

DEMENTIA

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

3rd Edition

BLUE MOUNTAINS
GP NETWORK INCORPORATED

University of
Western Sydney
Bringing knowledge to life



Health
Nepean Blue Mountains
Local Health Network

This booklet
contains a lot of
information, which
may or may not
be relevant at the
time of reading. We
suggest you look at
the list of contents
and read only the
sections that are of
interest to you at the
moment.

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Introduction

The involvement of relatives and friends in the care of people living with dementia is invaluable, regardless of where the care is provided. Sharing care helps to maintain the best possible quality of life of the person with dementia.

This booklet describes the final stages of dementia. The information provided may be distressing to you. Please take your time to read the booklet and talk over any issues you may have about dementia with your general practitioner (GP) or other service providers. It may also help you to discuss any concerns you have with a close family member or friend.

This booklet has been written for two reasons:

1. To inform you about what will happen to a person living with the final stages of dementia; and
2. To encourage you to consider in advance some of the issues that might require decisions from you about the care of the person with dementia.

Reading this booklet and talking about the issues that might arise may help you feel more informed and in control. It is very useful to discuss these issues with the person with dementia early in their illness if possible, so the person can talk about his or her values, beliefs and any preferences for care. Knowing this information can guide your future decisions.

Don't worry if you didn't have the opportunity to discuss these issues with the person with dementia before their illness progressed. Your GP or specialist doctor and other service providers will guide you as you need to consider any issues as they arise.

The information provided in this booklet is a general guide only.

The most common types of dementia are Alzheimer's disease and vascular dementia. If you need specific information about any type of dementia, please speak to your GP, other service providers assisting in the care of the person you know with dementia, including staff of the residential care facility if the person is living in one, or telephone Alzheimer's Australia. Their number is located on the back cover of this booklet.

Types of dementia

It can be difficult for service providers to tell what type of dementia a person has when the dementia is in the final stages. The changes that occur due to dementia, and the medical complications that arise as a result are similar for all dementias. Therefore, the information in this booklet is useful for anyone wanting information about the final stages of dementia, irrespective of the type of dementia.

‘Stages’ of dementia

When you read about dementia, or speak to service providers about the condition, you may notice that people use different terms to discuss the ‘stages’ of dementia. A ‘stage’ is simply a term used to conveniently describe a group of behaviours and medical issues that tend to occur together as dementia progresses.

There are no clear definitions of when a ‘stage’ starts or ends. Each experience of dementia is different, and the effects of the illness may change daily. However, as dementia progresses some behaviours of concern or medical issues gradually become less noticeable and other behaviours of concern and medical issues become more important. When this happens, service providers take note because the changes may signal a progression of the condition and a move to a new ‘stage’.

In this booklet, we are specifically talking about the final stages of dementia, when a person needs care 24 hours a day, 7 days a week, and is usually living in a residential care facility.

The terms *severe* stage and *end* stage dementia are used in this booklet. Other terms used to describe a similar time in the course of dementia progression are *late* stage; *third* stage; *advanced* stage and *terminal* stage.

Dementia is unpredictable and varies from person to person. The course of dementia does not follow a set pattern, or a set time period.

As a general guide:

- people with Alzheimer's-type dementias live with the condition from 2 to 20 years, with about 8 years the average;
- people with vascular-type dementias live with the condition for about 6 years;
- people with Fronto-Temporal Lobar Degeneration live with the condition from 2 to 15 years, with an average between 6 and 12 years; and
- people with Dementia with Lewy bodies live on average 7 years following the onset of symptoms.

Time frame for dementia

Dementia is a progressive, terminal condition that cannot be cured. It is a sad fact that people with dementia will have a shortened life span because of their condition. As dementia progresses, the brain stops working properly. All bodily organs and systems, which are controlled by the brain, are affected. As these bodily systems fail, a variety of medical complications occur. Death is the inevitable outcome.

The changes that occur as dementia progresses are discussed later in this booklet.

Who can legally make substitute decisions about medical care for a person with dementia?

People with dementia may have impaired capacity to make decisions. Capacity to make decisions about health care is a contentious issue. People with dementia are presumed to have the capacity to make their own decisions until this is proven otherwise.

In the severe and end stages of dementia capacity is always impaired. Another person will need to make all decisions on behalf of the person with dementia. This includes all decisions about the medical treatment the person living with dementia needs. Under the law, there are specific people listed who are able to consent to medical treatments for another person.

In NSW, the Guardianship Act (1987) refers to a person legally able to give substitute consent as a 'person responsible'. Under the Act, the 'person responsible' need not be a blood relative of the person needing a substitute decision-maker. The order of who can legally make decisions about medical care for another person in NSW is: a guardian (appointed by a Court or Guardianship Tribunal or by the person with dementia when they had capacity); if none, then a spouse or defacto spouse (including a same sex partner) with a close relationship to the person; if none, then an unpaid carer (the person can be receiving the Carer's Allowance); if none, then a relative or friend who has a close personal relationship with the person needing decisions made on his or her behalf.

It is important to understand that a person with dementia, like any other member of the community, may die suddenly and unexpectedly, especially if the person has a history of other medical conditions like heart or lung disease, or high blood pressure.

Death for a person with dementia may occur from the moderate stage onwards, depending on the other medical conditions of the person. This needs to be kept in mind as you discuss likely scenarios with the doctors or specialists you consult.

If you are in doubt about who the 'person responsible' is in your situation, or want to discuss the matter further, please speak to the GP caring for the person you know with dementia.

Severe and end stage dementia

It is wise to have some plans in place in case a crisis situation such as an unexpected stroke or heart attack occurs.

In this section of the booklet, the severe and end stages of dementia will be discussed. Not everyone will experience all of the symptoms mentioned.

The severe stage of dementia may last for about 2 years, and the end stage for 6 to 12 months, although these time scales are an average and may be shorter or longer for any individual. Changes that the person with dementia experiences are generally very gradual.

As the brain fails due to dementia progression, changes can be noticed in four major areas:

- cognitive ability (the way the person thinks and remembers);
- ability to talk;
- behaviours (the way the person acts) and emotions (feelings);
- functional ability (the person's ability to walk and look after basic tasks and needs).

Each of these areas will be considered in turn. Remember that we are discussing here common changes that may be seen.

One of the earliest signs a person with dementia experiences is that they become forgetful, and unable to solve problems, or start and finish any activities. These memory problems continue as the dementia progresses.

Cognitive (thinking) ability

In the severe stage of the illness, the person with dementia:

- will only remember little snippets of events that happened a long time ago, and memories of recent events such as having a shower or meal that day will not be remembered;
- may forget both the name of their husband, wife, partner, or children and the relationship they had with them, but will usually remember their own name;
- will lose the ability to solve problems, start tasks and carry them through, or understand requests from other people.

As dementia progresses a further decline in cognitive skills occurs, so the person is unable to remember who anyone is, including a spouse, partner or other close relatives and friends.

Being unable to recognise even your closest loved ones is one of the signs that the person with dementia has entered the end stage of the condition.

Ability to talk

The ability to talk is also affected as the brain fails. At first the sentences become jumbled, then the words themselves may become jumbled. A person with Fronto-Temporal Lobar Degeneration may have language problems from very early in the condition.

As dementia progresses, the ability to talk is steadily lost, until only a few words are left that can be said, or the person may become mute and unable to speak at all. *Being able to speak only about 6 words or less is one of the signs that the person has entered the end stage of dementia.*

Instead of talking, people with end stage dementia may sometimes make strange sounds, or even scream. If this happens, it usually means that they are trying to communicate something, such as that they are uncomfortable (maybe they are hot, cold, or in pain for example).

Family members and other carers who know the person well can usually work out what is wrong, and help to settle the person.

Remember that although a person in this stage of dementia may not be able to talk to you in a meaningful way, he or she is still aware of your presence, and you can still provide comfort and reassurance.

Changes in behaviour and emotions are extremely common, and can be very difficult for everybody involved with the person with dementia. Some of the behaviours of concern listed here occur much earlier in the course of certain types of dementia than others. For example, people with Fronto-Temporal Lobar Degeneration may become apathetic or disinhibited early, while people with Dementia with Lewy bodies often experience visual hallucinations early.

Behaviours (actions) and emotions (feelings)

People living with severe dementia may experience some of the following:

- delusions (mistaken beliefs) which may cause them to think, for example, that other people are trying to poison them, or that a close relative is an impostor;
- hallucinations (seeing, hearing, feeling, tasting, or smelling something that doesn't really exist);
- being agitated or anxious and distressed, and seeking reassurance from other people;
- wandering aimlessly, or pacing up and down;
- being intrusive (going in to places where they are not invited such as other people's rooms in a residential care facility);
- being sexually disinhibited (having inappropriate sexual behaviour);
- appearing to be depressed, apathetic and withdrawn (having no energy, or interest in what is happening around them);

- being aggressive or violent;
- not allowing carers to look after them (known as being resistive).

The number of behaviours of concern may lessen as the person with dementia progresses towards end stage.

Monitoring and managing behaviours

Behaviours are a form of communication for the person with dementia, and need to be monitored and assessed to try to establish their cause. For example, a new behaviour such as agitation may be due to a physical condition like a sore throat or headache that can be easily treated. The behaviour starts because the person with dementia is unable to tell another person he or she is feeling unwell. When the physical complaint is managed, the behaviour lessens or stops.

Any change in the behaviour of a person with dementia, whether an increase or decrease in the behaviour, or a new behaviour starting, needs to be assessed in case there is a treatable cause for the behaviour.

The regular carers, family and friends of a person with dementia are often in the best position to work out the cause of the behaviour. After all, they know what the person is usually like, and know how the person reacts when unwell.

A key aspect of caring for people with dementia who may be agitated and wandering is to offer them a safe environment where they can move around without the need to limit their movements.

Gradually the ability of people with dementia to look after themselves will be lost as the condition continues to damage the brain.

Bathing and Grooming

People with dementia need more and more help to bathe and groom as the dementia progresses. Eventually the ability to perform any of the grooming and personal care tasks like showering and dressing is lost.

The person may become afraid of having a bath or shower, and become resistive to care (fight against having care attended), or insist they have had a shower when they haven't. *In the end stage of dementia the individual may not even seem to be aware that grooming is being attended.*

Walking and movement

People with Dementia with Lewy bodies may experience difficulties with walking and falling, quite early in the condition. For other types of dementias, the ability to walk will be gradually lost as the dementia advances into the severe stage.

**Functional
ability
(ability to
walk and
look after
basic tasks
and needs)**

At first you might notice that the person seems to be walking awkwardly and appearing to be off balance. They may become more likely to have a fall, and need to use a walking stick or frame. Falls may occur despite everyone involved trying to prevent them.

Eventually the ability to walk is lost. When this happens, the individual with dementia needs to spend most of the time sitting in a chair or being cared for in bed. *Losing the ability to walk is one of the signs that the person with dementia has entered the end stage of the illness.*

There are a number of serious problems that occur once the ability to walk is lost. The person's muscles become weak and waste as a natural outcome of not using the muscles anymore. The person becomes frailer and increasingly likely to develop medical complications, like infections and pressure ulcers caused by lying in the one position for too long.

Facial expressions

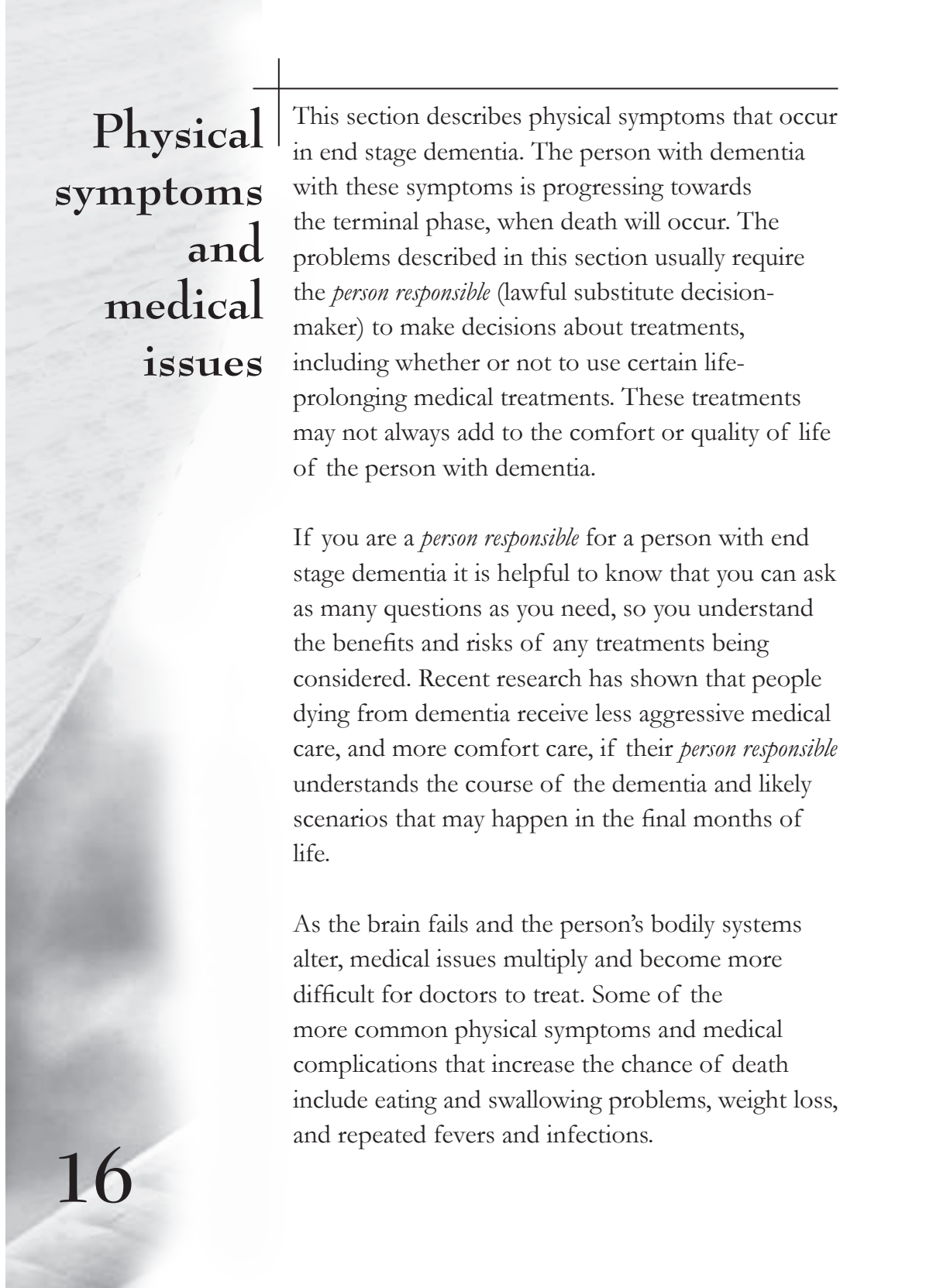
People with end stage dementia may lose the ability to smile or show any expression on their face, because of the muscle weakness already discussed. *Losing facial expressions is one of the signs of end stage dementia.*

Having lost the ability to smile and show facial expressions does not mean that the person with dementia is not aware of their surroundings. They can feel the touch of your hand, or a breeze blowing on their face. The ability to hear remains, so music and laughter and family stories and the sounds of activity around are heard.

Toileting

The ability to go to the toilet without help is also lost as the dementia advances. One of the first changes that occurs to a person with dementia is confusion about direction, so he or she cannot find the toilet. As time progresses, the usual activities associated with toileting are forgotten, like flushing the toilet and washing the hands. Gradually the person forgets why they need to go to the toilet and becomes incontinent, firstly of urine. This means they may start to wet their pants and need to wear pads.

Forgetfulness and problems with walking eventually lead to the person with dementia becoming unable to use the toilet for bowel motions as well. *One of the signs of end stage dementia is that the person is doubly incontinent: he or she soils and wets the bed and clothes, and needs to wear a pad all the time.*



Physical symptoms and medical issues

This section describes physical symptoms that occur in end stage dementia. The person with dementia with these symptoms is progressing towards the terminal phase, when death will occur. The problems described in this section usually require the *person responsible* (lawful substitute decision-maker) to make decisions about treatments, including whether or not to use certain life-prolonging medical treatments. These treatments may not always add to the comfort or quality of life of the person with dementia.

If you are a *person responsible* for a person with end stage dementia it is helpful to know that you can ask as many questions as you need, so you understand the benefits and risks of any treatments being considered. Recent research has shown that people dying from dementia receive less aggressive medical care, and more comfort care, if their *person responsible* understands the course of the dementia and likely scenarios that may happen in the final months of life.

As the brain fails and the person's bodily systems alter, medical issues multiply and become more difficult for doctors to treat. Some of the more common physical symptoms and medical complications that increase the chance of death include eating and swallowing problems, weight loss, and repeated fevers and infections.

Other problems may include pain, shortness of breath, and pressure ulcers. Unexpected events may also occur that require treatment.

Eating and drinking problems

Difficulties with eating and drinking, refusing to eat, swallowing, and chewing problems are common in end stage dementia, so common that about 86% (8 or 9 people out of 10) with end stage dementia have an eating problem.¹

Earlier in the course of the illness, the person with dementia needs help to eat and drink, because confusion and lack of coordination of the muscles stops the person getting enough food and fluids.

Eventually other problems with eating begin. The food is held in the mouth for a long time without swallowing, or the food is chewed and chewed, as if the person has forgotten how to swallow. Towards the end of life, a person with dementia may let the food fall from the mouth without any attempt to eat it, despite encouragement from carers. *Often when a person appears totally uninterested in food it is a sign that they are nearing the very last weeks and days of life.* Watching a loved one refuse to eat can be distressing for family members and carers. If this happens to the person you know with dementia then talk it over with the carers and your family so that you get some support for yourself.

A person with end-stage dementia usually eats and drinks a lot less than normal. As a result he or she may lose weight and become dry (dehydrated). The dryness in turn can cause other problems, such as constipation.

Swallowing problems

Swallowing problems are very common, and are one of the main signs of end stage dementia. A person with dementia who develops swallowing problems may have a very limited life span of only a few months, although this is not true in every case.

Signs of swallowing problems include appearing to choke when eating, and/or coughing after eating. The medical term for swallowing problems is *dysphagia*. A Speech Therapist can assess dysphagia and provide detailed information to allow carers to feed the person correctly.

If dysphagia is not managed, food and fluids may go down the wrong passage and enter the lungs. This can cause a condition called *aspiration pneumonia*, which is a type of lung infection caused by the food or fluid. Antibiotics and possibly admission to hospital are needed to treat aspiration pneumonia.

A person with swallowing problems can usually continue to eat, with the food mashed or pureed, and fluids thickened. Sometimes however,

no matter how carefully the right-textured food and fluids are given, repeated bouts of aspiration pneumonia occur. One of these bouts will be fatal to the person. The options may be to continue feeding, knowing the high risk of death from pneumonia, or to stop feeding and maintain the person's comfort until natural dying occurs. The comfort of the person with dementia is the most important factor in this difficult situation.

When a person has swallowing problems from dementia it is sometimes suggested that a feeding tube be inserted into the stomach to give the person nourishment through the tube. Recent expert opinion² is that feeding tubes are not advisable for people with dementia. There is no evidence that they prolong life, prevent aspiration pneumonia, or improve the quality of life of the person with end stage dementia, which are the usual reasons for inserting them.

The decision about whether or not to use a feeding tube is very complex, and needs to be considered carefully for any person with dementia. Sometimes if tube feeding is started, a decision needs to be made when the person is dying to stop the feeds, because otherwise death will be more uncomfortable. The decision to stop feeding is often more emotional and difficult than the decision to start the feeds. Careful spoon feeding, with food and fluids of the right texture, allows a person living with dementia to enjoy the smell and taste of the food for as long as they are willing and able to eat.

Weight loss

Weight loss is commonly associated with the final stages of dementia. Earlier in the course of the illness weight is lost because the person is too restless to eat, or does not recognise the food and doesn't eat enough.

In the end stage of dementia, weight is lost **despite the person being given adequate amounts of food and fluids**. This is due to complex changes in the body due to advanced disease. This kind of weight loss also occurs when a person has advanced heart, lung or liver disease, or advanced cancer. Weight loss due to advanced illness, including dementia, cannot be reversed, even if food supplements such as fortified drinks are offered.

Infections and fevers

A person with dementia who is eating and drinking less and unable to walk has a weakened immune system. The likelihood of an infection increases. *Repeated infections are one of the signs of end stage dementia.* Developing a fever, a change in behaviour or an increase in confusion due to delirium are signs that a problem has emerged.

Common sites of infection are the bladder and /or kidneys (urinary tract infection) or lungs (pneumonia). The chance of the person with end stage dementia having pneumonia is very high. About 40% (4 in 10) people with end stage dementia can be expected to have at least one episode of pneumonia.

Infections of the lungs or urinary tract can make the person extremely ill (septic). *These infections are often the cause of death in end stage dementia.*

Treatment of an infection will depend on the goal of care. If the goal of care is to prolong life, then strong antibiotics, possibly provided intravenously (IV) via a drip line into a vein, or as an injection into the muscle (intramuscular or IM injection), will be given.

Prolonging life by giving antibiotics is not always possible. A time comes when the burdens of giving IV or IM injections, which include possible transfer to hospital for the antibiotics; pain due to the injections; and an upset stomach and loose bowel motions caused by the antibiotics, outweigh any benefits from the antibiotics.

The alternative choice is to provide palliative (comfort) care at this time. Antibiotics may be given by mouth if there is a chance they will increase the comfort of the individual with the infection.

Other treatments to maintain comfort include pain medication (analgesics) and medications to dry up secretions. Extra oxygen may be used if required. Care can usually be given in the residential care facility.

Pain

As many as 80% of older people living in residential care facilities are known to have pain from conditions like arthritis. Most of them, even those without dementia, don't say anything because they think that feeling pain is normal. It is every person's right to have his or her pain assessed and managed so they are comfortable. If the person you know with dementia has a painful condition like arthritis, always tell the GP so any pain treatments can be reviewed.

In the last few months of life, distressing pain affects about 40% (4 in 10) of people with end stage dementia. Pain is difficult to assess when the person with dementia cannot respond to questions. As discussed earlier, signs of distress include a change in the person's behaviour (an increase or decrease in an existing behaviour, or a new behaviour starting). Everyone who knows the person with dementia well can have a role in observing for possible pain, and making sure he or she is kept comfortable.

Management of pain

Mild pain can be managed using simple measures such as changing the position of the person in the chair or bed, massaging, distracting the person by playing music, or taking them in a wheelchair outside, as well as giving medications.

The individual's GP will prescribe the safest and most beneficial medication if pain is present. If pain persists, strong medications and treatments will be discussed and started if needed.

Shortness of breath

Shortness of breath (dyspnoea) is a distressing symptom that may be present for some of the time in almost half of people with end stage dementia. Treatment should be discussed with the doctor so plans are made to manage the breathlessness if it is distressing. Extra oxygen may be given for a period to help keep the person comfortable.

Pressure ulcers

Pressure ulcers are also known as *bed sores* or *decubitus ulcers*. They are mainly due to lying or sitting in the one position for a long time so that pressure on one spot cuts off the blood flow to that area. The skin in the area starts to die, and ulcers can develop, which can quickly enlarge. Most commonly affected sites are the bony areas on the body, particularly the skin over the tail bone (coccyx), hip bones, heels and elbows.

Pressure ulcers can be difficult to treat and have severe complications, including infections and abscesses. To prevent pressure ulcers, the person needs to be moved regularly so that they are lying or sitting in a new position to protect the skin in the risk areas. Often aids like air mattresses are used to distribute the body pressure evenly and keep the blood flowing to the areas where pressure ulcers might start.

Unexpected events

Unexpected medical events can occur to any person, including a person with severe or end stage dementia. Some of these events may include heart attacks, strokes, falls that cause injury, seizures (fits) and problems associated with other medical conditions the person has. This group of problems can lessen the quality of life of the person with dementia, without actually being the cause of death.

The unexpected events may require admission to hospital for investigation (often quite invasive) to find out their cause and provide treatment. How unexpected events are managed will depend on the goal of care for the person with dementia. Goals of care are discussed on the next page.

Goals of care

Doctors always have a goal in mind when they order a medical treatment. Some treatments are given with the goal of curing disease, prolonging life or avoiding premature death. Other treatments are given to maintain functioning, or relieve suffering and provide the best possible quality of life for the patient.

It is important to remember two things about medical care for a person with dementia. Firstly, **no matter what treatment people with severe or end stage dementia need and receive, it will not improve their brain function. Their deteriorating health is due to dementia which is not curable.** Secondly, medical treatment provided to any person, with or without dementia, is based on the clinical judgement of the treating doctor(s). Doctors are under no obligation to provide treatment that is burdensome and of no benefit to a patient. Patients or their family members cannot demand medical treatment that offers no benefit to the patient.

The goals of medical care will change over time for a person with dementia. Early in the illness, care is focussed on slowing the dementia progression, improving or maintaining the functioning of the person with dementia, and supporting the carer. The broad goal of care can be thought of as *full treatment possible*. The person with dementia is given all care possible, to prolong their life, including being hospitalised if necessary for investigations, treatments, and surgery if indicated for co-existing conditions. However, more aggressive treatments aimed at prolonging life, like using ventilator machines to keep a person breathing, are not necessarily appropriate and may not be given.

As the brain fails due to the dementia, the goals of care slowly change. The emphasis shifts from keeping the person alive and prolonging life, to making sure the person is safe, comfortable, and having the best possible quality of life.

The goal of care becomes *limited additional interventions*. Some life-prolonging treatments are offered to support the person, such as IV or IM antibiotics, intravenous fluids for dehydration, and nutritional supplements if the person has weight loss that can be reversed.

Unexpected events such as a fractured hip following a fall are treated with surgery if necessary, because treating the hip fracture will keep the person comfortable.

Limited additional interventions are an appropriate goal of care for people with moderate to severe stage dementia.

As a person approaches end stage dementia the goals of care move away from using any treatments that may prolong life, towards using interventions that improve comfort. This goal of care can be thought of as *palliative (comfort) care*.

A person with dementia receiving *palliative (comfort) care* will be actively monitored to see if symptoms like pain, breathlessness or agitation occur. If the symptoms are causing problems, they are managed so the person is comfortable.

The doctor may still want pathology tests and other tests done, but they are done only if knowing the result leads to an intervention that improves comfort.

Palliative (comfort) care is given until natural death occurs. It is the most appropriate goal of care for a person with end stage dementia. The person receives careful assistance with eating and drinking while they are willing and safely able to swallow. Oral antibiotics may be given, only if they assist in managing discomfort. Transfer to hospital generally does not occur and is often not advisable for people with end stage dementia.

If a person with end stage dementia is living in a residential care facility they may be enrolled in a special program, called Namaste Care, where they will receive high-touch care individualised to their needs that is designed to stimulate their senses, and honour the spirit within the person. Namaste Care results in respectful end of life care for the person with dementia.

From reading this booklet you will realise that major health issues face a person with end stage dementia. Planning for those issues can relieve anxiety and guilt for the *person responsible*, and other people close to the person with dementia. This process is called *advance care planning*, and is discussed in the next section of this booklet.

Advance care planning is all about talking ... about the future health care of a person. The point of talking about future health care for a person living with severe or end stage dementia is that medical care for both expected and unexpected health issues can be considered well before a crisis. In this way, decisions can be made calmly, based on what the person with dementia's wishes would be if they could talk for themselves. Misunderstandings and possible areas of conflict can be dealt with so everyone comes to a clear and agreed understanding about the care to be given to the person with dementia.

Advance care planning

Usually a number of advance care planning discussions are needed. Key times when a discussion might be held are when the person with dementia is diagnosed with a new medical condition that will impact on their health, after a hospital admission, or on admission to a residential care facility. Topics that might be discussed, depending on the circumstances, include:

- the values, wishes, beliefs and expectations of the person with dementia regarding what quality of life means to him or her. The *person responsible* and other family and friends contribute by recalling conversations and events where the person with dementia indicated their beliefs.

- the role and importance of the *person responsible* as a substitute decision-maker. This person needs to “put himself in the shoes of (the person with dementia)” and make decisions from that person’s viewpoint.
- the understanding of everyone involved about the dementia diagnosis, and what may happen in the future.
- benefits and risks of any treatment options.
- the goal of care, so the person with dementia will have the best possible quality of life, with their wishes respected.
- the person with dementia’s preferences for end of life care.


Making decisions about another person’s health care is a major responsibility. Some families prefer more than one person to help with the decision-making. However, the *person responsible* is the person who legally can consent to, or refuse consent for, any treatment, so that person has the final say. By involving other family members in advance care planning discussions, the *person responsible* can make sure everyone concerned understands the issues and the reasons for decisions.

Asking questions

As stated earlier, the more the *person responsible* and family members know about dementia and the changes that occur over time, the more likely it is that the person with dementia will receive care that respects their wishes and improves comfort and quality of life. Asking lots of questions can help.

Some questions to think about and discuss with other family members or close friends, your GP and other health professionals:

1. Would the person I know with dementia want to be transferred to hospital for *full treatment possible*?
2. Would the person I know with dementia want to have intravenous antibiotics for every infection, which might make their life longer but will not improve their memory or function? What about if that meant they would need to go to hospital, would they still want the intravenous antibiotics, or would they prefer to remain in their home (including a residential care facility), receiving comfort measures which could include oral antibiotics?

- 
3. If the person I know with dementia had a heart attack, would they want to have treatment to try to restart their heart if it stopped?
 4. If the person I know with dementia had a stroke and couldn't swallow, or they were having difficulty swallowing due to the effects of the dementia, would they want a feeding tube inserted into their stomach?

Some people want to continue to provide a lot of care to their loved one after they move into a residential care facility. Other people prefer not to help at all. If you want to share care, please discuss your involvement with the staff at the facility.

Even though the person with dementia may not be able to talk to you, there are a number of things you can do while visiting to express your affection and concern. You could consider:

- massaging the person's hands, feet or scalp;
- reading a favourite book, newspaper, or letter from another family member to them;
- talking to them about family and community life;
- bringing in photographs from times you've shared and reminisce out loud;
- playing some favourite pieces of music;
- bringing in some favourite food and giving the person a little taste of it. Even if the person with dementia can no longer swallow properly you can put a little taste on the end of their tongue, using a cotton bud or similar.

Regardless of whether or not you are involved in the care of the person living with dementia, be assured that the best possible care will be given to them.

Your involve- ment in the care of the person with dementia living in a residential care facility

The dying process

In spite of good care, and regardless of where that care is given, the time will come when the person with dementia becomes so sick that they are likely to die.

The next section of this booklet contains information about this stage of life. This may be difficult for you to read, so if you have any questions or concerns after you read it please discuss them with the health professionals caring for the person with dementia you know, your religious or spiritual advisor, or contact one of the support services listed on the back cover of this booklet.

No-one can tell you exactly when death will occur. In the final stages of dementia, signs such as swallowing problems, weight loss and muscle weakness together point to the fact that the general health of the person is getting worse.

A person with end stage dementia may also become uninterested in food and fluids. It has been suggested that this is also a sign that the body is beginning to prepare for death.

Any infections the person has been experiencing may continue throughout these final months of life, and will be treated according to the agreed goals of care for the person.

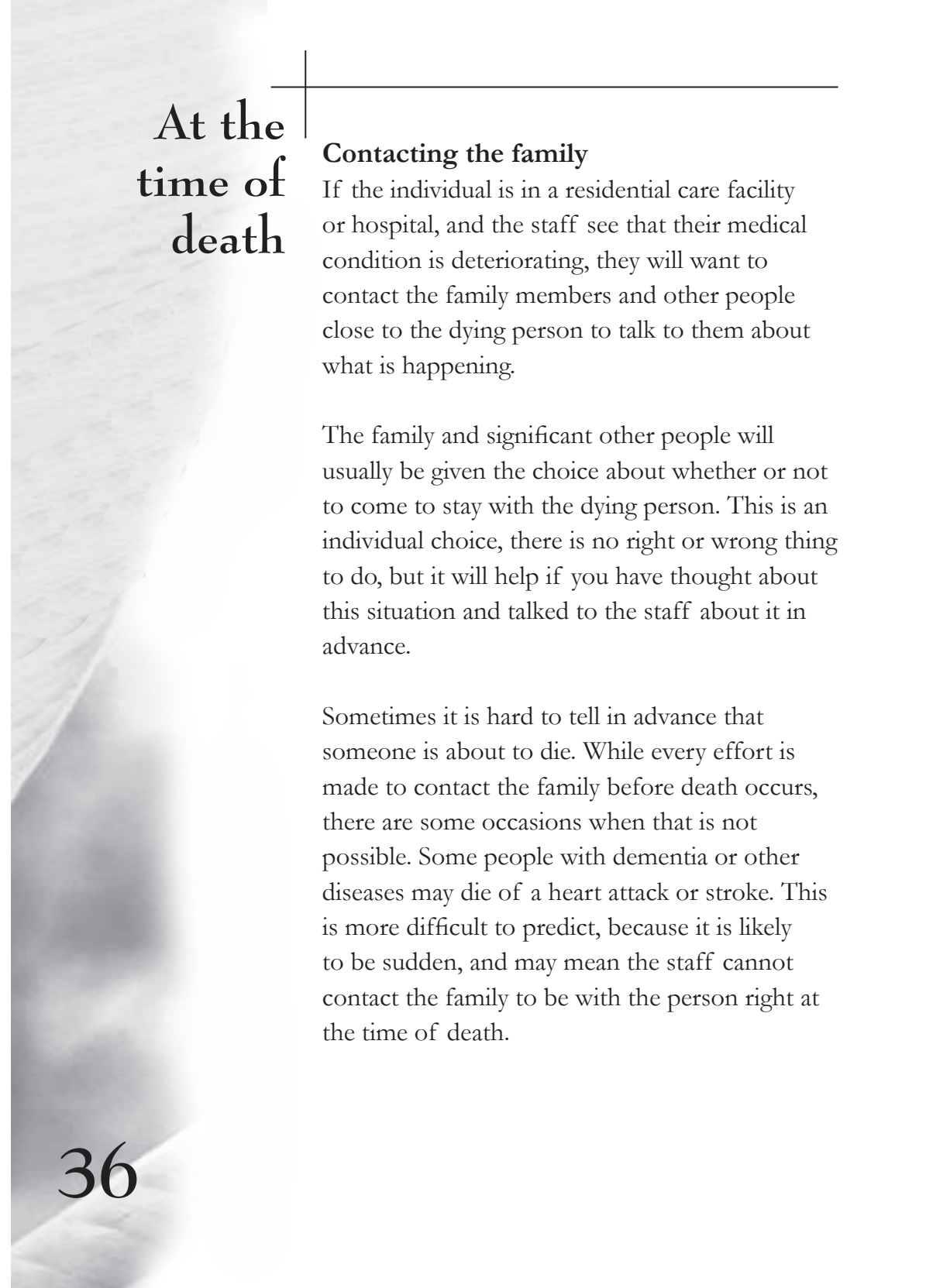
Eventually no amount of treatment, with antibiotics or any other method, even if the person is in hospital, will prolong life.

The person will no longer want to eat or drink, and may seem to sleep all the time. A person who is no longer eating or drinking may continue to live for a few days, sometimes even longer. Gradually over the final days or hours the person may slip into a coma and be unable to respond to anything. It may be difficult for you to come to terms with, but once the person is in a coma they will usually die within a short period of time.

The doctors and nurses looking after the person with dementia will do everything possible to keep them comfortable during this time. This may include giving medications or extra oxygen to improve their comfort. The nurses will keep their mouth moist, the skin clean and dry, and will reposition them every few hours. They will not experience hunger at this late stage of life.

You can help at this time should you wish to do so. Simple acts like massaging the person's hands and feet, and keeping their lips moist with lip balm can add to their comfort.

Playing soft music, keeping the light dimmed in the room and noise kept to a minimum can all add a sense of peace.



At the time of death

Contacting the family

If the individual is in a residential care facility or hospital, and the staff see that their medical condition is deteriorating, they will want to contact the family members and other people close to the dying person to talk to them about what is happening.

The family and significant other people will usually be given the choice about whether or not to come to stay with the dying person. This is an individual choice, there is no right or wrong thing to do, but it will help if you have thought about this situation and talked to the staff about it in advance.

Sometimes it is hard to tell in advance that someone is about to die. While every effort is made to contact the family before death occurs, there are some occasions when that is not possible. Some people with dementia or other diseases may die of a heart attack or stroke. This is more difficult to predict, because it is likely to be sudden, and may mean the staff cannot contact the family to be with the person right at the time of death.

Issues immediately after the person's death in a residential care facility or hospital.

If no relatives are present at the time of death, one of the nurses caring for the person will invite them to the facility or hospital to spend some time with the deceased person. The family are under no obligation to come in if they prefer not to.

Some families prefer not to be contacted overnight but request that they be informed of the death the next morning. This is a personal decision. There is no right or wrong thing to do, but it is always better if the family can advise the staff of their preference.

The GP or hospital doctor is contacted to attend to the legal documents. In some facilities and hospitals the staff call the appointed funeral director to make plans for the deceased person to be taken into their care. In other facilities, the family are expected to contact the funeral director themselves, so again it is important for you to talk to the staff about your own circumstances and arrangements.

Death is never easy to talk about. Even health professionals with a great deal of experience have difficulty thinking about death and talking

about it. If the person with dementia is living in a residential care facility then the staff may have spoken to you about the funeral many months or years previously. Although you may choose not to discuss this issue, you are **strongly** encouraged to make some preliminary plans in advance. Even when death has been expected for a while, at the time you may still feel shocked and numb. Decisions about the choice of funeral director, type of service (burial or cremation), who will officiate, whether you want music or readings, and who will speak about the deceased person can be planned in advance.

Looking after you - the carer

If you are looking after a family member or friend with dementia you are a carer. To be able to carry out your role as a carer you need to maintain your own physical and emotional health. This may involve seeking assistance and support with everyday caring needs. Taking time off from your caring duties and having time away from the person you care for is also vital.

Being conscious about your own diet, exercise and ensuring you get enough sleep will keep you strong and help to maintain your resilience. If your health begins to deteriorate, you may not be able to help your loved one.

From reading this booklet you know that dementia is an incurable condition. Most of us can never prepare ourselves fully for the death of a relative or loved one. Everybody involved in the care of the person with dementia will have a different way of coping with his or her death. Although you will feel pain and sadness when the person with dementia is no longer with you, in time you will be able to remember the happy times you had together.

When the one you have cared for has died, you may feel at a loss as you adjust from being a carer. You may find yourself reminiscing on the past instead of focussing on the future. There are many support services available to help you get through this time, some of which are listed on the back cover of this booklet. Your GP, religious and spiritual advisors can help you through this difficult time. Please do not hesitate to call them.

Glossary of key terms

Alzheimer's disease

Alzheimer's disease is a progressive, degenerative disease that affects the brain. It is the most common form of dementia. Approximately 50% to 70% of all dementia is Alzheimer's disease.

Aspiration pneumonia

An acute inflammation of the lungs, caused by breathing in infected material such as saliva or gastric material.

Coma

Complete unconsciousness, when the person has lost all reflexes and cannot respond to stimuli such as pain or speech.

Dementia

Dementia is the term used for a loss of intellectual capability (called cognitive function) that affects:

- memory and learning;
- attention, concentration and orientation;
- thinking (eg problem solving, abstraction);
- calculation;
- language (eg comprehension, word finding);
- geographic orientation.

Dementia is a sign of brain disease, and has about 100 known causes.

Dementia with Lewy bodies

A type of dementia similar to Alzheimer's disease. Abnormal spherical structures, called Lewy bodies, develop inside nerve cells in the brain, and cause degeneration and death of the nerve cells. Visual hallucinations, tremors and stiffness similar to Parkinson's disease, and fluctuations in mental state are typical of this condition.

Dysphagia

Difficulty with swallowing.

Fronto-Temporal Lobar Degeneration

A group of dementias which have degeneration of one or both frontal or temporal lobes of the brain. Includes Pick's disease. Effects may include changes in personality, emotions, behaviour, and use of language, depending on what part of the brain is affected.

Vascular Dementia

A type of dementia caused by a variety of problems that affect blood flow to the brain, which results in multiple strokes. Vascular dementia is the second most common form of dementia after Alzheimer's disease.

References

- ¹ Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN et al 2009. The Clinical Course of Advanced Dementia. NEJM Vol 361 No 16 pp 1529 – 1538.
- 2 Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. Cochrane Database of Systematic Reviews 2009, Issue 2.

For further information or support, contact:

National:

Alzheimer's Australia Helpline - 1800 100 500.

Website: www.alzheimers.org.au

Commonwealth Carelink Centre--1800 052 222.

Website: www.comcarelink.health.gov.au

Commonwealth Carer Resource Centre

1800 242 636.

Website: www.carersnsw.asn.au

Lifeline - 13 11 14

Palliative Care Australia

Website: www.pallcare.org.au

NSW:

TARS The Aged-Care Rights Service

1800 424 079

Grief Support Inc. - 9489 6644

Salvo Careline - 9331 6000

Palliative Care NSW - 9282 6436.

Website: www.palliativecarensw.org.au

Guardianship Tribunal - 1800 463 928.

Website: www.gt.nsw.gov.au

Local:

Your General Practitioner

Your local Dementia Advisory Service