



## Section 9

# Later stages of dementia

The Dementia Guide is for anyone who has been impacted by any form of dementia. The information in this guide is divided into sections. Each section relates to a particular stage of your dementia journey.

It is important to remember that everyone living with dementia is unique. The content in this guide is general in nature and we recommend you seek professional advice in relation to any specific concerns or issues you may have.

While we strive to keep content accurate and up-to-date, information can change over time. For updates, please visit [dementia.org.au](https://dementia.org.au) → or call the **National Dementia Helpline** on **1800 100 500**.

Web: [dementia.org.au/the-dementia-guide](https://dementia.org.au/the-dementia-guide) →



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**I feel like I've sort of got a closer relationship with my wife. It's rewarding emotionally to be able to help someone. ”**

Rob, a Dementia Advocate who is a family carer.

## Section 9

# Later stages of dementia

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**Scan** the QR code to find out more about Rob's story or visit:

**[dementia.org.au/news/meet-rob](https://dementia.org.au/news/meet-rob)** 

Most people in the later stages of dementia will need total care. It can be difficult to accept this final stage of the disease, but planning can make it a little easier.

Advance care planning allows you to express your care preferences at a time when you are still able.

Advance care plans can be oral or written.

It can be a positive and empowering process to go through soon after your diagnosis. You can let people know your wishes in case decisions need to be made on your behalf in the future.

Your family and carers can then honour your values and choices. It helps to reduce their worry and stress when it comes to treatment in times of crisis.

# Understanding palliative care

Palliative care is specialised care and support for people with a life limiting condition.

It focuses on relieving a person's symptoms in the advanced stages of their disease. It can also provide emotional and practical support to family members and carers.

People who deliver palliative care include:

- general practitioners
- specialist doctors, such as oncologists, cardiologists, neurologists and respiratory physicians
- nurses
- allied health professionals, such as pharmacists, occupational therapists and physiotherapists
- social workers
- grief and bereavement counsellors
- pastoral care workers.

# Supporting your needs with palliative care

## Providing personal comfort

There are active ways that palliative care can provide comfort. This can include:

- changing body positioning
- mouth care
- assisting with difficulties in breathing
- skincare
- bowel management
- mobilisation
- spiritual and cultural care
- music and aromatherapy
- massage
- pain management.

## **Managing symptoms**

How your symptoms are managed depends on the stage of your dementia and whether you have other medical conditions.

With symptoms management, there can be difficult decisions to make. Your family and carers will need to consider your wishes and values. They should also consider the following questions.

- How useful will the treatment be?
- What choice will promote the best comfort?

## **Managing pain**

Pain management is an important aspect of good quality care. There should be an ongoing, person-centred approach to recording, assessing and managing your pain.

## Supporting nutrition and hydration

Advanced dementia can lead to a reduced desire to eat. It can also make eating and swallowing difficult. There is no evidence that artificial nutrition or hydration helps prolong life or provides a peaceful death.

## Managing antibiotics

Decisions about taking antibiotics need to be made in context and on an individual basis.

When the time is right, your palliative care will need to be organised by your family members, carer or health professional.

Visit [palliativecare.org.au](https://palliativecare.org.au) → for state office contact details and further information.



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**When it comes to dementia,  
health and taking care  
of yourself, it's a journey.  
Persistence pays off.  
There are big things we  
can't control but try and  
do the little things better.** ”

Val, a Dementia Advocate who lives with dementia