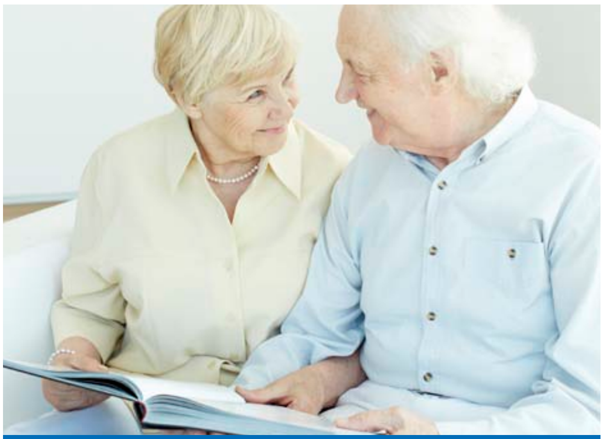
Understanding late stage dementia

Understanding dementia



Alzheimer National Helpline
1800 341 341

About this factsheet

This factsheet is for relatives of people diagnosed with dementia. It provides information about what to expect as dementia progresses to late stage. It aims to help families to understand some of the issues that can arise and to know where they can go for support and services.

How does dementia progress?

Dementia is a progressive condition and currently it cannot be cured. Each person's experience with dementia is unique, and that means it is not possible to know exactly how a person's dementia will progress, or how long they will live with dementia.

How dementia progresses is influenced by a number of things:

- the type or cause of dementia, (e.g. Alzheimer's, vascular or Lewybody);
- age when dementia develops;
- general health and well being; and
- other illness or health issues that may emerge.

In general, it can be useful to think about dementia as moving through stages; early, moderate and late stage dementia. For most people, there is a gradual progression through these stages and there is time to adjust to the changes that can occur.

What is late stage dementia?

Late stage dementia can also be called advanced or severe dementia. It usually means a person has had dementia for some time and so there is now significant damage to their brain. This means high levels of support and care are needed.

Symptoms of late stage dementia

During the later stages of dementia, people become increasingly frail. The damage caused to the brain means that a person with dementia can no longer do many of the things they used to do.

The following gives an outline of symptoms that may emerge. Not every person with dementia will experience all of these symptoms and usually the symptoms emerge gradually.

A person with late stage dementia may:

- **experience significant memory loss.** They may not be able to recognise those close to them or identify everyday objects. As a result they may feel vulnerable and unsure as to what is happening. Reassurance and maintaining a calm environment is important. A person may have moments of recognition and connection and this can be an opportunity to engage. Ongoing engagement is valuable.

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A person with late stage dementia may:

- **believe they are living in a time from their past** and may ask for someone from that time. This can be an opportunity to talk about their past and people or places they knew and loved. See our factsheet on activities for ideas and tips about reminiscence and life story books.
- **find it difficult to communicate with speech.** It is important to continue to talk to the person, tell them your news or talk about areas of interest or read from a favourite book, even if you are unsure they understand. People with dementia often continue to communicate through their expressions, body language and emotions after they loose their speech.
- **gradually lose the ability to walk and move.** Falls can be common. Families need support to help a person to move without injury, particularly if a person becomes confined to a bed or a chair. There are strategies and equipment that can help, an occupational therapist or physiotherapist can advise.
- **need help and encouragement eating and drinking.** Supporting a person to eat foods they want and enjoy can help. Small regular snacks may be better than set meals. However, eventually, chewing and swallowing can become more difficult as the muscles and reflexes are not working as they should. This can cause a person to choke or develop chest infections. Food textures may need to be changed and drinks thickened. A referral to a speech therapist or a dietician for advice is important.
- **become incontinent.** A person may loose control of their bladder and their bowel. It is important to get support from your doctor and / or public health nurse to get advice about continence aids and how to prevent and manage infection.
- **doze regularly during the day** and eventually may seem to be asleep more than they are awake. This is common during late stage dementia and can be difficult for families to adjust to. Talk to your doctor or nurse if you have any concerns about prolonged sleeping.

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A person with late stage dementia may:

- **behave in ways that seem unusual.** This can include periods of restlessness and agitation and repetitive movements. They may also experience hallucinations where the person believes they see, hear, feel or taste things that are not there. It is important to talk to your doctor or nurse about changes in behavior and how best to provide support.

  Changes in behaviour can be a form of communication. They could be a response to pain or discomfort. Mouth and dental care and undiagnosed infection such as a urinary tract infection can be areas that need to be checked. If a person has a painful condition such as arthritis they may need a review so their pain can be assessed and managed. Sometimes simple steps like changing position and massage can be effective.

It is important to know that while this is a very difficult part of dementia and is a signal that the person is moving into the final part of their life, a person with late stage dementia can know that they are loved and cared for. A smile, a caring touch, music or hearing a kind voice can ensure they feel safe and comfortable.

Family and friends often have important knowledge of a person's life, their preferences and their wishes. Sharing this knowledge with those who are providing care can lead to good care and a quality of life throughout the journey with dementia.

Family members, particularly those who are caring for the person with dementia, will need help and support. This help can come from family, friends, health and social care professionals and services.

For more information about tips and strategies to support a person with late stage dementia and to find out about who you can talk to about accessing supports and services:

- **speak with your doctor or nurse**
- **call 1800 341 341**
- **visit www.alzheimer.ie**

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Caring during the final stages of dementia

As dementia moves into the final stage, it can be difficult to know how to meet your loved ones needs and spend time with them. It is important to know that people's emotional memory can remain present even during late stage dementia. This allows people to enjoy interactions with people and sensory experiences, particularly those that relate to things they previously enjoyed.

The following suggestions may support you to continue to spend time with your relative during this stage of dementia.

Adapt your communication style.
90% of all communication takes place through non-verbal communication such as gestures, touch and facial expressions. People with advanced dementia, who have lost their ability to verbally communicate, can still often interpret and express themselves through these avenues of communication. Similarly, hearing the voices and laughter from family and friends allows a person to be in familiar company and share conversations with the most important people in their lives.

Tailor the environment to the interests or preferences of the person. This can allow the person to emotionally and positively relate to things that they previously enjoyed. Whether it is the smell of their favorite flowers, the feel of satin sheets, their favorite radio programme or a crisp breeze, these experiences can capture the individuality of the person, evoke pleasant memories and provide comfort and assurance to the person.

Simply being present with the person.
This allows for human connection which can be hugely rewarding and reduce the person's feelings of isolation. However, if sitting in silence feels awkward, introducing music or reading aloud a favorite book or both of you just holding a significant object (i.e. wedding ring or seashell from a recent holiday) can help to put a focus to the time you spend with the person.

Medical care during the final stages of dementia

When a person reaches the final stages of dementia, the goal of care focuses on dignity and quality of remaining life.

There are a range of options which can help address the changing needs of the person. Health care will focus on ways to ensure a person is comfortable and ways to provide relief from pain and other distressing symptoms.

In the final stages, people with dementia can have complex care needs. The medical team will determine if certain medical interventions would be effective or not, and if they could cause unnecessary discomfort. This includes interventions such as feeding tubes and Cardiopulmonary resuscitation (CPR). At certain times, the health care team may seek advice from specialist palliative care experts to help them to determine the best care.

These care decisions may also influence the decision to send a person to hospital. A transfer to hospital can be very distressing for the person with dementia and should only be arranged when absolutely necessary. If a transfer to hospital does happen, the needs of the person should be clearly communicated to hospital staff so they can provide the best possible care.

Family members can discuss all aspects of care with the health care team, including the decision to transfer to hospital. You can seek information from the doctors and nurses to ensure you understand the care that is being provided and are confident that your relative is receiving care that maximises quality of life.

Who is responsible for making medical care and treatment decisions?

A person with late stage dementia will be unable to make decisions about their own medical care and treatment options. In this situation, a person's doctor will check if the person has set out their wishes and preferences in an Advance Care Plan (this can also be known as an Advance Care Directive or a living will). The doctor will respect the Advance Care Plan unless there are specific circumstances that lead the doctor to conclude that the plan should not apply.

If there is no Advance Care Plan and the person has late stage dementia then the doctor will be in charge of making medical decisions on behalf of the person. While a family member does not automatically have the authority to make healthcare decisions for a relative, they can often share valuable information with the doctor about the person's wishes and preferences.

When a doctor is making medical decisions on behalf of a person with late stage dementia they should consider:

- the person's past and present wishes if they are known,
- the views of other people close to the person who may be familiar with the person's preferences, beliefs and values, and
- the views of other health care professionals involved in providing care.

You can talk to the doctor about your knowledge of your loved ones wishes and preferences and they should take this into account when making healthcare decisions.

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For more information

- talk to your doctor
- read the Medical Council guidelines “The Guide to Professional Conduct and Ethics for Registered Medical Practitioners “ at **www.medicalcouncil.ie**

Advance Care Plans

An advance care plan is made when a person has the capacity to make and express their wishes and preferences about the care they would like in the future, which is usually in the early stages of dementia.

For more information when and how to develop an Advance Care Plan you can read our booklet **I have dementia... How do I Plan for the future** which as available on **wwww.alzheimer.ie** or by calling **1800 341 341.**

The Alzheimer Society of Ireland

The Alzheimer Society of Ireland’s National Helpline

Helpline: 1800 341 341
Email: helpline@alzheimer.ie
Website: www.alzheimer.ie

The Irish Hospice Foundation

Call: 01 6793188
Visit: www.hospicefoundation.ie

Notes

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The Alzheimer Society of Ireland, ASI, has taken great care to ensure the accuracy of the information contained in this factsheet. ASI is not liable for any inaccuracies, errors, omissions or misleading information. The factsheet was part funded with a grant from The Irish Hospice Foundation.