

DEMENTIA

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

2nd Edition

BLUE MOUNTAINS
DIVISION OF GENERAL PRACTICE

University of
Western Sydney
Bringing knowledge to life



SYDNEY WEST
AREA HEALTH SERVICE
NSW HEALTH

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 select the sections that are of interest to you at the moment.

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For further copies of this booklet contact:

Professor Esther Chang
Director of Research
School of Nursing, College of Health and Science
University of Western Sydney
Locked Bag 1797
Penrith South DC
Penrith NSW 1797

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

Some information provided in this booklet may be distressing to you. Please take this booklet home with you to read, and talk over any issues you may have about dementia with your General Practitioner or other health professional. It may also help you to discuss any concerns you have with a close family member or friend.

By reading this booklet and discussing the issues raised you will be better able to understand what is happening to a person with severe or end stage dementia, and you will feel more informed if you need to make decisions about future care.

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

It can be very difficult and distressing for the family and friends of a person with dementia who is progressively becoming more frail, not able to talk or recognise loved ones.

This booklet has been written for two reasons:

1. to give information about what to expect as dementia progresses, and
2. to encourage you and the person with dementia to consider some of the issues that health professionals will need to discuss with you.

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 General Practitioner (GP), other health professionals assisting in the care of the person you know, including staff of the residential aged care facility if the person is living in one, or telephone the Alzheimer's Association. Their number is located on the back of this booklet.

Types of dementia

‘Stages’ of dementia

When you read about dementia, or speak to health professionals about the disease, you may notice that a number of terms are used to describe the ‘stage’ of dementia.

Some people will talk to you about ‘early’, ‘middle’ and ‘late’ stage; others about ‘first’, ‘second’, and ‘third’ stage; or ‘mild’, ‘moderate’ and ‘severe’ stages. When discussing the final stages, terms like ‘advanced’, ‘severe’, ‘terminal phase’, and ‘end stage’ dementia may be used.

There are no clear definitions of when a ‘stage’ starts or ends. Each disease is as different as the person who is living with it. In this booklet, we are specifically talking about the most advanced stages of dementia, when a person needs care 24 hours a day, 7 days a week, and is usually living in a residential aged care facility.

The terms ‘severe’ stage and ‘end’ stage are used to group the most common symptoms and signs together to make the effects of the disease easier for you to understand.

Time frame for dementia

Dementia is unpredictable and varies from person to person so it is important to bear this in mind. No two people with dementia will be identical, and the symptoms found in a particular stage of the disease will not follow a set pattern, or a set time period. This may be frustrating for you, because there will be times when you want a clear answer to a question such as “how long will the person with dementia be like this?”

As a general guide:

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

One thing that is known is that dementia is a progressive disease that cannot be cured. It is a sad fact that people with dementia will have a shortened life span because of their disease. The actual cause of death will probably not be the dementia. Rather, other diseases that the person has, or complications that arise due to the inevitable changes the dementia causes will be the probable cause of death.

The changes that occur as dementia progresses will be discussed in the next section of this booklet.

Who can make decisions about the medical and dental care of people with dementia?

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 general practitioner or nurse caring for the person you know 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, and another person will need to make decisions about the medical and dental care on behalf of the person with dementia.

It is important to consider who is legally able to make healthcare decisions on behalf of another person.

In NSW the Guardianship Act (1987) refers to a person able to make lawful substitute consent as a 'person responsible'. Under the Act this person need not be the next of kin, but either a guardian (appointed by the person with dementia when they were well enough to make health related decisions for themselves); a spouse or defacto spouse (including a same sex partner) with a close relationship to the person; an unpaid carer (someone who does not receive a wage for being a carer of the person) who provides support to the person with dementia; or a relative or friend who has a close personal relationship with the person.

Severe and end stage Alzheimer's disease and similar dementias

On average, the severe and end stages of dementia may last for three years or more, so any deterioration discussed in this section may be very gradual.

Changes to the brain start to occur to people with dementia from the early stages of the disease onwards. Changes in the brain cause changes to occur in four major areas:

- cognitive ability (the way the person thinks and remembers);
- functional ability (the way the person looks after their basic needs like bathing, dressing and eating);
- behaviours (the way the person acts) and emotions (feelings); and
- physical ability.

Each of these areas will be considered in turn. Remember that we are discussing here common changes that may be seen. The person with dementia may have a number of changes that can be noticed in one area of their life, and less in another area. They may also experience symptoms that are not listed here.

Cognitive (thinking) ability

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 disease progresses.

In the severe stage of the disease, 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 begin to lose the ability to communicate by talking. At first the sentences will become jumbled, then the words themselves may become jumbled. (A person with Frontotemporal Lobar Degeneration may have language problems from early in the disease process);
- will lose the ability to solve problems, start tasks and carry them through, or understand requests from other people.

As the disease progresses the person will experience a further decline in their cognitive skills.

They may not recognise anyone, including even a spouse or other close relatives and friends; the ability to communicate by talking will get steadily worse, until only a few words are left that can be said, or the person may be unable to speak at all. Instead of talking, people with end stage dementia may sometimes make strange sounds, or even scream out. 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 people in this stage of dementia may not be able to talk to you in a meaningful way by this time, they will still be aware of your presence, and you can still provide comfort to them.

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

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

Bathing and Grooming

People with dementia need more and more help to bathe and groom as the dementia progresses. Earlier in the disease process, the person may have been able to complete some of the task while being reminded what to do. However, as the brain function continues to deteriorate, 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 during this time, and become resistive (fight against having care attended), or insist they have had a shower when they haven't. In the end stage of the dementia the individual may not even seem to be aware that grooming is being attended.

Sleep

During the severe stage of the dementia the sleep cycle may become disturbed, so that the person may be awake at night and frequently dozing during the day. The dozing during the day will happen more and more often during the end stage, until the person will appear to be asleep more than awake.

Walking and movement

People with Dementia with Lewy bodies may experience difficulties with walking, and falling, quite early in the disease process. For other types of dementias, the ability to walk around will be gradually lost as the dementia advances into the severe stage. 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 find ways to prevent them. Eventually the person will forget how to use the frame or walking stick and the ability to walk around at all will be lost. When that happens, the individual with dementia will need to spend most of the time sitting in a chair. Muscle weakness and deconditioning may cause a further change, so that towards the end stage of dementia the ability to sit up and hold their head up may also disappear, meaning that the individual will be more comfortable in a water chair or bed.

Facial expression

People with end stage dementia may have their ability to smile or show any expression on their face affected, because the muscles are too weak, and the brain is affected by the disease. Even at this stage, they are able to interact with the environment. They will be able to feel the touch of your hand, or a breeze blowing on their face, and the ability to hear will remain, so music and laughter and family stories and the sounds of activity around will be heard.

Toileting

The ability to go to the toilet without help will be lost as the dementia advances. One of the first changes that occurs to people with dementia is that they become disoriented, and cannot find the toilet. As time progresses, they forget to complete the usual activities associated with toileting, like flushing the toilet and washing their hands. Gradually they will forget why they need to go to the toilet and become incontinent, firstly of urine. What this means is that they may start to wet their pants and need to wear pads all the time.

The forgetfulness and problems with mobility eventually lead to the person with dementia becoming unable to use the toilet for bowel motions. In the end stage of dementia, they will be incontinent of both urine and faeces. The nurses or family members caring for them will need to give them medication or other treatments so their bowel movements continue normally.

Eating

Difficulties with eating and swallowing also occur during the final stages of dementia. Initially people with dementia will need help to feed themselves, because the confusion from the dementia will stop them remembering what to do.

They may seem to be 'playing' with the food, mixing it around and staring at it instead of eating it. The time will come during the severe stage of dementia, when other problems with eating begin. The food may be held in the mouth for a long time without swallowing (called 'pouching'), or the food may be chewed and chewed, as if the person has forgotten how to swallow it.

As the damage to the brain from the dementia continues, further swallowing difficulties are noticed. People with dementia at this point in the disease may seem to be choking when they eat, or be coughing a lot after eating, and need to be assessed for a condition known as dysphagia.

A Speech Pathologist may be called in to complete this assessment. It is very important that dysphagia is recognised and care taken with food and fluids, or there is a chance that the food and fluids may go down the wrong passage and enter the lungs. This can cause a condition called aspiration pneumonia.

The food texture may need to be changed so that it is mashed up or pureed. All fluids that people with dysphagia drink need to be thickened so they can be swallowed.

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 food and fluids. Recent expert opinion¹ is that feeding tubes are not advisable in severe or end stage dementia. There is no evidence that they prolong life, prevent aspiration pneumonia, or improve the quality of life of people in this stage of dementia, which are the usual reasons for inserting them.

The decision about whether or not to provide people with dementia with a feeding tube is very complex, and needs to be considered carefully. The staff in residential aged care facilities are very experienced in providing the right type and amount of food and fluids to a person with end stage dementia, and know how to feed them correctly.

The ability to swallow is commonly the last of the functions to be lost. When this happens, it is often a sign that the final stages of the disease are being experienced, and death may be expected to occur in the next few months or so, although this does not always happen. Again, it must be stressed how unique each person's experience of dementia is.

Symptoms associated with behaviours (actions) and emotions (feelings)

These symptoms are extremely common, and can be the most difficult of all the symptoms experienced for everybody concerned. Some of the symptoms listed here occur much earlier in the course of certain types of dementia. 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. Any behaviours that are causing distress to a person with dementia need to be assessed and medical advice sought so that treatment can be started once the cause is established.

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 aged care facility);
- being sexually disinhibited (having inappropriate sexual behaviour);
- appearing to be depressed, apathetic and withdrawn (having no energy, emotions or interest in what is happening around them);
- being aggressive or violent;
- not allowing carers to look after them (known as being resistive).

Monitoring behaviour

Behaviours are a form of communication for the person with dementia, and need to be monitored and treated if possible so the person is comfortable.

The people who know a person with dementia best, such as the family members, friends, and health professionals who see the person regularly are often in the best position to be able to work out the cause of the behaviour. After all, they know what the person was like before the behaviour started, so may be able to interpret what's happening.

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 or restrain them.

Physical Symptoms

As people move gradually from the severe stage of dementia to the final, end stage two things frequently happen. Firstly, the number and type of behaviours that have caused distress (either to the people with dementia or to other people seeing them) seem to lessen. Secondly, physical signs and symptoms seem to increase, as the people with dementia stop moving around, and become less aware of their surroundings.

The physical symptoms may be caused by either the dementia, or because the individual has other medical conditions as well as dementia, which are also causing problems.

It is very difficult to assess people in the severe and end stages of dementia for physical problems, because they cannot say what the problem is, or where they may be hurting. As mentioned earlier, a change in behaviour may be the first sign that there is a problem, such as a sore throat or earache. People with severe or end stage dementia need to be closely monitored for signs of pain or discomfort. If you suspect that the person you know with dementia might have pain or a physical complaint please discuss it with the health professionals involved in providing care. Tell them about how the person acted when they were ill in the past, as that might give some clues to what is happening.

Some of the more common physical symptoms are pain, weight loss, infections and uncontrolled limb movements.

Pain

As many as 80% of older people living in residential aged care facilities are known to have pain from conditions like arthritis, and 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 health professionals looking after them so any pain treatments can be reviewed.

Because it is so difficult to assess someone with severe or end stage dementia for pain and other physical symptoms, a team approach is considered best. Everyone can play a role in making sure a person with dementia is comfortable.

Treatments for pain

Treatments for mild pain/discomfort include 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 for a walk, as well as giving medications.

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

Weight loss

Weight loss is also common in the severe and end stages of dementia. Earlier in the disease process weight may be lost because the person is too restless to eat, or does not recognise the food. 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. Some people in the end stage of dementia lose interest in eating and drinking, and refuse the food or drinks offered. This is very distressing for everyone concerned, and needs to be discussed with the health professionals caring for the person.

Infections

As the dementia progresses and mobility declines, the person will stay in a bed or chair for most of the day. They may become more at risk of having infections, particularly of the urinary tract (bladder and kidneys) and lungs (pneumonia).

Sometimes a blood infection may also occur (septicaemia).

Antibiotics can be given for these infections, by mouth (oral), by injection into the muscles, or via a drip (intravenous). Intravenous medications usually mean the person needs to be transferred to an acute care hospital, but this is not always the case. A person in the final stages of dementia may have many of these infections during the last year or so of life. These infections are the most common cause of death from end stage dementia.

Changes in limb movements

A person in the end stage of dementia may develop uncontrolled movements in the arms and legs ('myoclonic jerks') and very stiff limbs. Eventually they may lie in bed in a contracted position, that is, all curled up. Again, these are common occurrences in the final stages of dementia. The nurses caring for the person if they are in a residential aged care facility will frequently turn them to prevent pressure sores (called decubitus ulcers) from forming, and may do some passive limb movements (gentle physiotherapy) each day to help keep the muscles stretched. The GP can be consulted if the muscle jerking is a big problem.

Vascular- type dementias

Our knowledge about vascular dementia is limited at the present time, due to the lack of research evidence available.

A person with vascular dementia is very likely to have a history of heart disease, hypertension (high blood pressure), possibly diseases of the circulation, strokes (cerebro-vascular accidents or CVAs) or transient ischaemic attacks (TIAs – ‘mini-strokes’).

Some researchers believe that vascular dementia slowly progresses like Alzheimer’s disease. Other researchers think people affected by vascular-type dementias go through a series of ‘steps’ as the disease advances, having a decline caused by a stroke or mini-stroke or similar, then remaining stable for a period of time, before having another stroke or mini-stroke. Each time they have one of these episodes their health is affected, with a poorer memory, more behavioural signs, and more problems experienced.

The final stages of vascular dementia are similar to those of Alzheimer's disease, in that the person will become unable to walk, talk or do any of their usual activities like personal care or grooming. Some recent research has shown that while people with Alzheimer's disease experience a decrease in the number of behaviours that might cause distress, a person with a vascular-type dementia may show an increase in behaviours like aggression in the months prior to death. They may also experience an increase in the number of seizures (fits) or mini-strokes in the final months.

People with vascular dementia may die as a result of a large stroke or heart attack before the end stage of dementia is reached.

**Your
involvement
in the
care of the
person with
dementia
living in a
residential
aged care
facility**

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

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 them to express your affection and concern. You could consider:

- massaging the person's hands, feet or scalp;

- reading a favourite book or the newspaper out loud, or read out loud a letter from another family member;
- talking to them about family and community life;
- bringing in some 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.

From reading this booklet you will know that a number of major health events may happen to a person in the final years of living with dementia. These health events could include a fall that results in injury; problems with swallowing food and fluids; repeated major infections; or for some people strokes or a heart attack. The amount and type of treatment the person with dementia receives needs to be considered.

**Important
decisions
about the
health
care of the
person with
dementia**

Ideally, the best time to discuss the likely health events that may occur to people in the final stages of dementia is early in the disease process, while they are capable of making their own health care decisions. A formal discussion can be undertaken, where the person with dementia and their General Practitioner or other health professional can discuss the likely scenarios and complete a document called an 'Advance Health Care Directive' or 'Living Will', and appoint an 'Enduring Guardian' to make healthcare decisions on their behalf.

Other people may prefer to have less formal discussions, where they talk about their values and the things that give them quality of life. They may choose to document their values and ideas in a letter or note. These discussions can guide the family and health professionals when they need to make decisions in the future about health care issues.

It is important to try to involve the person with dementia in discussions about their health care if at all possible.

If the person you know with dementia is incapable of making decisions already, then try to recall conversations you may have had in the past that could indicate to you what their wishes may be. You will be able to use this information to assist you in making decisions. Many people do not discuss their possible health care needs in advance, which makes it very hard for others to decide what is best for them.

The important point to remember is that no matter what treatment people with severe or end stage dementia need and receive, it will not improve their memory. They will not be cured of the dementia, which is the cause of the deterioration in health.

If the person with dementia is living in a residential aged care facility then you may be invited to attend a 'case conference' or 'family conference' to talk with the health professionals about the future goals of care of the person with dementia. Included in this discussion will be information about the person's current health, and potential problems that may arise in the future, such as those outlined in this booklet.

Making decisions in advance about the type of care the person with dementia will receive, and where the care will be provided is very useful. Firstly, the family and friends can consider the potential problems more calmly, as there is no immediate crisis to deal with. Secondly, there is more time to ask questions when a planned conversation about future care needs is held. There is also time to involve many of the people interested in the care and wellbeing of the person with dementia, so that they maintain the best possible quality of life. Finally, decisions that may have been made in the past about the goals of care can be reviewed and changed if necessary.

One way to think about the type and location of care that might be needed is to think about 'levels of medical care'. The four levels described here give you an idea of the whole range of care available. Some care can only be given in an acute care hospital, which would mean transferring the person in the final stages of dementia from their usual living place. This may not be an appropriate choice, because the underlying cause of the problems, the dementia, cannot be improved. The decision about whether to transfer a person from their usual place of residence for treatment requires careful consideration, as the disruption to the person with dementia may outweigh the benefits of any treatment offered.

Levels of medical care

Medical care can be thought of as being available in four levels²:

- An 'intensive' level of care means that everything available to be used to maintain life would be used. Life support (ventilator), antibiotics, transplants, blood transfusions, x-rays and scans would be used to keep the person alive. The person would usually be cared for in an Intensive Care Unit, which means they will need to be admitted to a well-equipped hospital.

- An ‘active’ level of care aims to prolong life but not maintain it indefinitely through life-support technology. This level of care would include elective surgery, investigations such as blood tests and x-rays, antibiotics and blood transfusions if indicated. It would not include using a ventilator, or admission to an intensive care unit. This level of care is also provided in an acute care hospital.
- A ‘limited’ level of care means that only a limited number of options are taken to prolong life. Oral antibiotics, x-rays, oxygen, transfusions, and blood tests would be used. Surgery would be used to offer comfort only, such as if the person had a fractured hip after a fall. The person would not be put on a life support machine, nor have treatment with a kidney machine if the kidneys failed. Some of this level of care would be provided in an acute care hospital. Other aspects of the care could be delivered in the residential aged care facility if the person was living in one.
- A ‘palliative’ level of care aims to keep the person comfortable and pain free, but not to prolong life. This approach aims to give the person the best quality of life possible, but does recognise that the person will eventually die as a result of the disease they have. This level of care may include surgery, if it is aimed at keeping a person comfortable rather than

curing them, and tests and a range of medications would be used to help any symptoms the person was experiencing. This level of care would usually be delivered in the residential aged care facility, unless something unexpected like the need for surgery arose.

You may not know exactly what type, or level, of care the person you know with dementia would want, because you have not discussed it. Many people are in the same position. It is important to have such discussions with your loved ones.

The responsibility to make decisions about future care needs for another person is enormous. Some families prefer more than one person to help with the decision-making. Our intention in giving you this booklet is to provide you with information about the sorts of health problems that may happen to a person with severe or end stage dementia. This can assist you to consider these issues and talk them over with the health professionals, your family and other trusted people.

We are all concerned that the person with dementia lives a comfortable, safe and dignified life. That is why health professionals caring for people with dementia, whether they are from a residential aged care facility or another service, will want to discuss the care from time to time.

-
1. *Would the person I know with dementia want to be transferred to hospital for intensive or active levels of care?*
 2. *Would the person I know with dementia want to have intravenous antibiotics with every infection they had, 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 aged 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 make their heart start again 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 severe or end stage dementia, would they want a feeding tube into their stomach?*

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

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 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 disinterested in food and fluids at this time.

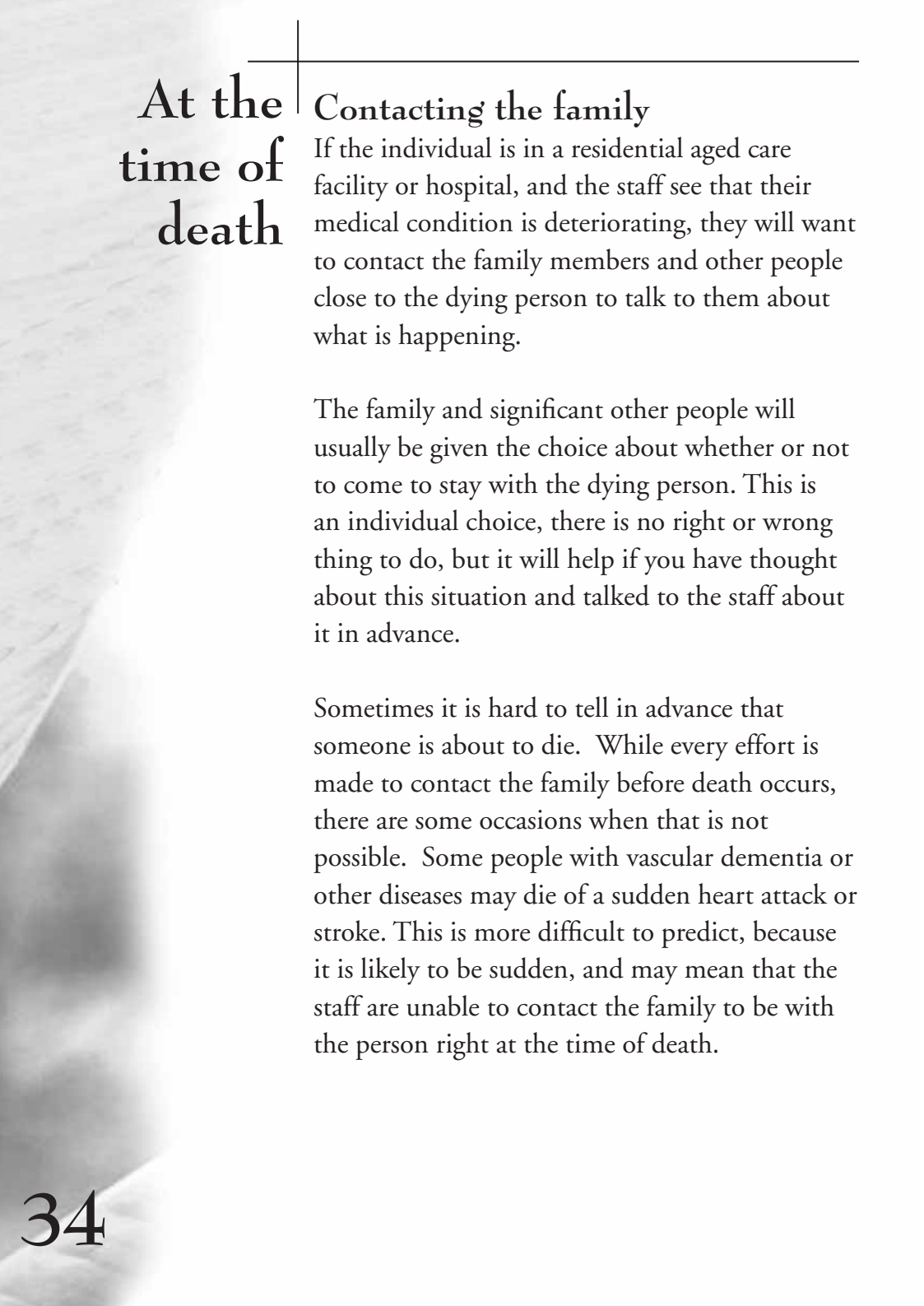
It has been suggested that this is also a sign that the body is beginning to prepare for death. If the person with dementia has other major diseases like heart disease or lung disease, they may die because of these conditions before the final stages of dementia are reached.

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 be able to 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 any more to anything. It may be very 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 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 also if you would like 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 aged 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 vascular dementia or other diseases may die of a sudden heart attack or stroke. This is more difficult to predict, because it is likely to be sudden, and may mean that the staff are unable to contact the family to be with the person right at the time of death.

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

If no relatives are present at the time of death, then one of the nurses caring for the person will contact the family (and/or very close friends) and 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 do not wish to.

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

The General Practitioner 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.

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 aged care facility then the staff may have spoken to you about the funeral many months or years previously. While 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 carer³

In 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. Ensuring that you take time off from your caring duties and having time away from the person you care for is also of vital importance.

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.

As you have read through this booklet you will now be aware that dementia is an incurable disease. Most of us can never really 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. While 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.

You may feel at a loss as you adjust from being a carer. With a lot more time on your hands it is often easy to reminisce on the past instead of focusing on the future. There are numerous support services available to help you get through this time; some of them are listed on the back page of this booklet. Be mindful to accept the support and kindness of family members and friends who are also moving through the grieving process and feeling similar feelings to you. Your GP, religious and spiritual advisors can also help you through this difficult time. Please do not hesitate to call them.

Carer Do's

- ✓ Do get enough sleep
- ✓ Do get plenty of exercise
- ✓ Do eat healthy food
- ✓ Do drink plenty of water
- ✓ Do limit/cease your alcohol/cigarette consumption
- ✓ Do be patient
- ✓ Do keep your own appointments
- ✓ Do keep in touch with your local GP and services
- ✓ Do try to understand that the person with dementia has no control over what is happening to them
- ✓ Do ask about what services may be able to support you
- ✓ Do talk to others who have similar experience

Carer Don't's

- × Don't be afraid to ask 'silly' questions
- × Don't forgo regular meals
- × Don't isolate yourself from friends or family
- × Don't be ashamed to feel frustrated and angry
- × Don't use alcohol/cigarettes as a crutch
- × Don't think you are alone
- × Don't neglect your own health and wellbeing
- × Don't forget to take time to remember the good times

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 to describe 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. ⁴

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 disease.

Fronto-Temporal Lobar Degeneration

A group of dementias, which have degeneration of one or both frontal or temporal lobes of the brain in common; 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.

Dysphagia

Difficulty with swallowing.

Mixed dementia

Many people have a mixture of different types of dementia, such as vascular dementia and Alzheimer's disease, or Dementia with Lewy bodies and Alzheimer's disease. In this case, health professionals say they have 'mixed dementia'. The issues discussed in this booklet are relevant in this instance also.

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 Finucane T CC, Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA*. 1999;282(14):1365-1370.

² This information comes from “My Health, My Future, My Choice: An Advance Care Directive for New South Wales” by Sara Graham, Anne Hampshire, Elizabeth Hindmarsh, Barbara Squires and Sharon Wall. Published in 2003 by the Advance Care Directive Association Inc. Available from the publishers at 18/113 Johnston St Annandale NSW

2038. Cost including postage and handling is about \$15. Used with permission of the authors.

³ Information adapted from “Carer’s Handbook- A practical Australian guide to caring for people who are sick, elderly or who have a disability” by Carer’s Australia and St John’s Ambulance Service. 2002 Camberwell: Dorling Kindersley Ltd

⁴ World Health Organization. Regional Office for South East Asia Mental Health and Substance Abuse Facts and Figures. Alzheimer’s disease Available online at <http://w3.whosea.org>

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

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