

Providing care at home



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Getting support

If you decide to care for someone with a life-limiting illness at home, it is important to recognise your limits and only do what you can reasonably expect of yourself at this time. You may reach a time where the person you are caring for has physical needs that are beyond your capacity. This may necessitate having additional care support come into the home or for care to be given in a different environment such as a care facility or hospital. It may be better for everyone if physical care can be delivered by skilled professionals so that you have more time to offer your love, and personal and emotional support.

There are number of service providers offering in-home support that also provide specialist Palliative Care. In addition to providing nursing care, a community nurse visiting can provide guidance and advice to you and person you are caring for as well as help coordinate care from other services, health and allied professionals.

Preparing the home

Caring for someone at home may necessitate the need to rearrange rooms, use additional fittings and equipment or even make some structural changes.

Changing the home can be disruptive to other family members, so having a discussion to consider everyone's needs first is important. The arrangements you make may need to change as the person's condition changes.

It is best to discuss your needs with a healthcare professional as you may be eligible to loan equipment through a local service provider.

They can also make referrals to physiotherapists or occupational therapists who are well-placed to review the physical needs of the person you're caring for and suggest what will make the home safe for everyone.

An occupational therapist can identify strategies to make your caring role easier, safer and maintain quality of life for the person you are caring for. Occupational therapists have expertise in changing the way you do important daily activities and manage fatigue, pain, breathlessness or memory changes by education,

task redesign, prescribing specialised equipment and creating a more accessible home environment for the patient and carers. They may also help minimise the risk of falls, manual handling injuries and pressure injuries.

They may suggest hiring equipment, such as:

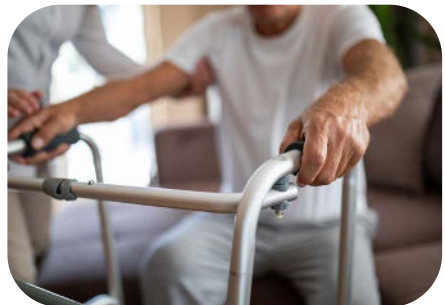
- Walking frames or walking sticks
- Wheelchairs
- Ramps and handrails
- Shower chairs or commodes
- Toilet raisers and surrounds, to assist with getting on and off the toilet
- Pressure relieving products, such as an air mattress
- Bed rails, for ease of movement and preventing falls
- Tables designed to sit over the top of the bed
- Washable incontinence sheets to protect the mattress
- Bedpans and urinal bottles
- Hospital beds
- Hoists to assist with getting in and out of bed.

Setting up the bathroom and toilet

Ensure there is easy access to a toilet and ideally a bathroom close to where the person you are caring for spends most of their time. You may need to ensure there is room for a bedside commode if they cannot get to the bathroom.

Space can be tight in a bathroom when you are helping someone to shower. If you have a drain hole in the bathroom floor, you might find it easier to shower them seated on a plastic shower chair or stool outside of the shower cubicle using a flannel and warm water. Another space saver is changing the way the bathroom door swings, so it opens out of the room rather than into it.

Non-slip mats can make floor tiles safer, particularly if they are slippery when wet. A raised toilet seat with hand rails can make it easier to sit down or get up from the toilet.



Setting up a space for the bed

Consider where the person you are caring for will sleep or spend most of their time. If they are mostly in bed, they might enjoy having their bed set up somewhere aside from the bedroom, where they can still feel part of everyday life. If the person can move around safely from their bedroom, think about setting up a comfortable chair or day-bed in the living room, ideally with a garden outlook or another interesting view.

If they start finding it difficult to get into or out of bed, seek advice on what specialised equipment might make it safer and easier. For your benefit and theirs, reduce trip hazards and make getting around easier by removing unnecessary furniture and floor rugs away from the bed.

A small table that can be positioned over the bed is useful for meals and other activities. If they are confined to bed reduce how often they may need to call on you for help by ensuring they can reach items such as a drink, telephone, television and radio controls. Having a radio, music centre, computer or television will help to maintain contact with the outside world and provide entertainment.





A small chair near the bed is useful for visitors and for the person to sit on while you make their bed. You may need a small table or drawer for medical equipment or dressings to keep them clean and dry, and a convenient place for medications that is safely out of the reach of any children.



You are unlikely to be sitting with them the whole time, so it can be reassuring for them to know they can reach you for help if they need it. A simple bell or baby monitor alarm, which you can hear from any part of the house or garden, might bring you both peace of mind.

Useful contacts



Australian Indigenous Health InfoNet

-  (08) 9370 6336
-  healthinfonet.ecu.edu.au/learn/health-system/palliative-care



Cancer Council NSW

-  13 11 20
-  cancercouncil.com.au



Carer Gateway

-  1800 422 737
-  carergateway.gov.au



Carers NSW

-  (02) 9280 4744
-  carersnsw.org.au



Caresearch

-  (08) 7221 8233
-  caresearch.com.au



Centrelink

-  13 27 17
-  servicesaustralia.gov.au




Dementia Australia NSW

-  1800 100 500
-  dementia.org.au

GriefLine National

-  1300 845 745
-  griefline.org.au



Leukaemia Foundation

-  1800 620 420
-  info@leukaemia.org.au
-  leukaemia.org.au

Lifeline

-  13 11 14
-  lifeline.org.au

My Aged Care

-  1800 200 422
 -  myagedcare.gov.au
-

My Health Record

- ☎ 1800 723 471
- 🖱 myhealthrecord.gov.au

National Disability Insurance Service (NDIS)

- ☎ 1800 800 110
- 🖱 ndis.gov.au

National Stroke Foundation

- ☎ StrokeLine: 1800 787 653
- 🖱 strokefoundation.org.au

NSW Trustee & Guardian

- ☎ 1300 109 290
- 🖱 tag.nsw.gov.au

Palliative Care NSW

- ☎ (02) 8076 5600
- 🖱 palliativecarensw.org.au

Relationships Australia

- ☎ 1300 364 277
- 🖱 relationships.org.au

Services Australia

- ☎ servicesaustralia.gov.au/individuals/contact-us/phone-us
- 🖱 servicesaustralia.gov.au

The Department of Veteran's Affairs

- ☎ General enquiries: 1800 838 372
- ☎ Counselling Service: 1800 011 046
- 🖱 dva.gov.au

If you require an interpreter, contact the Translating and Interpreting Service (TIS National)

- ☎ 13 14 50
- 🖱 tisnational.gov.au

If you have a hearing or speech impairment, contact the National Relay Service

- ☎ 24 hour relay call numbers
TTY/voice calls: 133 677
Speak and Listen: 1300 555 727
SMS Relay: 0423 677 767
- 🖱 relayservice.gov.au

Caring for someone as they approach the end of their life can be both rewarding and demanding. It is hoped that this book will help to explain what caring involves, so you are better equipped to make informed decisions which reflect your needs and circumstances.

You matter.



Palliative Care
NEW SOUTH WALES

Palliative Care NSW

706/50 Clarence St Sydney NSW 2000

(02) 8076 5600

info@palliativecarensw.org.au

palliativecarensw.org.au