

# Live Well, Die Well

Information for carers, families and friends  
of people with end stage dementia



*Resthaven*  
Incorporated

## **Resthaven**

Resthaven Incorporated, established in 1935, is an aged care community service of the Uniting Church in Australia. Resthaven is separately incorporated and financially independent of the Uniting Church. Our Statement of Purpose reflects our commitment: Resthaven provides outstanding care and support to older South Australians and their carers.

Each year, Resthaven provides community services to thousands of older South Australians, in their choice to remain living at home. Services include early intervention, therapy and allied health services, basic home care, packaged care including personal care, nursing care and palliative care. Services also include support for Carers through the provision of respite and information. More than 1,000 older people are accommodated in our residential care services and independent living units.

Resthaven has adopted a palliative approach to care, with Advance Care Planning, Palliative Care Volunteers, community-based palliative care in end-stage dementia, development of evidence based clinical guidelines, staff training and ensuring our services meet the National Standards for Providing Quality Palliative Care for all Australians. Our achievements were acknowledged at the inaugural South Australian Palliative Care Awards 2009, where Resthaven received the Aged Care Award and Volunteer Award.

For more information phone 8373 0211 or visit our website [www.resthaven.asn.au](http://www.resthaven.asn.au)

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## **About this Information**

This information was identified by past and current carers as information they wanted to know more about and found difficult to access. Some of the information may not be relevant at the time of reading. You may find some of the topics challenging. We suggest you read the content list and choose the topics you are interested in now to read.

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# Stages of dementia

Dementia is a progressive disease which is often described in stages that are likely to occur over time. These stages tend to have identifiable behaviours and associated medical issues.

However, it is important to note that not all people with dementia will necessarily experience all of these issues, nor in any specific order. There is no distinct beginning or end to each of the stages.

The table below has been provided to give you a guide to what may happen. However, every person is different and the person you care for may or may not experience all the signs and symptoms of the dementia process.

Many people with dementia are able to maintain their lifestyle within the community with the support of families, carers, friends and health and community care services.

	Early onset	Mild
Memory	Slight forgetfulness that happens regularly, such as getting lost on a familiar route.	Noticeable short term memory loss that affects everyday life, such as false memories, forgetting the layout of home.
Orientation: time, place and persons	Generally clear, correct and aware. Reduced attention span, repetitive talk, anxieties or suspicion about partner's behaviour.	Confusion about dates and times; sometimes mistaking places and becoming lost; difficulty in recognising familiar people.
Judgement and problem solving	Slightly less capacity to problem solve.	Difficulty problem solving, such as handling money, driving a motor vehicle.
Community participation	Slight communication difficulties that affect participation in social activities.	Difficulty finding words or following conversation; needs support in social activities.
Home and personal interests	Slight change in the ability to do home based activities, hobbies and intellectual interests.	Difficulty functioning at home, undertaking or completing tasks.
Personal care	Manages own self-care.	May need prompting.

## Time frame for dementia

There are no definitive time frames with dementia, as it affects each person differently. As a guide, a person with Alzheimer's can live from 2 – 20 years after diagnosis, with about eight years being the average.

Advanced stage dementia is when the person's neurological deterioration is severe, and they will more than likely need assistance with all their activities of daily living. Although it is hard to put a time frame on how long people stay in this stage, it can typically be from 1 – 2 years. But remember, this can differ for each individual.

The person you care for may still have moments when they remember things and can converse easily. Enjoy these moments as much as possible.

The end stages of dementia can be very difficult, especially if you are not receiving enough support. The person's brain can no longer tell their body what to do any more. This stage can last between 6 – 12 months. However, this is different for everyone, so please use this information as a guide only.

Moderate	Advanced
Substantial memory loss when only old information can be recalled and new information is rapidly lost.	Severe memory loss when only parts of old memories remain.
Substantial difficulty in recognising time, places and people, difficulty finding right words, mood swings, wandering.	May recognise people but not recall why; may no longer recognise close family; may no longer talk; may lose mobility. May be up all night, and not know the difference between night and day.
Increased difficulty problem solving; occasional sexual disinhibition; may become upset when faced with change.	Unable to make judgements or problem solve; severe depression often accompanied by agitation or psychosis.
Lack of interest or willingness to attend social activities, difficulty communicating more apparent, requires constant supervision.	Very limited ability to engage and interact with others socially, even with supports. Speech may be severely affected. May be anxious, agitated or sometimes violent.
Only effective in simple tasks, lacks interest in usual home-based activities and interests, often suffering from depression.	Unable to find their way around the house.
Requires assistance.	Full assistance needed.

## Stages of dementia

### **You may find that a person in the end stages of dementia:**

- Is unable to dress, toilet or walk without help,
- Becomes rigid in their muscles, which may feel like they are resisting your care,
- Will be in bed most or all of the time,
- Will be unable to communicate verbally, or only make noises,
- Can no longer make facial expressions or smile,
- May be completely incontinent,
- May be dehydrated, or suffer pneumonia or urinary tract infections in the last three months,
- May experience major weight loss even though you try to give them a lot to eat.

This can be a very demanding and upsetting time. You and your family and friends may need support. If you already receive support services, but feel you need more help, please talk to your service contact person.

The person's General Practitioner (GP) will be able to answer questions you may have about advanced Dementia and end-stage signs and symptoms. If you don't feel comfortable speaking with them, talk to your own GP.

# Activities in the home

It is important that the person with dementia feels they are included and that they contribute to their situation. This can be achieved by identifying their skills and enabling them to partake in daily household chores. Sometimes it may feel easier to do it yourself, but being able to achieve something helps the person's self-esteem. Challenging behaviour exhibited by a person with dementia may be due to unmet emotional need, pain, or the need to maintain some sort of order and control in their lives. One need may be to feel worthwhile. This can be gained by being involved in a productive activity.

## Be imaginative

You know the person well and understand what they enjoy doing and the skills they have. With imagination, you can create something they can do with these skills that is as typical as possible.

## For someone who likes sorting

It might be the washing, or the untidy drawer we have in every kitchen which has take-away menus, old letters, and stationery items like paper clips, pens, and rubber bands. For some, this would be a delight to sort, but for others, it would be a waste of time or beyond their skills. Be mindful and observant whenever setting up an activity and stop it immediately if you can sense it is causing anxiety. Another sorting task could be a tin of buttons, an old jewellery box where the chains are tangled or a tin of mixed nails and bolts.

## For someone who likes to fix things

You could give them an old fan or something with fairly simple mechanics to dismantle as long as you are not going to set up any frustration if they are unable to put it back together. Old televisions could keep someone busy for hours. They enjoy dismantling something to see the parts inside. They may create a sculpture with these parts. Be mindful of their safety; perhaps remove cords so they cannot plug them in to test. Explain that this needs to be done at the 'shop' when they have fixed it. Old mechanical clocks could be another option.

## Preparing meals

Can the person help with the chopping up of vegetables safely, or setting the table? Can they pick some herbs from the garden? What about going through recipe books to choose something for a meal, especially cook books they may have created? If they cannot read these, try those with pictures. Preparing fruit for jams or for stewing and preserving could be something they have done for many years and may bring back memories of their childhood.

## Music

If you both enjoy music, it can create a wonderful ambiance if played gently in the background. Have a little dance from time to time, or sing along with the words.

## Activities in the home

### Books, magazines or newspapers

Some people with dementia will go through the motion of reading, as it is something very familiar to them. Have materials available for them where they are sitting down. It does not matter if they are not actually reading. They are connecting with an old habit of turning the pages, and may get some cues from looking at the words or pictures. You could make a book of memories with the person with photos, drawings and a few large words telling the story of the picture.

### Cleaning

For some people, cleaning will be very familiar. Give them a broom to sweep around the house or a duster to dust, being careful with any precious objects that could be broken. It can be a great opportunity to reminisce while dusting the objects around your home. Each one often has its own story of how it came to be in your home. Polishing brass or silver can be very therapeutic for us all!

### Try something new

Just because the person didn't enjoy an activity before they developed dementia, it does not mean they won't want to do it now. Try sketching to music using adult materials. Could they create something with glue that could be given to the grandchildren as a gift from grandpa or grandma, such as seed pod people? Seed pods make great figures and you can add eyes and smaller seed pods as hats. They can be glued to pieces of wood as a replica of the family.

### Those less able or with poor vision

Give the person something nice to feel, such as soft materials or metallic objects. Pearls are lovely to hold. You could give them a container of corn and ask them to find the coins in it. The corn has a nice sensation against their hands. Finding coins among the corn promotes fine motor skills, which are used for tasks such as buttoning up a shirt. Be mindful that if the person is prone to putting things in their mouth, this may not be appropriate. Do not mix activities such as these with food as this will only cause confusion.

Anything that creates a sense of wellbeing and happiness will have longer lasting effect than the moment it occurs. When we feel happy or do something energetic, brains release endorphins. Their effect can continue, creating that peaceful calm environment and a sense of well-being, even when the event is forgotten. This is the same for something that may upset the person. They may stay agitated after the event is forgotten.

Those with poor vision may be able to feel large pieces of wooden jigsaw puzzles that are cut into the shape of what they are, such as animals. Wood is another interesting texture to touch and smell. Everyone needs to feel wanted, important, useful and that they are able to contribute, it is no different for a person with dementia.

# How do I talk to the health professionals?

Whilst caring for a person with dementia, there will be the need to talk with health professionals. Talking openly is important. It will lead to better understanding of the situation and any needs and concerns. Health professionals do not always understand the complexities of the family carer's responsibilities.

Often a number of health professionals are involved in caring for the person with dementia. This may mean a number of conversations about their medical condition and how everyone is coping. This can be difficult if there are different opinions from the health professionals over time. It might be easier to talk with just one health professional who can then keep the communication flowing between all involved. This will help to avoid repeating information and reduce any confusion or mixed messages.

In some families conversations are held openly between all members. In others, family members accept that one or two key people have the information and this is shared when considered appropriate. You may not want certain people to be aware of what is happening. Let the health professionals know who they can and cannot share information with.

- Tell the people managing the person's care how much you want to be involved with decisions about their treatment.
- Ask as many questions as you need to, and do not worry about asking the same question more than once.
- No questions are stupid. Do not be afraid to ask about anything you want to know.
- Write down questions when they occur to you so you can remember them when you meet with members of the health care team.
- Ask a relative or friend to come to any appointments or be present for the home visit and ask them to write down what the doctor or nurse says.
- If your doctor agrees, record the discussions so you and your family can listen again later.
- Ask your doctor or nurse to write down what was said during their appointments or visits.
- Ask your key health care professional if you can meet with them to go through any other questions you might have.

## How do I talk to the health professionals?

Don't be afraid to ask for a meeting with all the health providers to discuss issues. This is called a case conference and can be very useful to ensure everyone is working with the same information.

You have the right to get as many opinions as you want. If you are not comfortable with a certain health professional, you can change to another.

Alzheimer's Australia SA operates the National Dementia Helpline. You can use the free call number: 1800 100 500. They can give you a list of specialists who diagnose dementia.

It is useful to have an **Emergency Medical Information Book**, obtained by calling the SA Ambulance Service on 1300 136 272. These booklets are used to list the person's medical history and current medications, which is very useful when dealing with hospitals and specialists. The booklet has a magnet and can be kept conveniently on the fridge.



# What is Advance Care Planning?

An Advance Care Plan is a written or verbal record of a person's choices about their own future medical care and life style. These plans are only ever used if the person is unable to independently communicate their choices for medical care and lifestyle.

The plans help to guide families, friends and medical staff on the type of care the person would and would not like, and where they would like to receive it. It helps families and friends to make decisions for the person.

## How do I make an Advance Care Plan?

As long as you are an adult who has the capacity to make your own decisions, you can make an Advance Care Plan.

- You can nominate another person to make decisions for you and complete the relevant forms;
- You can have a conversation with a trusted person about your wishes; or
- You can write a letter, stating what your wishes are.

## Why is Advance Care Planning so important?

Advance Care Planning can be very daunting and confusing, but it is really important to have a plan in place. Involve the person's doctor, family, carers and any other important people in their life to talk about the medical treatments that they may or may not want, should something happen in the future. This gives the opportunity for the person to have a voice and their wishes followed, in the event that they should become seriously ill and no longer able to communicate.

Some people have very strong beliefs about not being kept alive through artificial means, such as breathing tubes. Others feel just as strongly about all measures being taken to sustain their life. Because no one person is the same, it is vital that the person's wishes are written down, so that there is no confusion when decisions are being made. It also means that their family won't have to make difficult decisions on their behalf if something does happen.

## What is Advance Care Planning?

### **Advance Care Planning and Dementia or Alzheimer's Disease**

Under legislation, it is assumed that people have capacity to make decisions. It needs to be proven that a person does not have capacity before a substitute decision maker is sought. People with early to moderate dementia may still have sufficient capacity to make their own decisions. Someone with advanced dementia would most likely be deemed as incapable of being able to appoint a formal substitute decision maker or prepare an Advance Care Plan. The Statement of Choices form, which can be obtained from the Respecting Patient's Choices website [www.respectingpatientchoices.org.au](http://www.respectingpatientchoices.org.au), has been developed for people who do not have the legal capacity to independently decide about future medical treatments and life style choices and who have not recorded a formal Advance Care Plan. This form is generally completed by someone who knows the person well and could anticipate their wishes, such as their partner (husband, wife) or adult child in consultation with the person's General Practitioner.

### **Would you be surprised if the person you are caring for died in the next 12 months?**

If the answer to this question is 'no', you would not be surprised, it is a good indication that you should start thinking about future plans. Future planning can be challenging or confronting, and some people may believe that if they plan for illness or death, then it will happen. This is not the case at all.

Making future plans can help alleviate the 'surprises' that can happen when caring for someone who is in the end stages of life. You can be prepared and understand what is happening and what is likely to happen.

To plan the end of life stages for the person you care for helps to reduce the stress of having to think about this when the time actually comes. It can be documented so you do not have to think about it or answer questions about it during a time when you are emotionally stressed.

# Looking after yourself

Carers should try to preserve time for themselves free of guilt and worry. Most carers know exactly what they should do to care for themselves, but in reality, they tend to care more for the person they are caring for than themselves.

When caring for someone, it is very easy for all of your thoughts and energy to go into caring for them, and to forget about your own needs. This is understandable, as you just want what is best for the person you care for. However, your own health and wellbeing is important too. If you do not look after yourself, how can you look after them as well as you would like?

Having time to yourself, either in or away from your home, can be very daunting, especially if the person you care for cannot be left alone. You may have to get in extra help, and it is a huge step to allow someone into your very personal life. Talking to friends and family about this is important, as one of them may be happy to come and spend time with the person you care for. Often they just need to be asked. If this is not possible, there are services available to support carers in your situation.

## Tips for caring for yourself

- List what you have always done to look after yourself and try to maintain some of those things regularly.
- Make a list of things other people can help with, so that if they ask, you have an answer straight away.
- Involve family and friends from the beginning so that they are aware of the potential impact it will have on the person you are caring for as the disease progresses.
- Friends and family may have their own grief and may need advice or counselling to be able to continue to support you.
- Who are the friends and family you think will support you and in what way? Make a list.
- Get enough sleep, have a chat to your doctor if you are struggling to sleep or with any other self-care issues you may be concerned about.
- See your doctor for you alone. It is so easy to discuss the person you care for at your doctor's appointments and forget about yourself.
- Having a nap during the day when the person you care for is sleeping. Even 20 minutes is better than nothing. The jobs will wait for you.
- Get some exercise each day, if you cannot leave the house, maybe laps of the backyard in the fresh air or even sitting in the backyard with a pet for a while if you are too tired to exercise.

## Looking after yourself

- Try to eat well, although it can be difficult to make time. If people ask how to help you, let them know that cooking you a meal would be wonderful. Do not feel guilty for asking. People want to help, that is why they ask. Try to eat regular meals. This can sometimes be hard when you do not know what the day will bring.
- Although it is easy to snack on junk food when you are tired and short of time, you will not feel any more energised. Try to have some fruit or healthy snacks around for you to grab. Fruit, fruit bars and nuts can be a healthy, satisfying snack.
- Keep your water intake up to prevent feeling lethargic or getting headaches at the end of the day.
- Try to find some time in your day to relax and listen to a 15-20 minute relaxation tape.
- If you smoke or enjoy an alcoholic drink, it is best not to increase these whilst caring. It is easy to turn to smoking or drinking when under stress.
- Do not cut yourself off from other important people in your life. They care for you and often want to be part of both of your lives. Sometimes hearing about someone else's day is a wonderful break from your own.
- Delegate some of the things you need to do in the day to others. People feel better when they can help; even the smallest things such as walking the dog or doing the dishes make them feel as though they are helping you. Let them do this and you will all benefit. You may feel guilty, but they will appreciate that you have allowed them to help.
- If possible, pamper yourself with a massage, or something you feel is pampering just for you.

## Taking a break – respite support

Sometimes regular, planned respite can help you continue in your role. There are many forms this can take. It could be an experienced worker coming into your home for a few hours each week to care for the person while you have some time to yourself. It could be overnight respite in a respite cottage, depending on the level of care the person requires. Or it could be in a Residential Aged Care Facility. Discuss this with your health care providers or contact your local Commonwealth Respite and Carelink Centre for information about supports in your area (available 24 hours, 7 days a week). See the Useful Contacts section at the end of this booklet for details.

## Understanding dementia

If you feel you do not know enough about dementia and its effects on the person you are caring for, Alzheimer's Australia may be able to help. They have fact sheets available on their web site and offer education courses and counselling. They can put you in touch with support groups in your area. See the Useful Contacts section at the end of this booklet for details. They can also help you to explain to others what is happening to the person you are caring for.

## Don't forget the positives

The following quote reminds us that there is much to be gained from caring for someone close to us:

*It is 'not just deep sadness and distress that are intrinsic to the experience, but also humour, love, compassion, forgiveness, reconciliation, and other sentiments involved in caring for a loved one with dementia. Caring is not only about shouldering day-to-day responsibilities, but is also an opportunity to repay kindness and warmth to parents, relatives, or friends in their time of need and an invitation to slow down and become more introspective in one's own life.'* (George D R pp586-587)

We need to remind ourselves to speak positively about our role and not allow the language of 'burden' or 'stress' to overtake us. Feeling that we are doing something worthwhile will help us to face the daily challenges.



# What can I do to help?

You may feel helpless and that there is nothing you can do when the health professionals visit to provide care for the person you care for.

Although you may or may not have medical knowledge, you do know the person better than anyone else. This knowledge is important, especially if the person can no longer communicate. Whilst the health professionals' medical knowledge is vital, your knowledge of the person's likes and dislikes is of equal importance. It may be 'small' things like them being called by their first name when you know they would rather be called by their title of Mr or Mrs. Whilst this may seem like a small issue, it is important that you share this with others, so that you can all be satisfied with the care being given.

There are many things you can do, if you are comfortable, to assist the person you care for. Working together with the health professionals can have a significant positive outcome on the quality of life for the person. You are in the best position to report any changes in their health and wellbeing. If the person is having problems with pain, you could record when the pain is occurring, if there is anything making the pain worse, or what helps in relieving their pain.

Sometimes health professionals need to know about habits such as how often and how much the person is eating or goes to the toilet. You can help by writing this information down. The health professionals may have a form that you can use to keep track of these important facts. It is helpful for the health professionals to know what is happening when they are not there.

Some of us do not feel comfortable with these tasks, and that when the health professionals visit, we need that time to have a break. If you do feel this way, do not feel guilty. Let the health professional know. Caring for a person with dementia can be exhausting and challenging. You are entitled to a break if you need one.

# What does comfort care mean?

Comfort care refers to the palliative and supportive care given to someone who is in the end stages of life.

The aim is to make the person as comfortable as possible. It encompasses the holistic care of the person which includes their physical, psychological, spiritual, and cultural needs.

## **Some tips for keeping the person comfortable:**

- Keep their room, which may be their bedroom or lounge room, clean and pleasant. Ensure the temperature of the room is comfortable.
- Keep in mind that illness can change body temperature dramatically, and they may experience extremes in temperature. You may feel very comfortable, but they may not.
- Try to keep the room ventilated, without being too cold and creating a draught. Fresh air can be wonderful when you are confined to the house.
- Lighting is also very important. Some people cannot tolerate bright light, so low level lighting may be needed.
- Adding flowers to a room can help brighten it up. Some people enjoy aromatherapy oils. If you decide to use oils, just remember not to overpower the room, as this may add to their discomfort.
- Music that they enjoy can be played in the room. Music can help evoke memories and thoughts of a past time in their life.
- Having photos of all of the special people in their life can not only comfort them, but you as well. It can help you remember all of the people who love you and are thinking of you. This is especially important on the 'hard' days.
- You may find that you get a lot of visitors. If the person you are caring for can still communicate, ask them if they are up for the visit. It is best to keep the visitors to the people they feel comfortable with. Always know you can cancel visits, if neither of you are 'up to it'.
- Keep visits short and frequent. Always know that you can tell people this, and not feel guilty. The person being cared for needs you to protect them from 'exhaustion'. As lovely as visitors are, it can be physically and emotionally draining for everyone.
- They may slowly show less interest in food and drink. This may bother you, as we are used to eating and drinking to survive. Things can change a lot as we near the end of our life.
- Even if they do not want to eat, see if you can get them to sip drinks. It can be any drink they enjoy.
- Giving them some indulgences is important. If they request chocolate, alcohol or other such things, give it to them. It is one way you can help them enjoy the time they have left.

## What does comfort care mean?

- They may still be able to help with personal hygiene. Enable and encourage them to do whatever they are capable of. This may help them feel a little more in control of themselves. If they are confined to bed, a bed bath can provide immense comfort.
- They may or may not get relief from having their teeth or hair brushed. You will need to gauge their response to these activities.
- If they are not confined to bed, encourage them to get dressed in day clothes. If they are confined to bed, clean, fresh night clothes are a good idea.
- They may or may not get up to go to the toilet themselves. If not, ask your care workers for appropriate toileting aids to help with this. There is a lot out there to make toileting in bed easier on both of you.
- If they are still mobile, see if they will come for a walk with you into the backyard for fresh air. It may give you both a boost. Sometimes even getting out of bed and sitting in a chair can do wonders.
- Do they have hobbies they enjoy? Is there any way they can still enjoy doing them? Knitting can be done in bed, as can many crafts. It may be as simple as setting up carpet bowls inside the house! Improvise to the best of your ability. If you cannot come up with activities, ask for help from your health care provider, family and friends. Some people are very imaginative when it comes to these things.
- Think about what you enjoy, as there is no reason that you cannot have your hobbies set up as well, to enjoy when you have the chance.
- Talking and holding hands can provide great comfort to both of you. They may be able to hear you and know you are with them, even if you think they cannot.
- There is nothing wrong with climbing into bed with the person. For many of us there is no greater comfort than the closeness of someone that we love. It is comforting for both.
- You both may find spiritual support important. Arrange for your spiritual advisor, priest or pastoral care worker to visit you regularly. You may wish to see this person together or separately for guidance.

# What is ‘anticipatory grief’?

Anticipatory grief refers to pre-grieving, and describes the sad feelings that can be experienced before the person being cared for dies. It is the anticipation of losing them.

Often, anticipatory grief can be experienced without realising it has a name and it can last for years, especially in the case of dementia, as the process can be very long. The person with dementia can also experience anticipatory grief especially in the early stages when they are aware of their changing level of ability. They may grieve for their independence, control in their lives and their self-identity.

It can be difficult to cope with the fact that the person being cared for may one day forget those closest to them. A person with dementia once wrote to her children, “I may forget your name, but in my soul I will always know you”.

## **Tips to assist in coping with anticipatory grief:**

- Recognise the feelings that you have about the changing abilities of the person you are caring for and the situation you are in. Allow yourself to experience your feelings, which may include sadness, anger, confusion, hurt, fear, loneliness or isolation or maybe you ‘feel out of place’. Try to make some time to have some privacy in the day to let these feelings out.
- Feelings of being very ‘alone’ may be experienced. This may not be typical for you, but grieving can make you feel isolated.
- It may be confronting to share your feelings with someone else, as you may think they will not understand. However, it can help to confide in someone who will just listen, without offering solutions or passing judgments. This person maybe someone with whom you had never expected to confide in before and now find comfort with.
- At times, it may be hard, but try to find moments of joy with the person being cared for. A good start may be to share a story of something you did together that made you laugh.
- Looking after yourself is important.
- Sometimes caring for a person with Alzheimer’s or another dementia can become overwhelming and leave you with a sense that you may not be able to cope anymore. If this happens to you, talk with your general practitioner or another health professional aware of your situation.
- The hardest time might be birthdays, Christmas, Easter, or Mothers’ or Fathers’ Day. The person you are caring for may not remember these events or be able to understand their significance. Try to make a point of celebrating or sharing these times with another close family member.
- You may find anger building up as the person you care for is unable to carry on the ‘normal’ everyday routines or they become annoyed and agitated over little things. Instead of reacting with anger, try to see it through their eyes and understand the pain of their fear and confusion.
- Remember, it’s alright to cry and laugh.

# Morphine: the myths

In the later stages of dementia, people may experience pain. It is important that this pain is relieved.

Morphine is one of the stronger pain killers used by doctors in Australia. There are many different ways of giving morphine, such as through the mouth or by injection. If pain persists, doses of morphine can be increased slowly and carefully to control the pain. Nausea and vomiting may occur initially but these can be easily controlled. If it causes sleepiness, this usually resolves within days. It will always cause a dry mouth and constipation, so these should be addressed with good mouth care and laxatives. Be alert for signs of constipation.

There are a number of myths about the use of morphine. It is important that you know the facts if you are being asked by doctors for permission to give morphine to the person you are caring for. The myths include:

- **The person will become addicted.** Physical dependence and tolerance may occur but addiction or psychological dependence is rare and almost never occurs in a person without a history of drug use prior to their illness.
- **It will eventually become ineffective.** As long as morphine is the correct medication for the pain, you are able to continue to increase the dose (called titrating) up until the person is pain free. As the dose is raised, pain relief (analgesic) effects increase.
- **Using morphine means the person is going to die.** Some people with chronic pain can be on morphine for years.
- **Morphine hastens death and should not be used with older persons.** As older people are more sensitive to the effects of morphine, the dose must be calculated carefully – ‘Start low, go slow’ – death will not be hastened. Relieving pain can prolong life.
- **Morphine causes respiratory depression.** When the dose of morphine is started low, and increased slowly, respiratory depression is very rare. If it does occur, it is usually in people who have never had it before.

The right dosage of morphine is the dosage that relieves the person’s pain without intolerable side effects.

# What do dying people need?

The needs of people who are dying will be different from one person to another and will also depend on their level of dementia. There are some basic needs relevant to all people during the final phase of life.

## **They need:**

- To know that they will be loved, cared for and supported until the end by people who care about them.
- Touch. Simply holding a hand can provide great comfort for a dying person and also allows for a time to be close for carers, family and friends.
- The people who care for them to be free of their own difficulties, enabling them to be alongside the person through their death. They need you to be strong advocates to ensure they receive the best care possible.
- People who can listen, generally with no advice or opinions required. Listening without talking can be a difficult but essential skill. Sometimes the thought of just 'being' with a dying person can be very challenging.
- To feel included in decisions regarding their care for as long as possible. It is their body and we need to respect that they should have the chance to voice their opinions if they can. Even when they become very unwell and may not talk anymore, they can still hear. They need to feel part of what is going on around them and to them.
- Open, honest communication. They want to know that their family, friends and caregivers will be there to listen to them.
- To be allowed to discuss their impending death. This may make some people uncomfortable, but the dying person needs to be able to share their thoughts in a trusting, supportive environment. They may pick only one or two people with whom they feel comfortable discussing this.
- The opportunity to 'get rid' of anything that they may feel ashamed of, sad or angry about, or other thoughts that are causing them emotional pain. It can be a huge weight for them to release these deep feelings.
- Excellent holistic care. This means considering all areas of their life and what makes them who they are.
- Not to be rushed. This may be difficult at times when there are so many things to do and very little time. Work out the things that can wait for another time and allow yourself quality time with the person.
- Their carers to take care of themselves and to feel that they are not burdening someone they love. Carers should take breaks to allow them to be the loving, supportive person that they need and want to be.

# Preparing for death at home

Some people like to be prepared for the difficult things in life, others prefer not to know. This information is not intended to cause distress, but will help you to prepare for some of the changes that the person you care for may exhibit. Keep in mind that everyone is different and may exhibit or experience all or none of these signs or symptoms.

Caring for someone during the last few weeks of their life is a privilege. It can also be a prompt to start wondering about what happens to our body as it prepares for death.

Although confronting and possibly upsetting, some people like to understand events as best as possible before they occur. This information may help those to prepare and respond to these changes if and when they occur.

It is very important that people feel they can ask for help if they find themselves struggling to cope with the nearing death of the person they care for. The person dying may experience all or none of the signs that will be discussed. Please remember that these signs are the natural and normal part of the body slowing down.

## What actually happens when someone is dying?

When people care for someone they love nearing the end of their life, a huge concern can be that the process of dying will be painful for them. Usually, for someone who has been unwell, there is a 'winding down' of their body that may take several days. This is generally a peaceful time.

### Restlessness

When the body winds down before death, circulation slows as well. This means that the blood flow slows down. It does not flow in and out of the vital organs of the body as well as it did. This causes these organs to slowly shut down and stop functioning. For example, the liver and kidneys filter out the toxins in the blood. The slowing of the blood flow will cause the toxins to build up which can cause restlessness and/or agitation. This can be very hard for family and friends to witness, as the last thing wanted is for the person we are caring for to be upset. If this does occur, try to remain calm and communicate in a calm, quiet voice. It may help if you turn down any bright lights or any loud noises. You may want to lightly massage their hand or play them soft, familiar, calming music. You will feel better knowing that you are trying to help with loving care. Restlessness can be reduced with medication. Be sure to inform someone on the medical team what is happening.

## **Appetite and Thirst**

You may notice that their appetite and thirst decrease, and they may not want to eat or drink. This can be very hard for carers to cope with, but it is a natural part of the process of dying. Trying to feed someone when they cannot swallow or do not want food, can cause them greater distress than just allowing them to 'be'. The body can no longer process food and fluid and it can cause more distress to the person. You can provide comfort by offering little sips of water, ice chips to suck, or wetting a mouth swab they can suck on.

## **Sleep and Alertness**

The physical changes that occur naturally in their body as it winds down, may exhaust the person. They may spend much of their time asleep or drowsy, and you may have trouble waking them at times. They are conserving their energy. Try and wait for them to be awake and alert to communicate. Quality conversations will be much more memorable for you.

## **Incontinence**

You may find that the person does not need to urinate as much as they once did; this is due to the fact that they don't need or want to drink as much anymore. Their urine may become very dark and have a strong smell. This is normal.

Sometimes people nearing the end of life lose control of their bladder and/or bowels; they have no control over this. You are able to get pads or absorbent sheets for the bed that will protect the mattress. The nurse or palliative care team that visits will be able to assist with this.

## **Breathing**

As death approaches, the breathing pattern changes. You may find that the person's breathing is very fast, and other times there may be big gaps between breaths. You may find yourself listening to their breathing closely, and you may find yourself wondering if each breath may be their last. Their breathing may be quiet or loud. This is not painful or upsetting for the person, although it may be for you.

## Preparing for death at home

### Secretions

As the person's swallowing and coughing reflexes wind down, there may be a buildup of saliva or mucus that collects in the back of their throat and can make a gurgling or bubbling noise. This noise may bother you and you may think that it is bothering the person as well, but usually it causes them no distress. If this occurs, you can try to support their head with an extra pillow or turn their head to one side. If this does not help, and it is causing you distress, contact the medical team. There may be medication to slow down the production of the saliva and mucus.

This may look like an overwhelming list of signs that death may be approaching, but please remember that these signs are a very natural part of the process. However, this will not take away the immense experience of losing a loved one. We hope that this information has given you some insight into what you may see in the person you care for. You are not expected to be at ease with any of these things, but try to remember that it is the body's way of winding down. If, at any time, you are concerned, please talk with your care provider. They will be able to offer you further information and support.

### How will you know when the person has died?

When a death occurs at home and there are no medical personnel present, you may worry that you will not know if they have actually died. Indications that the person has died:

- Their bodily functions will stop;
- They will no longer respond to you, and their breathing and pulse will cease;
- Their eyes will now be fixed and look in one direction, they may have their eyes open or closed;
- Their jaw will slowly relax and their mouth may open slightly as this occurs;
- They may experience a loss of bladder or bowel control as their body slowly relaxes.

Even though you have read the signs, when the time comes, you may (naturally) feel very overwhelmed and distressed. This is quite normal. Even though we know death is natural, it is difficult to lose a loved one.

### What should I do now?

An expected death at home after an illness is not an emergency. There is no need to call the police or an ambulance. At this time, it is important to take your time and think about what you want to do. It can be a very intimate time.

After the person has died, you may find you need private time with them. We all cope with these situations differently, and nothing you do is wrong.

Some people like to hold hands with the person for a long time, some need to sit and cry, others like to call family so everyone can say goodbye. It is a very personal time, and whatever you need to do, now is the time to do it.

- It is alright to hug, kiss or lay with the person.
- Some of us take a great comfort in helping care for their body; we can do this in ways, like bathing them or brushing their hair.
- Some people may feel uncomfortable with being alone with the body. It can be very confronting and upsetting for those who have not been with someone who has died. This is a normal reaction.
- You may want to call your support people and ask them to come and be with you.
- It is a good idea, after the person dies, to turn off any heaters that may be on in the room. You can also turn off any equipment that may be attached to them, only if you are comfortable to do so. Do not feel that you have to turn off or remove anything. The doctor, Funeral Director or one of the care team will do this for you.

It is important to have a plan already set up for the expected death of the person you are caring for with who will do what and when. This helps to avoid more stress at a very stressful time. If you do not feel comfortable arranging these things yourself, ask a family member, friend or someone from the care team. Things that should be arranged include:

- **Regular visits from their doctor throughout the final stages.** A doctor needs to have seen the person at least three months prior to their death. Otherwise their death becomes a coroner's inquest, which means the police need to be called when the person dies. This can be very upsetting and can be avoided if their death is expected and planned.
- **The signing of their death certificate.** You need to decide if you want their body taken out of the home as soon as possible when they die. If you do, arrangements will be necessary to identify who will sign their death certificate, should they die during the night. Their body cannot be removed until their death certificate has been signed. If you do not want the body removed as soon as possible, the doctor does not have to be contacted until the morning. If it has been discussed with the doctor and they are prepared to sign the death certificate, the body can be removed without the death certificate being signed, provided that someone in authority has confirmed their death.
- **Decide which funeral director you want.** Once you have decided, contact can be made to discuss what will happen when the person dies. They can come at any time night and day and take the body away, once their death certificate has been signed, if this is your wish. You may wish to keep the body home for a while for friends and family to say their farewells. This is quite alright.

# Now they have gone

I feel like I shouldn't talk about them anymore...

Your memories and stories of your time with the person you cared for are precious. It can be therapeutic over time to share these with others. It may be difficult at first, but give it time, it will get easier. Remember that you are allowed to cry, feel sad and feel angry or numb when you talk of your loved one. You may find that it makes you feel happy to remember them. We all deal with our grief differently.

Just because they have died, it does not mean you cannot talk about them anymore. They were, and always will be a significant part of your life and very important to you and your family and friends.

- Some people take comfort in talking about the person they have cared for and times shared. Others find it very difficult to do this and even struggle if they hear their name mentioned.
- Talking about the person can be a very healthy way of grieving.
- You may find some people are uncomfortable talking about the person.
- People deal with emotions differently, and whilst some people may prefer not to discuss the person at all, others will love sharing memories and laughing and crying with you.
- You will soon work out who you can share your memories with in a supportive environment, and enjoy doing this with them.
- Most people who are not comfortable with this are not this way because they do not love or miss the person, but may be due to their own emotions about death. You may be upset by this, but know it is not about you or the person you cared for.
- Sometimes people need to talk to a professional when they are having trouble sharing their feelings and thoughts. It can be very helpful at times to talk with a skilled counsellor to release feelings. They can provide strategies to help in dealing with loss.
- There are places you can call just to talk to someone, if this is more comfortable than face to face, or if things get tough in the middle of the night or on weekends. Always know that there is someone available 24 hours a day if you need them. See the Useful Contacts section at the end of this booklet for details of the supports available.

# Some helpful tips from past and current carers of people with dementia

Throughout a person's life, there may have been times when they had plans and preparations for a holiday or a move.

Especially in our western culture, the idea of preparing for the final journey as we leave this earth forever, is a frightening subject to be avoided or whispered about behind closed doors and out of earshot of the person involved.

How different it can be if this journey is embraced with openness, frankness and even excitement and anticipation! Everyone can be involved in the preparation for the journey and contribute to the organisation and management of everything involved. It may take time before people are comfortable with this attitude, and sensitivity is the key to helping it work. The freedom and acceptance as families talk and plan together, brings about a real closeness and comfort, and can be a wonderful support during the time of grieving that follows.

## **A few things to think about and plan:**

- Put all paperwork in order before the death.
- Have all the necessary legal documents, such as the Enduring Power of Guardianship or Advance Care Plan, in one place or folder for easy access.
- Attend to any unfinished business.
- Express goodbyes with love and thanks.
- Forgiveness sought and given.
- Rifts and misunderstandings discussed and put right.
- Decide who will 'feed the cat' and care for the partner or family left behind.
- Consider having memorials, such as plants in the garden or a special place, that will always be a 'thinking and remembering' spot.

# Useful contacts

for information, counselling, respite and support groups.

Organisation and Address	Region	Phone
<b>Resthaven Incorporated</b> PO Box 327, Unley SA 5061 www.resthaven.asn.au	Metropolitan Adelaide, Adelaide Hills, Murraylands, Riverland and Limestone Coast	1300 13 66 33

## Carer Support Services

<b>Carers South Australia:</b> Carers Advisory and Counselling Service	State Wide	1800 242 636
<b>Carer Support</b> 290 Glen Osmond Rd, Fullarton	South and East Metropolitan	8379 5777
<b>Northern Carers Network</b> Shop 15/130 Peachey Rd, Davoren Park	North Metropolitan	8284 0388
<b>Carers SA Western Carers</b> 66 Tapleys Hill Rd, Royal Park	West Metropolitan	8240 2900
<b>Carers Link Carer Wellness Centre</b> 39 Main St, Woodside	Adelaide Hills	8391 4476
<b>Carers Link</b> 26 Second St, Nuriootpa	Barossa and Districts	8562 4000
<b>Carers Link</b> 37 Old North Rd, Clare	Lower North	8842 1118 or 1800 246 300
<b>Carers Link</b> 9 Taylor Street, Kadina	Yorke Peninsula	8821 2444
<b>South Coast Carer Support</b> 63 Victoria St, Victor Harbor	Fleurieu Peninsula	8552 7419 or 0422 004 903
<b>Kangaroo Island Carer Support Centre</b> 20 Dauncey St, Kingscote	Kangaroo Island	8553 2262
<b>Carers SA: Northern Country Carers</b> 11 Loudon St, Pt Augusta West	Northern Country	8641 1844
<b>Carers SA: River Murray and Mallee Carers</b> Shop 4, Edwards St, Loxton	Riverland and Mallee	1800 806 580 or 8584 6855
<b>Carers SA: South East Carers</b> 61a Commercial St East, Mt Gambier	Limestone Coast	1800 654 429 or 8724 7188
<b>Carers SA: Eyre Carers</b> Shop 6, 2-4 King St, Port Lincoln	Eyre Peninsula, West Coast & Far North West	1800 350 004

Organisation and Address	Region	Phone
<b>Commonwealth Respite and Carelink Centres</b>		
33 Mackay St, Port Augusta	North and West Country	1800 052 222
77 Gibson St, Bowden	North and West Metropolitan	1800 052 222
290 Glen Osmond Rd, Fullarton	South and East Metropolitan	1800 052 222
95 Swanport Rd, Murray Bridge	South and East Country	1800 052 222

## Palliative Care Specialist Teams

<b>Southern</b>	Mon-Fri, 9am to 5pm	8275 1732
<b>Western</b>	Mon-Fri, 9am to 5pm	8222 6825
<b>Central</b>	Mon-Fri, 9am to 5pm	8222 2021
<b>Northern – Lyell McEwin Hospital</b>	Mon-Fri, 9am to 5pm	8182 9208
<b>Northern – Modbury Hospital</b>	Mon-Fri, 9am to 5pm	8161 2351

## Other Support Services

### Agedcare Alternatives

An information service that will assist you to navigate, decipher information and identify options to meet your aged care needs.  
[www.agedcarealternatives.net.au](http://www.agedcarealternatives.net.au)

Statewide  
 Mon-Fri, 9am to 5pm  
 8271 3888

### Lifeline

Statewide  
 13 11 14

### Alzheimer's Australia SA

[www.alzheimers.org.au](http://www.alzheimers.org.au)

Statewide  
 8372 2100

### National Dementia Helpline

Statewide  
 Mon-Fri, 9am to 5pm  
 1800 100 500

## Useful contacts

Organisation and Address	Region	Phone
<b>Other Support Services</b> continued		
<b>Dementia Behavioural Management Advisory Service</b>	Statewide 24 hours, 7 days a week	1800 699 799
<b>Palliative Care South Australia</b>	Mon-Fri, 9am to 5pm	8291 4137
<b>SA Palliative Care Packages: support for end of life care</b>	Statewide 8am to 8pm, 7 days a week	1300 110 600
<b>Metropolitan Referral Unit</b> For referrals for hospital avoidance support and the SA Palliative Care Packages.	Statewide 8am to 8pm, 7 days a week	1300 110 600

## Useful websites:

### Respecting Patient Choices:

[www.respectingpatientchoices.org.au](http://www.respectingpatientchoices.org.au) to obtain all documentation and information about advance care planning.

### Extended Care Paramedics website:

[www.emergencymedicalparamedic.com/extended-care-paramedic/](http://www.emergencymedicalparamedic.com/extended-care-paramedic/) to access call '000' and ask for this service or, to flag a client with them, call 1300 13 62 72.

**Enhanced Primary Care** initiatives enable GPs to be paid through Medicare for various items such as Multidisciplinary Case Conferences  
[www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-caseconf-factsheet.htm](http://www.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-caseconf-factsheet.htm)

[www.hospicepatients.org/karnofsky.html](http://www.hospicepatients.org/karnofsky.html) to download the **Karnofsky scale** used in end of life stages.

# Helpful resources

Dept. of Health and Ageing (2006) *Dementia – The Caring Experience: A guide for families and carers of people with dementia*. Commonwealth of Australia, Canberra. [www.health.gov.au/internet/main/publishing.nsf/Content/ageing-publicat-carerexp.htm](http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-publicat-carerexp.htm)

Resthaven (2011) *Advance Care Planning, Choices for Your Future*. [www.resthaven.asn.au](http://www.resthaven.asn.au) under 'Publications' (accessed July 2011)

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Office for the Ageing, Department for Families and Communities (2009) *South Australia's Dementia Action Plan 2009-2012: Facing the Challenges Together*, Government of South Australia.

### How do I talk to the health professionals?

CareSearch, *palliative care knowledge network* website. [www.caresearch.com.au](http://www.caresearch.com.au) (accessed July 2011)

Cancer Australia website. [www.nbocc.org.au](http://www.nbocc.org.au) (accessed July 2011)

### What is Advance Care Planning?

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Cartwright, Colleen (March 2011) *Planning for the End of Life for People with Dementia. Part One*. Paper 23. Alzheimer's Australia.

### Looking after yourself

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Carers Australia and St John Ambulance (2007) *Carers Handbook*. [www.stjohn.org.au](http://www.stjohn.org.au)

Carers Australia SA, *Supporting Family Carers: Who We Are, What We Do*.

### What is Anticipatory Grief?

Understanding Dementia website, [understanding-dementia.com](http://understanding-dementia.com) (accessed July 2011)

*Dementia Caregiving 101* website. *Anticipatory Grief: grieving your Family Members Lost Abilities*.

[www.dementiacaregiving101.com](http://www.dementiacaregiving101.com) (accessed July 2011)

Grieflink website, [www.grieflink.org.au](http://www.grieflink.org.au) (accessed July 2011)

### Morphine, the myths

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Blue Mountains GP Network Inc., University of Western Sydney, NSW Govt., Nepean Blue Mountains Local Health Network, *Pain management decisions making Framework – supporting information*. [http://uws.clients.squiz.net/\\_\\_data/assets/pdf\\_file/0004/76252/Pain\\_Supporting\\_Information.pdf](http://uws.clients.squiz.net/__data/assets/pdf_file/0004/76252/Pain_Supporting_Information.pdf) (accessed Aug 2011).

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Department of Health and Human Services, *Tasmania Dying at Home – Fact sheet*

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