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In the late stage of dementia, the changes in the person with the diagnosis become more pronounced to the point that they are unable to live independently.

They may need an extensive care package in place – for example, daily visits or live-in care from professional carers – or to move into a long-term residential care home.

This can be the most difficult stage of dementia for the person's partner, family and friends.

Seeing the changes in the person can be very upsetting, and making decisions about long-term care may cause feelings of loss and guilt, particularly if they previously made promises to their loved one about how they would be cared for in late stage dementia.

These are some of the changes you might expect in someone who is in the late stage of dementia.

Collapse all

Communication difficulties

The ability to communicate is significantly reduced in late stage dementia. The person may only be able to speak a few words and have difficulty understanding what people say to them.

Initially, they may be able to interpret gestures and non-verbal communication but eventually even this will become difficult.

Disorientation

The person with dementia may lose the concept of time and believe they are still a child or young person.

They may become unsettled in their home – even if they have lived there for many years – and feel a strong need to ‘go home’, usually to their childhood home.

The person may become very distressed when this belief is challenged.

This type of disorientation is often particularly intense towards the end of the day, when it is known as ‘sundowning’.

#### Loss of recognition

Loss of recognition is common in late stage dementia. The person may no longer be able to recognise their partner, family members or friends. They may think they are strangers and become quite distressed when they try to offer assistance or perform any sort of personal care.

They may expect to see family and friends as they looked many years ago (for example, believing that their adult child is still school age), and their current appearance could cause confusion or fear.

When they see themselves in a mirror or reflection, they may not recognise themselves. They may believe a stranger is looking back at them and be frightened or think there is an intruder.

*Most of the time my husband did not recognise me as his wife. He thought he was having an affair with me, and every evening felt very guilty and wanted to go home to his wife. This broke my heart but I kept reminding myself it was dementia making him feel that way.*

– Family carer

#### Distress

A person with late stage dementia may show distress by crying, pacing, screaming or shouting. This may be due to fear, anxiety, depression or difficulty understanding what is happening.

The person’s distress may be exacerbated by how their partner, family and friends behave towards them and communicate with them, for instance if they are impatient with them or try to correct them if they say or do something wrong.

#### Physical changes

As dementia progresses to the late stage, the changes to the brain can lead to physical problems including:

- mobility issues, with increased risk of falls
- infections, which may cause delirium (a state of intense confusion)

- incontinence
- difficulty with eating, drinking and swallowing

*My wife is now confined to bed and can only move into a special chair using a hoist. She is uncommunicative and needs help in every aspect of her personal needs. She is still with us, but no longer here.*

– Family carer

Coping with late stage of dementia

Even in the late stage of dementia, there are still many things that the person can enjoy, so it is important to focus on these rather than on the deterioration in their condition and how much time they have left.

For instance, music, art, spending time in nature, audiobooks or being read to, or simply spending time with family, friends or pets may continue to give enjoyment, help the person relax, and provide opportunities to make the most of time together.

Sources of support

To speak to a dementia specialist Admiral Nurse about late stage dementia or any other aspect of dementia, please call our free Dementia Helpline on 0800 888 6678 (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm), email [helpline@dementiauk.org](mailto:helpline@dementiauk.org) or book a telephone or video call with an Admiral Nurse in our virtual clinics.

- Tips for better communication
- Recognising the late stages of dementia and moving towards end of life care
- Understanding dying
- Looking after yourself as a carer