from him. Soon after admission, in a meeting with senior staff, she was gently told that her husband would gradually become weaker but that staff would know how to care for him at each stage along the way. She also realised that, given his heart condition, death may occur unexpectedly. She appreciated the opportunity to think and plan ahead, supported by staff.

Example 2: Miss D was a very independent person. “The doc told me I needed to be cared for 24 hours a day but I plan to live forever!” Miss D and her niece were invited to a care planning session where the seriousness of her illnesses was explained. Miss D realised she would not get any better, but had not wanted to “face the worst”. She was very much reassured by the nurse who said, “Whatever time you have left, we’ll support you in maintaining as much independence as possible.”

A palliative approach provides opportunity soon after admission for discussion about the resident’s plan of care, including goals for end-of-life care.
WHAT DOES “SPECIALIST PALLIATIVE CARE” MEAN?

Every aged care home has access to a regional palliative care service. A specialist palliative care team includes specially trained doctors and nurses and allied health professionals such as social workers, psychologists, physiotherapists, occupational therapists, music therapists, bereavement counsellors and coordinators of volunteers. The specialist palliative care team provides care to people with life threatening illnesses in their own homes, in a hospital, in a hospice or in an aged care home.

The specialised palliative care service does not replace the palliative approach in residential aged care; the service is available for residents who need additional, complex care that the aged care home cannot provide. This enables the resident to stay in their “home” (the aged care residence) supported by expert advice.

Q: Which residents are eligible for specialist palliative care?
A: Every resident who has symptoms that cannot be adequately treated by the GP and aged care staff. Counselling is available through the specialist palliative care team for those who need it, eg emotional support or discussion of ethical problems.

Here are some examples of specialist palliative care:

Example 1: Mrs A was suffering from severe osteoarthritis and because of her dementia she could not describe her pain. Mild pain medication seemed to have no effect. The GP was worried about giving her stronger pain killers so a specialist palliative care consultant was asked for advice on the most appropriate medication, which the GP then prescribed and monitored. The family was involved in all the discussions.

Example 2: Mr A was close to death and seemed to be very agitated and restless. Aged care residence staff had tried to calm him with mild medication and with other soothing, gentle care. The family was anxious that he was suffering and thought he should go to hospital. After the palliative care specialist suggested the right calming medication, Mr A’s family was relieved to see him relaxed and more comfortable during his final hours. “We’re glad now that he didn’t have to go to hospital,” was their response.

The specialist palliative care service can provide you with information on a broad range of issues related to end-of-life care. If you would like more support from a specialist palliative care team, please ask staff at your aged care residence or see the contact details at the end of this chapter.
WHAT CAN WE EXPECT AT THE END?

A palliative approach is not confined to the last days or hours of the person’s life. From the day a resident comes into care all the ingredients of a palliative approach are offered.

The last chapter in your relative’s life, however long or short, will always have an ending. Mostly, their condition will deteriorate slowly and progressively over several months. When it seems that your relative may only have hours or days to live, the type of care changes to what is called end-of-life or terminal care. The doctor will be notified, pain management will be checked, unnecessary medications might be ceased and careful attention will be given to all aspects of physical comfort. Psychological, emotional or spiritual factors will be discussed with you and specialist assistance provided if needed. Here are some commonly asked questions.

Q: How will we know when the end is approaching?
A: Staff will notify you or you may notice yourself that your relative’s condition is deteriorating. You may notice deterioration from week to week and then perhaps from one day to the next. For example, one week previously your relative might have been eating and drinking independently, now they are too weak to hold a cup. Or, your relative might have enjoyed a change of position from bed to chair each day, now they are too weak and frail to be moved.

Q: Now that dad’s stopped eating and he’s not drinking much that means the end is near, doesn’t it?
A: Not necessarily. As part of the disease process, your dad may not be thirsty and may refuse the offer of drinks. Some people can live for many, many days (sometimes weeks) while taking very little fluid. The important issue is to keep his mouth moist and continue to offer (without forcing) small sips of his favourite drinks.

Q: Can you predict the time of death?
A: Prognosis is a very inexact science. An oncologist can often predict the rate of growth of a cancerous tumour and therefore give an estimated prognosis. In the case of chronic disease, it is far more difficult to predict with any accuracy so it’s best to concentrate on giving the best care each day.

Q: Do we always get notice that a person is going to die?
A: Nurses know the most common signs that death is approaching; however, because every death is different, even experienced health professionals can be surprised by death’s timing. That is, it can be sooner than expected or later than expected or not expected at all. Close family members often have a sense that death is near. It’s best to discuss your own feelings with staff and to make the most of the time you have left with your relative.

It is important that you and your family talk with each other and with senior staff about what to expect. Some people want to know what particular signs they will notice that death is near. Others do not want detailed information; it is sufficient for them to sit with their relative.
Here are two examples of relatives’ responses.

Example 1: Mr S was dying and his family were unsure about the effect of his reduced fluid intake. Family members were afraid he would die of dehydration, and wanted him to have extra fluids. They were pleased to see a recent research study about dehydration in frail older people and learn that frequent small sips of fluid would be enough to keep him comfortable.

Example 2: Mrs T was keeping a bedside vigil of her husband for several hours per day. They were a close couple with no children and now Mr T was dying she was not interested in all the medical details. “I leave all that side of it up to you. All I want is to be near him.”

Staff will not be able to give you an accurate estimation of the time of death. However, they can discuss with you the signs they have noticed that death might be approaching. These signs may include changes in breathing patterns, noisy rattly breathing, changes in skin colour, increased restlessness, lapsing into unconsciousness, inability to swallow food or fluids. Not all of these signs occur in the same person and every person’s death is different.

Q: What kind of care is given in the last hours of life?
A: Even when death seems to be near (and remember, it is not always easy to tell) all comfort care will continue.

Q: Isn’t it better to leave them in peace rather than disturb them?
A: Even though it might seem to “disturb” the person, their hygiene, skin care, wound care, mouth care and change of position still require close attention. If moving your relative is likely to cause pain, a mild dose of pain medication can be given. Frequently changing their position can assist their breathing and prevent painful pressure problems. Gentle handling of their body can also reassure them that their comfort is still important, right up until the moment of death.

Q: What about medications?
A: It is important to continue pain management until a person dies. New medications for end-of-life symptoms may be introduced while other longer term medications may be ceased.

Q: Is there anything I can do to help at this time?
A: Discuss with staff whether or not you would like to assist with any personal care, eg massaging your relative’s hands and feet with skin cream. You can also help to keep their mouth clean and moist by frequent small amounts of their favourite drink. Research tells us that even when a person is in the last stage of dementia they can still feel emotions and may be able to “know” that you are there with them.
Q: How long should I stay?
A: You are the best person to answer this question and you may change your mind several times. If you need a break, it’s important to let staff know that you are leaving and to make sure they have the correct phone numbers if they need to contact you. Also remember, the aged care home is a 24 hour service and you are free to phone at any time. It is important to know that, in our experience, some people die when their relatives have left the bedside. Although you may feel disappointed, there’s no need to feel guilty if this occurs. The moment of death remains a mystery.

Q: How will I know how and when to say goodbye?
A: This is a very individual matter, but when you think that death is approaching you may ask yourself whether there’s anything more you want to say, even if you’re unsure whether your relative can hear or understand.

Although it is not possible to make accurate predictions, families often know or feel when the end is near. You are free to be creative and to plan a family ritual. Here’s one example of a family who asked whether it would be okay to bring the grandchildren in.

It was Friday night and Mr A’s family knew this might be their last visit. They were unsure what freedom they had to do “family stuff”, so they checked first with the nurse who encouraged them to do whatever was important to them as a family, providing it did not disturb other residents. “Friday was always fish and chips night. So could we bring the kids in and have fish and chips in his room?” asked the daughter. The daughter later told the nurse, “Dad opened his eyes and smiled at us all before lapsing into unconsciousness for the last time. Perhaps he even enjoyed the smell of the fish and chips. Dad always loved family parties so I don’t think he’d be offended by our laughing and joking. It all seemed so normal and now we’ll have such good memories.”

End-of-life (terminal care) ensures that physical, emotional and spiritual comfort needs are supported in the final days or weeks of life.
WHAT DO I DO AT THE TIME OF DEATH?

Families are often uncertain what to do when death occurs. Families usually know when a person has taken their last breath, but you may need to check with the nurse. There are no hard and fast rules and there is no need to rush. You are free to remain with your relative as long as you wish, although you may need to confirm from time to time with staff if it’s okay to stay a bit longer. You have the freedom to touch, talk to or embrace your relative, or to say goodbye in whatever way is meaningful to you. You may ask a member of staff to be with you or you may prefer to be alone at this time. While you may have lots of other questions, this one is very common.

Q: What will I do with mum’s belongings?
A: You should make it clear to staff whether you want to pack your relative’s belongings yourself or whether you would prefer staff to do this. For some people, it’s the final act of loving attention to carefully remove a resident’s clothing and other belongings. For others, these matters are not important and can be left to staff. It’s important to find out what the residence’s policies are about the final collection of a person’s belongings.

REATIONS TO DEATH

Every person reacts differently. We know from research that a variety of emotions and physical reactions can occur, sometimes within the same day or even within the same hour. You may experience relief, guilt, anger, resentment, peace, frustration, disbelief, wanting to blame someone, overwhelming sadness, shock, gratitude for the care. You may also experience physical symptoms such as signs of shock, confusion, palpitations, trembling, hot or cold, shaking, shivering, vivid dreams. It’s best to talk to a trusted friend or relative about what you are experiencing. In most cases all these reactions are a normal response to a major loss.

Physical and emotional reactions to death are discussed more in Chapter 7.

Death, like birth, takes its own time and can seldom be accurately predicted.
The goal is care rather than cure in palliative care.

There are three types of palliative care: a palliative approach, specialist palliative care and end-of-life care.

The palliative approach recognises that death is inevitable for all of us and that for older people admitted to residential care this is often the last chapter of their lives. For some it will be a short chapter and for others it will be a longer chapter.

Specialist palliative care is available for residents who have additional, complex palliative care needs that the aged care home cannot address.

End-of-life (terminal) care supports the physical, emotional and spiritual comfort needs in the final days or weeks of life.

Death, like birth, takes its own time and can seldom be accurately predicted.

Every person reacts differently to death.
Dementia has now reached epidemic proportions throughout the world and is one of the leading causes of death. According to a recent survey by Alzheimer’s Australia, most people are not aware that dementia is a life threatening, incurable disease. Many residents have more than one serious illness as well as dementia. As the goal of care for people with dementia is care not cure, a palliative approach is appropriate and has been shown to be beneficial for the quality of life of people with dementia.
WHAT IS DEMENTIA?

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with a person’s normal activities of life. The hallmark of dementia is the inability to carry out everyday activities as a consequence of diminished cognitive ability.

Doctors may diagnose dementia if two or more cognitive functions are significantly impaired. The cognitive functions affected can include:

- Memory
- Language skills
- Understanding information
- Spatial skills
- Judgement
- Attention

People with dementia may have difficulty solving problems and controlling their emotions. They may experience personality changes, agitation, depression, delusions or hallucinations.

The exact symptoms experienced by a person with dementia depend on the areas of the brain that are damaged by the disease causing the dementia. With many types of dementia, some of the nerve cells in the brain stop functioning, lose connections with other cells and die. This loss of normal brain cell function causes the symptoms of dementia.

There are many types of dementia caused by different brain diseases. The most common types are:

- Alzheimer’s disease
- Dementia with Lewy bodies
- Vascular dementia
- Frontotemporal dementia

Mixed dementia, where more than one disease affects the brain, is also very common.

The chance of developing dementia increases as we get older. Dementia is usually progressive. This means that the disease gradually spreads through the brain and a person’s symptoms get worse over time.
Here are some commonly asked questions about dementia.

Q: People don’t die of dementia, do they?
A: Dementia is caused by an incurable disease of the brain and is eventually fatal. It usually progresses slowly over several years before the final stage and is different for each person. Decline in the final stage usually happens very gradually, sometimes over many months after admission to residential care. Eventually, a person is likely to lose the capacity to care for themselves in any way. When a person is no longer able to get out of bed their appetite may also decrease and because of their lack of movement they may be prone to infections. Although the death certificate might state “pneumonia” or “heart failure” the underlying cause is dementia. During the final stage the palliative approach continues to offer comfort care aimed at reducing any distressing symptoms.

Q: I don’t understand why my aunt is so aggressive. Is that the way dementia affects everyone?
A: Not everyone with dementia becomes aggressive. However some people experience personality changes brought on by the disease. Some people who were always very quiet, tactful and considerate of others may become noisy, rude or even physically aggressive. We now know that this is often a response to an unmet need. That is, the person may be in pain, they may be hungry or thirsty, or they may need to go to the toilet. Because they have lost the language and words to express themselves they instead may lash out. It’s a way of trying to get carers to understand they need some kind of attention.

Q: Where can I get some more information and support if I need it?
A: At the end of this chapter you will see the phone numbers and online support offered by Alzheimer’s Australia. It is helpful to talk to others who have experienced similar concerns and receive the correct information so you can support your relative and, importantly, look after yourself.

Your relative may have lived with dementia for many years, but the time has now come for the last chapter in a long series of chapters.
Although most people are not aware of it, dementia is in fact a life threatening and incurable disease and needs a palliative approach to care.

When people with dementia behave in difficult ways it is often their only way to express an unmet need.

Help and information is available through Alzheimer’s Australia.
Palliative care provides specialised expertise in managing a person’s pain. Not all pain can be totally “cured” because pain is such a complex interplay of physical, psychological, emotional and spiritual factors. Managing pain requires assessment and understanding of all the factors contributing to pain. Drugs may be just one of the interventions used alongside non drug measures as well as psychological, emotional and spiritual support.

As every person is different, it is important you take time to discuss your relative’s pain management with nursing staff, not only on admission but regularly and continuously throughout their stay. Many family members are unaware of the facts about good pain management. It is the nurses’ responsibility to inform you of the latest research and “best practice” pain management. If you are not sure, please ask.

To cure sometimes
To relieve often
To comfort always
(Hippocrates 460-370BC)
PAIN MANAGEMENT AND DRUGS

Pain management specialists know the right drug to use at the right time and how to adjust the dose when needed. The best pain assessment is to observe your relative when they are moving, rather than lying down or sitting still. That’s why staff have a very detailed pain assessment chart for every resident. As family members you can contribute to this pain assessment because of your detailed knowledge of your relative and what you observe when visiting.

Example 1: Mr B was prescribed “prn paracetamol” for his back pain and sore hip following a fracture ( “prn” means “whenever necessary” rather than regular doses). At some periods of the day and night, Mr B would have no pain medication at all and his pain would become more intense. The paracetamol prescription was changed from prn to regular dosing. Mrs B found her husband resting in the afternoon but the nurse was giving him more paracetamol. “He doesn’t need any more,” said his wife, “he’s not in pain because he’s had tablets this morning”. The nurse explained that the effects of the drug wear off after a couple of hours and a steady presence of the drug in the blood stream is needed to control the pain effectively. She also explained that paracetamol was a safe drug with no side effects. Mrs B had never had this explained to her before so she was reassured by the nurse’s knowledge and care.

Example 2: Mr B had suffered a major stroke and had pressure ulcers (bedsores) on both heels. The senior nurse and the GP were sure Mr B would be much more comfortable if his pain was relieved. As he was unable to swallow tablets, the best way to relieve his pain would be via a “patch”. Mr B’s son had heard that Norspan was a powerful opioid drug. “I don’t want dad to have this drug. He could become addicted.” The nurse explained that when opioids are given for pain they never cause addiction. Mr B’s son had no idea that his father was suffering pain. “Thanks for the explanation,” he said, “I hadn’t realised all that and I can see now that it’s good for dad to have it.”

Example 3: Miss B’s only relative was her older sister, who was very protective. She didn’t want her sister to have regular, stronger pain medication. “I don’t want her to die before she’s ready”, said her sister, “Won’t these drugs hasten her death?” The nurse gently explained that when used correctly, in appropriate regular doses, the medicines would not hasten Miss B’s death, but would enable her to live more comfortably. When her pain was relieved, Miss B’s appetite improved and she could move more freely without pain. Miss B’s sister was amazed to see her sister’s quality of life improve over the next five months until her death.
Pain management is one of the main challenges in aged care where most people are suffering from one or more chronic illnesses with painful symptoms. The aim of a palliative approach is to provide relief from all distressing symptoms. That is why so much emphasis is given to good pain management. If you’re not sure what pain your relative might be suffering, please ask.

Here are some common questions:

Q: Mum doesn’t look as though she’s in pain, so why are you giving her more tablets?
A: When a person is in acute pain, such as appendicitis or gall stones or a fracture from a fall, they will usually look like they’re in pain. They might be pale and sweating, trying to protect the painful area, and they may cry out in pain. People who suffer chronic or persistent pain for many years seldom look as though they are in pain. That does not mean they are not experiencing pain. It requires skilled nursing to observe and document the presence of pain, not just on one occasion, but over a 24-48 hour period and when a person is in different positions (lying down, sleeping, in a chair, in the toilet, walking, changing position, etc). Because the pain is persistent (it may not ever disappear totally), the pain medication must be given regularly.

Q: Mum has dementia so how will you know whether she’s in pain?
A: We have a special pain assessment chart for people who can’t tell us about their pain. It means we have to observe your mum at various times of the day or night, observe how she responds to the pain medication and assess whether she needs further pain relief so that she is free from pain.

Q: What sorts of drugs are used for chronic pain?
A: Often the pain can be managed effectively and long term by a mild drug such as paracetamol. It’s only when the mild drug is not effective that stronger medication will be considered.

Q: I know Mum’s receiving drugs for pain but she still seems distressed. Is there anything else that can be done?
A: Management of physical symptoms may not address all the sources of pain. Unresolved resentments, past or present grief, and anger can cause great distress. This is one reason why opportunities for emotional and spiritual support need to be attended to (refer to Chapter 6).

Chronic, persistent pain requires persistent management. Pain medication should be given regularly every day.

When drugs are given to treat pain they will not cause addiction.

The use of opioids does not hasten death.

It is the underlying disease that causes death, not the medication.
NON DRUG MEASURES
Other “treatments” such as pleasurable activities, comfort food, change of scenery, music, massage, meditation, heat packs and a friendly visit can add to the effectiveness of medication. Physiotherapy and mild strengthening exercises are also effective in managing some chronic or persistent pain. It is also important to provide opportunities for a resident to express their emotional, psychological and spiritual concerns and to provide support to meet these needs.

WHAT OTHER COMFORT CARE IS AVAILABLE?
Medication is not the only treatment offered in the palliative approach. When you discuss your relative’s care plan you will see reference to the following:

- Skin integrity, with the aim of preventing bed sores
- Continence, with the aim of assisting a resident to the toilet wherever possible or keeping their skin clean and dry if they have no control of bladder or bowel
- Oral and dental, with the aim of keeping their teeth and mouth clean at all times
- Nutrition and hydration, with the aim of maintaining a healthy diet until the end stage of life
- Mobility, with the aim of maintaining a person’s independent movement for as long as possible

You will also see references to other needs such as spiritual and cultural, and to a resident’s “lifestyle plan” which covers pleasurable activities they wish to pursue. Other non medical care includes aromatherapy, massage, heat packs (under the direction of the physiotherapist), gentle exercise, music, etc. Psychological and emotional issues are also considered very important and if a resident is unable to describe their needs, you as a family member can contribute on your relative’s behalf.

All these issues are considered when developing a care plan appropriate to a person’s needs. Your involvement and contribution to this planning is an important aspect of partnership in care.
WILL MY RELATIVE BE IN PAIN?

KEY MESSAGES

• The palliative approach aims to provide relief from distressing symptoms

• Chronic, persistent pain needs persistent management. Pain medication should be given regularly every day.

• When drugs are given to treat pain they will not cause addiction

• The use of opioids does not hasten death. It is the underlying disease that causes death, not the medication.

• Medication for pain is only one option in providing comfort and relief. As there are many possible (non physical) sources of distress and suffering, and as there are so many dimensions that make up one’s identity, there is a great range of comfort care options that can support and address psychological, social and spiritual needs, maintain dignity and a sense of meaning.

USEFUL CONTACTS

• Senior nursing staff at the aged care residence

• Your relative’s GP

• The specialist palliative care team (if they are involved)
Grief and loss can put residents at risk of becoming depressed. And while the signs and symptoms of grief and loss are similar, it’s important to recognise the differences so the most appropriate help can be given.

WHAT IS LOSS?

When there are big changes in a person’s life, it can sometimes feel as if something has been taken away. Losses can be large or small or the build up of many losses.

For your relative this might include:

- Loss of health and independence due to ageing, illness or disability
- Loss of the ability to fulfil important roles that support their sense of identity such as parent, grandparent, colleague, volunteer, club member
- Relationship changes such as separation from or death of a spouse, family member, friends or other residents they live with

WHAT IS GRIEF?

When a person experiences a significant loss, it’s usually followed by a period of grief. Grief has no set pattern – how long or severe each experience is differs for everyone.

However some common reactions are:

- Shock, feeling of numbness
- Disbelief – “It can’t be real”
- Confusion and trying to make sense of it – “Why has this happened to me?”
- Anger
- Pining and yearning – wanting whatever was lost
- Guilt – “I wish I had done things differently”
- A sense of isolation and fear at facing the rest of life alone

 beyondblue, Fact Sheet 28
HELPING YOUR RELATIVE THROUGH GRIEF AND LOSS

Although it cannot be alleviated quickly, encouraging your relative to do the following can help them through a tough time:

- Staying connected to family and friends
- If possible: regular exercise, a good night’s sleep and minimum use of drugs and alcohol
- Relaxing, enjoyable or meaningful activities. Lifestyle workers at the aged care residence may be able to arrange these.

You can also help by:

- Listening to what your relative is going through but also talking about everyday things because life goes on
- Initiating contact and by being available
- Encouraging them to get help if they feel stuck

IS GRIEF THE SAME AS DEPRESSION?

It can be difficult to know whether someone is feeling down because they are experiencing grief and loss or if they are suffering from depression.

As someone who knows your relative, it is often family members who identify that something is different in residents. If you do notice something it is better that you bring it up with staff who could help rather than have your relative suffer.

Your knowledge of your relative is uniquely valuable in assisting them to get the most appropriate help.

WHAT IS DEPRESSION?

Depression can be triggered by loss and it may share symptoms with grief, such as difficulty controlling emotions and feeling teary and tired; however, it’s important to recognise the difference between normal grieving and depression. *(beyondblue, Fact Sheet 28).*

Depression is more than just a low mood or feeling sad – it’s a serious illness where people find it hard to function every day. It can have serious effects on physical and mental health.

*Like grief, recognising depression by getting a formal diagnosis can mean that it is better treated to preserve a person’s quality of life.*
HOW DO YOU KNOW IF AN OLDER PERSON IS DEPRESSED AND NOT JUST SAD?

Depression in older people is common and may happen for different reasons. The onset of physical illness or personal loss can be common but depression is not a normal part of ageing. An older person may be depressed, if for more than two weeks they have:

• Felt sad, down or miserable most of the time
• Lost interest or pleasure in almost all usual activities

AND experienced a number of the following:

FEELINGS

• Moodiness or irritability – your relative may present as angry or aggressive
• Sadness, hopelessness or emptiness
• Overwhelmed
• Worthless, guilty

PHYSICAL SYMPTOMS

• Sleeping more or less than usual
• Feeling tired all the time
• Unexplained headaches, backache or similar complaints
• Digestive upsets, nausea, changes in bowel habits
• Agitation, hand wringing, pacing
• Loss or change of appetite
• Significant weight loss or gain

Everyone experiences some or all of these symptoms from time to time, but when symptoms are severe and lasting or when they are causing you concern, it’s time to get professional help. Early detection and treatment may help to keep depression from becoming severe. Depression is treatable and effective treatments are available. (beyondblue, Fact Sheet 17).

DO YOU KNOW IF AN OLDER PERSON IS DEPRESSED AND NOT JUST SAD?

Everyone experiences the symptoms of grief or depression from time to time – it is when they are severe, lasting or causing concern that professional help is needed.
WHAT MAKES AN OLDER PERSON MORE AT RISK OF DEPRESSION?

- Losses to relationships, independence, work and income, selfworth, mobility and flexibility
- Social isolation
- Significant change in living arrangements, eg moving from an independent lifestyle to a care setting
- Admission to hospital
- More physical health problems or conditions such as heart disease, stroke, Alzheimer’s disease
- Chronic pain
- Side effects from medications
- Particular anniversaries and the memories they evoke

HOW CAN DEPRESSION BE TREATED?

Different types of depression need different types of treatment. Along with community support, the most effective treatments for depression in later life may include:

- Physical exercise for preventing and treating depression
- Psychological treatment, eg Cognitive Behaviour Therapy, Interpersonal Therapy
- Medication

Depression must be recognised in order to be treated. The key to successful treatment is an appropriate assessment by a GP or health professional. Both personal and professional carers are an invaluable source of information about personality or cognitive changes in a person and should be included in discussions where possible. (beyondblue, Fact Sheet 17)

Example 1: It was time for the regular review of Mr P’s care and his two sons were invited to attend. They were also anxious to discuss with the doctor what they saw as signs of their father’s depression.

Mr P, aged 89, suffered the debilitating effects of Parkinson’s disease as well as cardiac problems and signs of dementia. Given the choice, he wanted to come to the meeting “to speak for myself”. The process of asking him about his response to life in the aged care residence was painfully slow because his replies were given in halting, hesitant speech. “What do you miss most?” he was asked. “The loss of speech,” he replied, with some emotion. His older son explained that until he was 85, Mr P had been a regular participant in an elite play reading group, having significant skills in performing Shakespeare’s characters.

Through the discussion it became evident that more understanding was needed on the part of the aged care team when communicating with Mr P. It was also agreed that medication might help to lift his mood. His care plan was adjusted to highlight his preference for more time to be spent on verbal communication than trying to improve his mobility: “I don’t mind if I can’t walk, but I do mind if I can’t have a chat.”

Some of the aged care team and family members had perceived his low mood as indicating a wish for death. Although severely disabled and increasingly dependent, Mr P said with animation, “I hope I can look forward to a few more years yet.”
HELPING AN OLDER PERSON WITH DEPRESSION

It’s not always easy to help someone who may be experiencing depression. It can be hard to know what to say or do.

Here are some tips:

• Talk to your relative about how they’re feeling
• Listen to what they say. Sometimes, when a person wants to talk, they’re not always seeking advice, but just need to talk about their concerns.
• Maintain eye contact and sit in a relaxed position – positive body language will help both of you feel more comfortable
• Use open ended questions such as “So tell me about...?” which require more than a “yes” or “no” answer. This is often a good way to start a conversation.
• If conversation becomes difficult or if the person with depression gets angry, stay calm, be firm, fair and consistent and don’t lose control

Often, just spending time with the person lets them know someone cares and understands them. If conversation is difficult don’t feel like you have to fill up the silence. Remember that while comments such as “You’ll be fine!” or “Just snap out of it” may seem helpful and have good intentions, they almost always have the opposite effect.
GRIEF, LOSS AND DEPRESSION

KEY MESSAGES

• Depression in adults over 65 years is sometimes difficult to recognise as the symptoms are often similar to grief and loss

• Your knowledge of your relative is uniquely valuable in assisting them to get the most appropriate help

• Everyone experiences the symptoms of grief or depression from time to time – it is when they are severe, long lasting or causing concern that help from a health professional is needed

• It is important to address related factors that could be contributing to the depression, eg lack of meaningful activity or roles to play, isolation and loneliness

• Depression in an older person must be treated separately to issues of age

• Improvement and recovery is possible with the right treatment and management strategy

USEFUL CONTACTS

Lifestyle and diversional therapy workers at the aged care residence can arrange activities for your relative that may be enjoyable, relaxing or meaningful. If possible, this might include group excursions, games, visits from volunteers, music and massage.

The Centre for Grief and Bereavement
1300 664 786
www.grief.org.au

beyondblue
1300 22 4636
www.beyondblue.org.au

Your relative’s GP
Death can happen to any of us at any time. When we are healthy and well we don’t like to think about making a will or deciding how and where we would like to die or who should act on our behalf if we are unable to speak for ourselves. These are the questions at the heart of advance care planning. ACP is different from any of the other issues discussed so far, but it is a vitally important component of palliative care. ACP gives power and control to your relative over questions like going to hospital or having unwanted medical interventions at the end of their life. It is important that you know what your relative would want if they become unable to speak for themselves. That’s why an ACP form will be explained to you and your relative soon after admission.

Your relative should not be expected to complete the advance care plan form on their own. It should be part of a private discussion with a trusted, skilled health professional and those people who your relative wishes to be involved in the discussion.

ACP: WHO DECIDES?

When it comes to planning for the future, your relative may ask themselves questions like:

- Who would I like to make decisions for me?
- Where do I want to die: in the aged care residence, at home or in hospital?
- What do I hope for?
- Who would I like to be with me?
- Is there any medical treatment I would NOT want?
- Who can I trust to make sure my wishes are carried out?
- Can the plan be changed?

A written advance care plan reassures your relative and family that their last wishes will be respected.
HOW DOES ACP WORK?

Some of the answers to these questions about who decides and how ACP works are provided in these two examples.

Example 1: Mrs J had battled a lung disease for many years which often caused her extreme breathlessness. Now she was in the aged care residence she was pleased to have the discussion about her end-of-life wishes. “I want you to write this down,” she said to the nurse. “If I have a bad attack in the middle of the night and can’t speak for myself, please send me to ‘my’ hospital. They’ve got a huge file on me there. But if I’m really bad and they can’t fix me, then they can send me back here.” Two weeks later Mrs J suffered a very serious stroke and could not speak. She was sent to hospital with all the necessary forms filled in, outlining her wishes. It was clear to medical staff that she would not regain consciousness. Noting her wishes on the ACP form, the hospital doctor sent her back to the aged care residence where she was given all necessary palliative care by the staff she loved. She died peacefully 48 hours later. Her wishes were achieved.

Example 2: Mr K suffered breathing problems, epilepsy and dementia. He was unable to make his own wishes known. He’d had several trips to hospital which made him more confused and upset his family. Soon after admission to the aged care residence his two daughters were invited to a care planning meeting where his end-of-life wishes were discussed. “Dad hates hospitals and we know he would not want to be resuscitated or have tubes inserted. We know he’d rather stay here, so could we write down PLEASE DO NOT SEND HIM TO HOSPITAL?” A specialist palliative care physician assisted the GP and nurse manager to draw up a plan of care to put into action if Mr K had another severe attack of breathlessness. The plan worked successfully and Mr K was not sent to hospital against his wishes.

WHAT IF I DON’T WANT TO TALK ABOUT DEATH AND DYING?

We hope you understand the reasons why we think ACP is so important. However, we realise that for some people these issues are too difficult to talk about. We also know that in some cultures to speak about death and dying is harmful and offensive. If you have any such objections to talking about these issues, please feel free to make your feelings known to staff.
SUMMARY OF ACP

- Gives your relative the opportunity to make choices about how they want to live until they die
- Gives you the knowledge to act in your relative’s best interests
- Guides doctors and hospitals to know what your relative wants and meet their wishes
- Provides satisfaction for you and your relative that their wishes are known and respected and relieves relatives from the burden of making decisions that might not be in the resident’s best interest

Here are some common questions about the advance care planning process.

Q: Where do I find this form and how do I fill it in?
A: The form will be filled in by the resident (if they are able to do so) with an experienced staff member who can explain the process and discuss issues that often arise when filling out this form. You will be invited to be part of this meeting so that you are aware of your relative’s choices. It is best to arrange a meeting (of about 30-40 minutes) so the form can be completed on the spot and filed immediately with your relative’s notes.

Q: What if your relative is unable to make any decisions on admission to the aged care residence (for example, a person with advanced dementia)?
A: You will still be invited to be part of the discussion about planning for future care. This avoids decision making in times of crisis when, emotionally, it can be difficult for you to make clear choices.

Q: Why do we have to discuss this now? I’d much rather leave it until later.
A: Even if your relative’s health seems stable at the moment, nobody can accurately predict how long they will live or when a health crisis might occur. In fact, statistics show that many residents die within the first three months of admission to high care. For others, the average is about nine to 12 months. It is in your relative’s best interests to have this planning discussion as soon as possible after admission so staff are well prepared for any emergency.

Q: Is the form legally binding and can my relative change their mind?
A: The ACP form provides guidance to the aged care team so they can know what your relative’s wishes are if they are not in a position to make decisions at the time, and act accordingly. The form can be changed at any time.

Q: What happens when there is no form filled in?
A: The default position is that your relative will most likely be sent to hospital in any emergency. Or, you may receive a phone call at the time of emergency asking whether your relative should be sent to hospital.

As ACP can be a complex process for those who are not familiar with it, please ask for a meeting where you can discuss the issues and make sure your relative has an ACP form filled in. This way, you can have peace of mind that their wishes will be respected.

Like writing a will or getting medical insurance, a written advance care plan is about ensuring peace of mind. It’s a way to ensure your relative’s wishes are respected and the end is as peaceful as possible.
ADVANCE CARE PLANNING

KEY MESSAGES

- Your relative should not be expected to complete the ACP form on their own. It should be part of a private discussion with a trusted, skilled health professional and those people they wish to be involved in the discussion.

- A written advance care plan reassures your relative and your family that their last wishes will be respected.

- Like writing a will or taking out medical insurance, a written advance care plan is about ensuring peace of mind.

USEFUL CONTACTS

Your relative’s GP

Senior nursing staff, eg the Clinical Care Coordinator at the aged care residence

Office of the Public Advocate (OPA)
1300 309 337
www.publicadvocate.vic.gov.au
OPA has information about powers of attorney and other matters of responsibility.
Understanding the cultural meanings of death and dying is essential to a palliative approach when we consider that it is during times of great change that we often turn to the cultural beliefs and practices that are most familiar and comforting.

The best way to understand your relative’s cultural practices is to ask them. We know there are cultures within cultures and individuals practise their cultural differences in their own way. You can assist staff to understand your relative’s preferred cultural practices by discussing the matter with them or providing some written tips to help staff understand and avoid causing offence.

**Example 1:** Mrs VH was born in Vietnam and immigrated to Australia with her son and daughter-in-law 15 years ago. She is a devout Buddhist. Over the past week she has become increasingly unwell and her liver function has rapidly deteriorated. Her son is most concerned as he wishes the correct preparations to be made for her death.

Through discussions with her son, staff and a Buddhist monk, staff agreed that she would be nursed through the final hours of her life with minimal noise and activity in her room to ensure that her soul was as untroubled as possible. It was agreed that immediately after her death the family would advise staff, but that she would not be touched, allowing her consciousness to depart and embark successfully on the way to her next life.

On the day of her death, close friends and spiritual advisors were present to oversee the process. When it was deemed eight hours later that her consciousness had departed, she was examined and the death certificate issued. (Clark, 2010)

We know that people from some cultures do not want to talk about death and dying; they believe it can be harmful. If you have any concerns about discussing these issues please let staff know.

Another reason for an early meeting with you is to give you the opportunity to advise staff about any cultural or religious customs that are important to you and your relative.

**INTERPRETER SERVICES**

In Australia it is taken for granted that everyone speaks English; however, ours is a multicultural country where many languages are spoken. Speaking a language that is understood is essential if there is to be clear communication between residents, families, aged care staff and other health professionals.

As communication is such an important part of the palliative approach, interpreter and translator services are available to you. You can request that the interpreter be male or female.
CULTURAL CONSIDERATIONS

KEY MESSAGES

• Cultural values, beliefs and practices become especially important during times of great change and uncertainty. Therefore an understanding of the unique cultural meanings of the dying process is essential in the palliative approach.

• The best way to know what a person’s cultural beliefs and practices are is to ask them

• Interpreter services are available

USEFUL CONTACTS

Translating and Interpreting Service (TIS)
131 450
TIS National provides both telephone and on-site interpreting on a fee-for-service basis.

Palliative Care Australia
03 9662 9644 – Victoria
www.palliativecare.org.au
Palliative Care Australia has multilingual brochures available on their website.

Centre for Cultural Diversity in Ageing
03 8823 7900
www.culturaldiversity.com.au
The Centre for Cultural Diversity in Ageing website has numerous multilingual resources you can download on residential and community aged care services.

Possible resources for you to draw upon:

• Care staff at the aged care residence
• Cultural groups that your relative may be part of
• Objects that are culturally or personally significant to your relative
You don’t have to be religious to have spiritual considerations. Spirituality is about how we make meaning in our lives and feel connected to other things, people, communities and nature. Attending to the spiritual can provide a person with a feeling that “all is well”. An inner peacefulness and comfort can be found that can provide a sense of hope and purpose. These feelings, emotions and expressions are closely linked with a person’s own identity and sense of self that can provide a person with a sense of energy or power to cope with life’s struggles and challenges.

What we want for those we love is that they come to terms with their reality as authentically and peacefully as they can. There are many ways of expressing spirituality, and people may be of a particular faith or none. As a family member you might be aware of your relative’s preferences. You can assist staff to offer the most appropriate care in this matter. How a person interprets what is happening to them is critical to their wellbeing.

One of the spiritual needs that your relative might be experiencing is the need to have you alongside them on the final journey. As you journey with your relative you share their load. Your relative most likely will be searching for meaning in the present circumstances. There is often the need to tie up loose ends which may include being able to express forgiveness to others or being reconciled with God, self and/or others.

Your relative might need to openly express anger and doubt, which includes speaking about death and dying. They may need you to provide that listening ear to enable them to come to the acceptance and readiness to proceed on the final journey of life. By listening you are displaying the love for your relative that we all need, especially at the end of life. You are respecting your relative as a person of worth and preserving their personal dignity.

One of the ways of discerning your relative’s spiritual needs is to talk about their life story. Telling their life story has many advantages for your relative. Each person’s story is unique and when recognised as precious it adds to a person’s self worth. The story is also a gift to the family and future generations. As well as including facts, the when and where of events, a life story includes the meaning of the life journey. Meaning can often be found in the process of a life story by reframing the events or putting them in context of the whole life lived. In this way a sense of peace and completion can be found. It is also possible that your relative can identify how they coped in times of stress and anxiety. Those skills can be applied again in the present circumstances.
Questions such as the following may help you to know how best to be clear about your relative’s spiritual needs.

- Do you have any particular spiritual beliefs that would help you at this time of life?
- Do you have any religious customs or rituals that staff need to know about?
- Is there anyone you would like to talk to about spiritual or religious matters?
- What is hardest for you right now in all this?
These issues also involve family members, particularly when your relative is not able to speak for themselves. As we discussed in the section on pain, spiritual issues can cause distress. A skilled pastoral care worker can often help to relieve this distress.

When it comes to someone with dementia, attending to the spiritual needs of your relative and your family and carers is an important part of palliative care. The fact that a person has dementia and/or a mental illness must not mean that they are denied spiritual support. For people with dementia the familiarity of prayers, hymns or rituals, aspects of nature, music and art can be a comfort, a blessing and nourishment for them.

**Example 1:** Mrs C, a practising Catholic, is approaching death and extremely agitated. A sensitive pastoral care worker gently questions her about her fears. She finds out Mrs C had a child “out of wedlock” 70 years ago and is afraid she’ll be punished by God. The pastoral care worker offers a prayer for forgiveness and Mrs C is greatly relieved. In many cases a Catholic resident will appreciate the offer of anointing by a priest.

**Example 2:** Mr B had never been religious. “Just put ‘nil’ in the religion box,” he told the nurse and his response to visits by the pastoral care worker/chaplain were restricted to polite greetings. Mr B’s roommate was dying and Mr B watched intently as the chaplain came regularly to visit him even though he seemed unable to respond. Mr B attended his roommate’s funeral and was impressed by the chaplain’s service. Next time the pastoral care worker came past he said. “You know that religion thing I told you to mark ‘nil’? Well, could I change my mind? Do you think you’d come to see me?” Mr B had several conversations with the chaplain, resulting in her promising to take his funeral when the time came. Mr B’s funeral was held in the aged care residence chapel, conducted by the chaplain.

**Example 3:** Mrs C, a dementia care resident had been an active member of her church community when she lived at home. Mrs C was taken to the church service offered by a minister of her religion. She grabbed the carer’s hand saying repeatedly “Don’t leave me”. The carer reassured her and sat beside her holding her hand. As the service began the carer felt her grip loosen and Mrs C physically relax. While mindful to keep sitting physically close, the carer placed Mrs C’s own hands together who then clasped them loosely in a prayer gesture. Mrs C appeared to enter into the service peacefully. When the minister approached her to anoint her hands she opened them and responded, “Amen”. The agitation that was apparent prior to the service had, for the time being, left her.
Your relative does not have to be religious to have spiritual considerations. Spirituality is about how we make meaning in our lives and feel connected to other things, people, communities and nature.

Spiritual questions, beliefs and rituals are often central to people when they are in the final chapter of their lives. Talking to staff about your relative’s and family’s unique spiritual considerations will allow them to be properly respected and addressed.

Helping your relative tell their story can help them find meaning, affirmation and reassurance.

USEFUL CONTACTS
People who have been meaningful to your relative, who are based at the aged care residence or who are based in the community where you live.

Possible resources for you to draw on:
- Facility or local or familiar clergy; pastoral care workers
- Meditative or favourite music
- Aromatherapy resources
- Reflective books, symbols
- Favourite artworks
- Pictures of nature/pets
- Photos of family/friends/special times
- Objects of personal significance
No two people respond the same way when their relative is admitted to residential aged care; however, our research shows these are the most common responses. You may feel:

- Upset that you have to “give over control” of your caring role
- Overwhelmed by the gradual deterioration
- Relieved to have some of the burden of caring removed
- As though no-one understands what you are going through
- As though no-one understands how deeply you feel about your relative and the loss you are experiencing following their admission to residential care
- Afraid that your relative’s death may be near or you may be concerned that their death is not occurring as soon as you expected
- Guilty, especially if you haven’t been able to keep a promise such as, “You said you’d never put me in a home”
- Worried that your relative will not be cared for properly
- Anxious that staff will not know how to do things the way your relative likes or needs them to be done
- So confused you don’t know which way to turn
- Worried that you have made the wrong decision, especially if your relative has not been involved in the process
- Very confident that you’ve made the right decision
- Relief that your relative is now in care
You may experience the following range of emotions during this time:

Loss, relief, gratitude, guilt, separation, sense of mourning, frustration, fear, relief, security, freedom, challenge, anger, grief and loss, sadness and depression, loneliness, despair, shock (particularly if admission is unplanned and unexpected).

These are some of the feelings relatives have expressed on the transition to residential aged care:

- Mum doesn’t understand that I couldn’t cope anymore
- This is the hardest thing I’ve ever done
- It’s worse than death
- I’ve resisted this for so long; I’m almost at breaking point
- I’ve never been inside an aged care residence before and don’t know what to expect
- It’s okay when I’m here, but what about when I go home?
- I’m so lonely at home by myself
- I feel I’m left in the dark and don’t know what’s going on with my relative
- They want to take control of everything
- They don’t listen to me
- I ask to speak to someone and I’m left waiting
- They think I’m interfering
- I can’t visit very often but I don’t think they understand; they expect me to be there more often
- I feel I have to visit because I’m the only one who has time to feed him

Other feelings expressed by relatives when their relative’s death was approaching:

- I’m afraid to go home for fear something will happen when I’m not here
- I just wish I could have a break and let someone else take over
- I keep waking in the night wondering if it’s over yet
- I wish it was all over. I can’t bear to see him suffering anymore.

Remember, every feeling is legitimate because it is your feeling. There is no right or wrong way to feel. Your feelings may change frequently. If your feelings are causing you concern, please don’t hesitate to talk to a staff member. You may also seek help from a pastoral care worker or from a palliative care counsellor.

Every feeling is legitimate because it is your feeling.
DIFERENT VISITING PATTERNS

There’s no right or wrong way to visit your relative. It is important, however, that you communicate with staff so they have some idea what visiting pattern to expect. Staff often become worried when they do not see a particular relative for some time. This is not a matter of judging the relative but a sign of their care for you. Also, it is good if your relative has a clear idea of when to expect you – some residents may be disappointed if they go to an appointment or outing and find on their return that they have missed a visitor.

Here are some examples of different visiting patterns.

Example 1: Mrs J has only one daughter, Jane, who works full time, has four school age children and a variety of community commitments. The only time she can visit is around 9pm when she knows her mother, who goes to bed later, will be awake and possibly feeling lonely.

Example 2: Mr B is the only son and a bachelor living with his mother all his life. He lives close by and visits three times a day at meal times.

Example 3: Miss C is the only relative (a niece) to Mr C and they have not been close. Miss C has severe osteoporosis and finds travelling difficult. She’s made arrangements to visit by taxi once a fortnight.

Example 4: Mr and Mrs K have not been a close couple for many years; separated but not divorced. Mrs K still shows interest in her husband’s welfare and feels guilty about not visiting. She’s arranged with the staff that she will phone once a week and visit once a month.

Example 5: Mrs L, a widow, has three devoted daughters who have formed a roster to make sure their mother will be visited twice each day.

These examples are not intended to tell you when and how you should visit. They are intended to reassure you that there is no right or wrong way to visit. Remember, whatever you decide is right for you. Also remember you are free to change your visiting patterns. If there is any major change it may help to communicate with senior staff, particularly if your own health is interfering with your visits.

There is no right or wrong way to visit.
WHEN YOU DON’T FEEL LIKE VISITING

A palliative approach involves support for families. When you are unable to visit – for any reason – you can phone the aged care home at any time of the day or night. This communication keeps you informed about your relative’s condition and makes staff aware that you still care, even when you are unable to visit. Sometimes, particularly if you have been caring for your relative for a long time or if visiting becomes difficult for any other reason, you may need to take a break.

If you have concerns about your own health or your ability to visit your relative you can ask for assistance from aged care staff.

LOOKING AFTER YOURSELF

Here are just a few tips to help keep yourself “in shape” so you can continue to care for your relative:

- Talk to a friend, a family member or a professional about your concerns
- Join a support group, eg Alzheimer’s Australia
- Be patient and gentle with yourself
- Be prepared for a long journey, but also be aware of the unexpected
- Take extra care with exercising, sleeping and eating
- Keep the communication channels open with staff
- Accept help from others when it is offered
- Consider keeping a journal or diary where you can write things down as they come into your mind
- Take time out to do something pleasurable for yourself each day

“What is also painful is knowing where to ‘split yourself’. I mean my husband had an illness, my children were doing VCE and uni, I was working and I had to split my time and energy between visiting my mum and being a mum. The time for ‘me’ was almost non existent.”

– Relative
HOW WILL I FEEL AFTER THE DEATH?

Every person responds in their own way to death. Your response depends on how close you were to the person who died, whether the death was expected or unexpected, and what support you have from family and friends. Let’s look at the physical reactions first.

Don’t be surprised if you feel any or even all of these very common responses:

- Hot flushes
- Cold shivers
- Shaking
- Trembling
- Weak at the knees
- Numb all over
- Palpitations
- Tiredness
- Nausea
- Headaches

Both mind and body are involved in grief; each influences the other. You may feel any or all of these emotional responses:

- Total shock and disbelief
- Relief that it’s all over
- Sadness, loss and grief
- Guilt that you weren’t there
- Guilt that you could have done more
- Satisfaction about your continued care
- Resentment about past memories
- Anger that this “shouldn’t have happened”
- Calm and peaceful

You may also feel overwhelmed and out of control; you may drop things, forget things, feel muddled, confused and uncertain what to do next. Many people experience a variety of these physical and emotional responses all in one day, and sometimes all in one hour! Remember, none of these feelings are wrong; they are your feelings and therefore normal for you.

One relative, who had sat by her husband’s bedside for many hours, said when he died, “I just feel empty, totally empty.”

Another said, “I can’t go on without him. Life will never be the same.”

Others have a more matter-of-fact response, for example:

“I’ve known this was coming for a long time. I’ve prepared myself well and now I feel so relieved that it’s all over. I can now make plans for my own life.”

If you feel you have no one to turn to, or you need help with your own emotions after your relative’s death, please speak to staff who will know how to arrange bereavement support for you.
Every person responds differently when their relative is admitted to residential aged care

Every feeling is legitimate because it is your feeling

There is no right or wrong way of visiting your relative

It is helpful to communicate changes to your visits to the staff and, if possible, your relative

It can be a difficult time for relatives and as a relative there are many ways that you can look after yourself

Every person responds to death in their own way. This can include a range of physical and emotional reactions.

Help and support is available to you

USEFUL CONTACTS

Centre for Grief and Bereavement
03 9265 2100
www.grief.org.au

National Association for Loss & Grief – Victoria
1800 100 023
www.nalagvic.org.au

Carers Victoria
1800 242 636
www.carersvic.org.au

Alzheimer’s Australia – Victoria
1800 100 500 (National Dementia Hotline)
www.alzheimers.org.au

Alzheimer’s Australia offers a variety of services available ranging from counselling to support groups.
By gaining correct information about the palliative approach, and through your involvement in your relative’s care, you can greatly influence their journey in the last chapter of their life.

There is a lot of information in this book and you can select what is important for you. If you want further explanation about any of the issues discussed, please ask staff or look through the contacts listed in this booklet. No question is unimportant or silly. If it’s on your mind, it’s best to discuss it.

We finish where we began. It is your right and your relative’s right to expect the best care possible. Our hope is that your relative may have the best death possible.

This would mean:

- That family and staff communicate openly and with compassion with the person in care and with each other
- That pain control and comfort is achieved as far as possible
- That your relative has every opportunity to communicate with those who are important to them
- That their physical, emotional, social, cultural and spiritual needs are addressed, and as far as possible met

This is best achieved through partnership where each member of the team – your relative, yourself and the aged care staff – work together towards a common goal. The goal of palliative care is to provide comfort and care when cure is no longer possible.

*How people die remains in the memory of those who live on.*

*Dame Cicely Saunders (1918-2005)*
* Founder of the Modern Hospice Movement
GLOSSARY

ADVANCE CARE PLANS
Written documents that explain to aged care team members what your relative has decided about how they want to face their own death. They are called “advance care plans” because your relative lets people know his/her wishes in advance. Ideally an advance care plan involves an ongoing discussion with your relative, family, doctor and facility to ensure that your relative’s and/or family’s wishes are current.

BEREAVEMENT
The total reaction to a loss including the process of “recovery” or healing from the loss. Although there are similarities in people’s responses, there are also marked differences. Each person will grieve and “recover” in her/his own way.

CARE PLAN
Documents that are made up of a statement of your relative’s care needs, which are determined during assessment, with strategies, interventions or actions that are intended to help them achieve or maintain those goals.

CHAPLAIN/PASTORAL CARE WORKER
A person who works within a holistic approach to health to enable individuals and groups to respond to spiritual and emotional needs, and to the experiences of life and death, illness and injury, in the context of a faith or belief system.

CHRONIC ILLNESS
An illness that is long term.

COUNSELLING
Counselling covers a number of processes of interviewing, testing, guiding, advising, which are designed to help a person solve problems, plan for the future, etc. There are different levels of expertise depending on the practitioner’s training and experience.

DEPRESSION
Clinically, it is a group of symptoms which include tearfulness, guilt, irritability, loss of interest in life, loss of energy, poor concentration, poor sleep and either a gain or loss in weight.

END-OF-LIFE (TERMINAL) CARE
A form of palliative care that is appropriate when your relative is in his/her final days or weeks of life. End-of-life care requires your relative’s care decisions to be reviewed more often and that the goals of care be more focused on their physical, emotional and spiritual comfort needs, as well as support for the family.
FAMILY/RELATIVE
Family can be considered as any person who is part of the central core in the support network of an individual, including carers. Family are those individuals who are closest to the resident in knowledge, care and affection.

GRIEF
Our response to loss. It is a natural and inevitable response to loss, and it can affect every part of our life, but it is different for different people.

OPIOIDS
A specific term used to describe drugs (natural and semi-synthetic) that are derived from the opium poppy.

PALLIATIVE APPROACH
A palliative approach aims to improve the quality of life for individuals with a life limiting illness or who are dying due to the ageing process. Quality of life is improved by reducing suffering through early identification, assessment and holistic treatment of pain, physical, psychological, social, cultural, and spiritual needs. A palliative approach is not delayed until the end stages of an illness or the ageing process. Instead, a palliative approach provides a focus on active comfort care and a positive approach to reducing an individual’s symptoms and distress, which helps residents and their families understand that they are being actively supported through this process. A positive and open attitude towards death and dying underpins the philosophy of the palliative approach.

PALLIATIVE CARE
The World Health Organization’s most recent (2003) definition of palliative care describes this type of care as a palliative approach.

PROGNOSIS
A prediction of the likely course and outcome of a disease.

QUALITY OF LIFE
Quality of life is defined as an individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. It incorporates the person’s physical health and psychological state, level of independence, social relationships and personal beliefs.

SPECIALIST PALLIATIVE CARE TEAM
A specialised team that is trained in providing a palliative approach. The individuals work as a multidisciplinary team providing specialist advice, education and support to residents requiring a palliative approach and/or aged care team members providing this care.

SUPPORT GROUPS
Groups comprising people with similar problems or illnesses. A formally trained, professional leader may lead these groups; however, depending on the purpose of the group, this may not always be the case.
REFERENCES

**ALZHEIMER’S AUSTRALIA (2005).**

**BEYONDBLUE (2010).**

**BEYONDBLUE (2011).**

**CLARK, K. AND PHILIPS, J. (2010).**

**COMMONWEALTH OF AUSTRALIA (2006).**

**WORLD HEALTH ORGANIZATION (2003).**
We are interested in ways to improve the way we do things and acknowledge that the palliative approach is relatively new. Therefore we welcome your feedback, either in writing or speaking openly to staff and senior management.

Your feedback is a constructive way to improve the care we give.
What families say

“It’s not all doom and gloom. The end result, if everyone cooperates, is that it really does work out for the best... If people can see the light at the end of the tunnel it may not be as daunting.”

“When I was reading the booklet, all the experiences I had were coming back to me and it was such a special time. My mum had a lot of suffering in her life. The ‘light’ and ‘positivity’ was her relief from the suffering.”

“If you choose to ‘walk the path’ with them, then you can really ‘gain’. It’s about looking at a situation in a different way.”

“This booklet is something that I would have LOVED to have had when I was going through it.”

“I would really like to congratulate you and think it’s such a beautiful booklet. Convey my thanks to the author. I think it’s absolutely brilliant.”