



The later stages of dementia

In the later stages of dementia most people become increasingly frail. Knowing what to expect can help people with dementia and their carers prepare. There is usually time to think through some of the issues that are likely to arise in the final stages.

Symptoms in the later stages

Each person with dementia will experience the illness in their own individual way, but there are some common symptoms that may occur in the later stages.

Memory loss

People with dementia will eventually experience severe memory loss. This means, for example, that they may be unable to recognize people, identify objects or find their way around their own home.

It is important to remember that although memory may be affected, the person with dementia will still be able to appreciate and respond to outside stimuli such as music, scent and touch, for example.

Physical dependence

People with dementia gradually lose their ability to walk, wash, dress and feed themselves unaided. These symptoms may begin by the person walking unsteadily or bumping into things. A stroke, arthritis or the effects of a fall may also have an impact on mobility. An occupational therapist can advise on aids and adaptations that may make surroundings safer. Carers can seek advice on how to help the person move more easily.

Please contact the DEMENTIA SA Office

Support | Awareness | Education | Counseling | Training | Resource centre | Advocacy
info@dementiasa.org or support@dementiasa.org *www.dementiasa.org*

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Eating



Most people with dementia lose weight in the later stages. Occasionally people eat too much and put on weight. The person with dementia may need help with eating and drinking.

If chewing and swallowing are a problem because the muscles and reflexes are no longer working properly, a speech therapist may be able to help. Ask the GP for a referral. For more information see the advice sheet on *Eating* from Dementia S.A.

Incontinence

Many people with dementia lose control of their bladders. Some may also lose control of their bowels. Contact your GP for assistance. For more information see the advice sheet on *Continence* by Dementia SA.

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Communication

In the later stages the person with dementia will experience problems understanding what is being said. They may gradually lose their speech, or they may repeat a few words or cry out from time to time. It is important to remember that communications is more than verbal language.

It may be possible to pick up clues to the way the person with dementia is thinking and feeling by being aware of their body language, the expression on their face and the way they move and hold themselves. For more tips see the *Communication* advice sheet by Dementia SA.

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Unusual or puzzling behavior

The person with dementia may, at an earlier stage of the condition, have exhibited what may have appeared to be unusual behaviour. This might have included 'wandering' or pacing. They may have been aggressive because they felt threatened.

As the dementia progresses and reaches a later stage, such behaviour usually diminishes or vanishes.

Health Risks Immobility

If someone remains in the same position for too long due to immobility, it is possible that they will develop pressure sores. It is therefore important that they shift their position frequently. For more information see the advice sheet on *Pressure sores* by Dementia SA.

As people become less mobile they are also more likely to become vulnerable to infections and are at greater risk of developing a blood clot on the lung.

Carers might try helping the person with dementia to walk. They may also think about helping the person with dementia to do arm and leg movements in a chair – so long as they don't find this distressing. A physiotherapist can advise on safe forms of exercise.

Illness or discomfort

Someone in the later stages of dementia may have another illness but they may be unable to tell their carers that they feel unwell or are in pain. A sudden change in behaviour or an increase in confusion is often a sign that something is wrong. If you suspect that the person is ill contact the doctor immediately. Even if the person is not ill, they may still be in discomfort. They may be constipated, have sore gums, or their shoes may be uncomfortable, for example.

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Medication

The side-effects of certain drugs can sometimes increase confusion. There is also some evidence that people in the later stages of dementia have been over-prescribed certain drugs, such as tranquillisers, in residential and nursing homes.

If carers are concerned about any aspects of the person with dementia's medication they should talk to their doctor. It may be possible to change the drug or alter the dose.

Pain and discomfort

When someone reaches the final stages of life one of the main concerns is to try to ensure that they are as comfortable and as pain free as possible. Carers may wish to discuss their concerns with the doctor or nurse caring for the person with dementia.

Carers' needs

If you are caring for someone with dementia you will need to find ways of taking care of your own needs.

Talking helps

Try not to keep your negative emotions bottled up. It is always better to express your feelings in a safe environment with someone you can trust.

A social worker, day centre worker, doctor or other professional may also be able to offer counseling. Think about contacting other carers. They are likely to know exactly what you are going through. A phone call to a fellow carer when the strain is getting too much can help a great deal.

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You can contact other carers through Dementia SA. Dementia SA runs support groups where carers can meet together to offer each other support. They will be able to give you help and advice.

Involve other people

You may want to think about involving other family members or friends in the care of the person with dementia. Other family members may simply not realize what you are going through, or may not be aware of the ways they could help.

You might consider having a special family meeting or a meeting with friends of the person with dementia, where the practicalities of caring are discussed.

Take breaks

As a carer you will need to take regular breaks. This might mean getting someone to stay with the person you are caring for while you catch up with friends, or just have some time to yourself.

It may also mean taking time to take a short holiday, a weekend away or a week or two on your own. There are more formal respite schemes.

Many residential homes or nursing homes take people for short stays of up to three weeks, giving you an opportunity to have a proper holiday.

Ask your GP, social worker or community nurse for information about local respite care.

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Look after your own health

Many carers postpone sorting out their own health problems indefinitely as it never seems to be a good time as far as the person with dementia's needs are concerned. Once again, you need to look after yourself for their good as well as your own.

Make sure that you seek help for any of your own health concerns as they arise. Have regular medical and dental check-ups.

It may seem obvious, but eating as well as you can and getting enough exercise will make you more able to cope.

Who can provide terminal care?

Most people who reach the final stages of dementia will be in residential or nursing care. Some may be in hospital and a few may still be at home. It is worth thinking through the issue of where the person with dementia will be cared for in advance. In the earlier stages of dementia the person affected may be able to express an opinion about where they would like to be cared for in the future.

Home

If the person with dementia is going to be cared for at home it is important to find out whether adequate community nursing will be available. Check with the GP.

Care homes

Some homes are prepared to care for people at the end of their lives. However, interventions (see below) available in a hospital may not be available in a residential or nursing home.

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Hospices

Hospices typically cater for people with terminal illnesses such as cancer, although some do care for people with dementia.



Hospitals

If the person with dementia is admitted to hospital because they are dying from another illness, ensure that the doctors and staff are aware of the dementia.

If the staff are not used to dealing with someone with dementia, carers may need to discuss this with the nurse in charge of the ward. The person with dementia will need reassurance and, as far as possible, a clear explanation of what is happening to them.

Interventions

Medical interventions may include resuscitation after a heart attack, antibiotic treatment for pneumonia, or giving food or liquids other than by mouth. If the person with dementia needs some form of intervention there may be a discussion about whether to try to prolong their life.

Although only the doctor can make the final decision about whether to give or withhold treatment the views of carers of the person with dementia should always be considered.

In the early stages of their illness the person with dementia might have written what is known as an advance directive (or living will) giving instructions on those interventions that they would or would not wish to be carried out towards the end of their lives.

A living will is a way of outlining the treatment and care the person with dementia would like in the future, when they may not be able to communicate their wishes.

They can say whether they would consent to a particular form of treatment, for example. In the absence of a living will carers, family members and medical staff may try to assess the 'quality of life' of the person with dementia. This is always a difficult issue. Our ideas of what constitutes 'quality of life' are likely to differ widely.

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It is also important to be aware that resuscitation may be unsuccessful in people in the final stages of dementia, and that even where it is successful there is a risk of causing further brain damage.

Death certificates and cause of death

Despite the fact that dementia is a life-shortening illness, other causes of death may be given on the death certificate. This is because the actual death may be triggered by another condition.

Recent research has shown that the three most common causes of death in people with dementia are pneumonia, heart attacks and blood clots on the lungs. The person with dementia is likely to be very frail towards the end of their lives. Their inability to cope with infection and other physical problems will be impaired. In many cases death may be hastened by an acute illness such as broncho-pneumonia. In many instances people die of natural causes.

Depending on the circumstances and the practice of the doctor, dementia may be entered as the sole or main cause of death, or as a contributory factor. Dementia should always be mentioned on the death certificate – if it is not you should ask the doctor to include it. In some people no specific cause of death may be found apart from dementia and ageing. If the person is over 70, age may be given as a cause of death, together with dementia.

Many people die of other causes such as cancer or heart problems before they reach the final stages of dementia and these conditions will then be given as the cause of death. People who are affected by vascular dementia are more at risk of dying from a stroke.

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Coping with death

Grief is a very individual process. Some carers describe how they feel they have already grieved for the person they knew before the dementia came into their lives and report little grief.

Others find it hard to remember the many happy years of their relationship together and find their minds are full of thoughts of a difficult and stressful final phase of their life together.

You may find that it helps to talk over your feelings with family, friends or professionals.

Former carers

It may feel difficult to begin to restart your life after the person you have been caring for dies. You may have given up your job or lost contact with friends or even family during the person's illness. Other carers may be able to help you as you pick up the pieces and make sense of the experiences you have been through.

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