

Dementia

Home death

This factsheet is written for primary care practitioners that have not had the opportunity to support a home death for a person living with dementia (PLWD). The factsheet is a guide to understanding how aged care and palliative care sectors work together, and the planning required to ensure services are in place early. Either of these services will support the family to understand death and dying and plan for the home death.

What services are required to support a home death?

It is important to encourage the family unit to plan early. Services required include:

- Home Care Package through [My Aged Care](#) – a PLWD can receive a dementia supplement, which provides more hours per week
- support for carers through the [Carer Gateway](#) - emotional support and additional respite care
- [NDIS](#) for PLWD under 65 years.

Local health and other services:

- pharmacist
- palliative care services
- funeral director
- spiritual support people and engaging with specific cultural practices that provide for a good death.

What are the key health and family needs?

Carers

For older carers, the risk of exhaustion is particularly high. Families and carers may consider a mix of supports:

- a schedule of in-home respite in the months leading up to the death, through their Home Care Packages and Carer Gateway
- developing a schedule of family or friend support for the carer in the last weeks and days.

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Health needs

The two most common health needs for a PLWD no longer managing at home with their carer relate to incontinence and behavioural changes. All behaviours are need-driven and observation of the behaviour by the carers will usually reveal what the need is - for example, dealing with pain, toilet seeking - thirst or hunger. If families are supported early to manage these needs, a home death is more achievable.

These supports are through:

- Home Care Packages Registered Nurse (RN)
- Community Health Continence Specialist RNs
- [DBMAS \(Dementia Services Australia\)](#)

What do in-home services do?

Home care packages and palliative care services are available to support carers and a PLWD in the home. It is important to understand which service provides what element of care.

Level 4 Home Care Package (HCP)

This support provides:

- nursing and end-of-life support
- equipment such as a hospital bed, home modifications or continence aids
- in-home respite and home help
- dependent on the amount in the person's package, potentially BD to TDS visits particularly in the last days for support such as hygiene needs and turning.

Specialist palliative care services

HCP staff may refer to specialist multidisciplinary palliative care services who provide symptom management (for example, for pain, restlessness, nausea) and equipment related to symptom management such as syringe drivers.

Palliative care staff will contribute to the visit schedule, particularly in the last days, to ensure symptoms are effectively managed.

They will also provide important education and advice about:

- medication regimes to ensure the primary carer and family understand how to manage oral and potentially SC medications in the last days
- terminal needs of the PLWD, for example, moving them in bed safely, managing dry mouth and eye hygiene.

Grief, loss and bereavement

The PLWD and family unit will experience many losses throughout the dementia journey. Guidance to understand and manage their grief and loss is provided ensuring spiritual and cultural needs are incorporated. The palliative care team specialises in bereavement support and early identification and assessment of abnormal grieving with referral on to specialist support.

Who will be there when the person living with dementia dies?

Potentially the family will be on their own, so it is important to educate them about the dying process. Families have access to varying levels of after-hours support from the HCP or palliative care service. Each service will outline their availability to the family.

Many families, if prepared well, find it peaceful to have this time to themselves as the next few days after the death are full of activity and are emotionally exhausting. Spiritual advisors are an important part of this time of reflection and grieving.

Resources for palliative care and home deaths:

[HealthPathways – Palliative care](#)

includes local referral pathways

[CareSearch - Planning for a home death - GPs and dying at home](#)



Learn more:
hnc.org.au/PCIdementia