

Caring for someone with a life-limiting illness



What do I need to know? Some practical tips

When someone is diagnosed with a life-limiting illness there is a lot of information you may need to help you care for them. This information has been developed in partnership with carers who have shared their experiences and offered suggestions as to what may help.

Navigating services

Getting help and support is important. There are a range of services that can help, but it can be confusing working out what to do next.

Find someone who you can talk to when you are not sure, this might be your doctor or another health professional. You can also call Carer Gateway on 1800 422 737 for guidance.

"It may be overwhelming dealing with different services so it's important to get as much support as you can to help you do this."

Being an advocate

As a carer, it's important that you feel you can speak up for the person you care for and advocate for their needs. It helps to learn as much as you can about how the health system works.

Regularly talking to your health care team and others involved in care is important. Asking questions and being clear about your needs will assist you to understand more and work together.

"Knowledge helps me to be a confident advocate. Don't be intimidated by the system and don't be afraid to ask questions. Let others know what you need."

Accessing palliative care services

Palliative care services help people live their life as fully and comfortably as possible when living with a life-limiting illness. They recognise the carer as a valued member of the care team and are available to provide helpful information to support you, including end of life care. They provide a range of services that can help with managing symptoms. Symptoms may be physical, emotional, spiritual or social. It can be useful to think of this type of care as quality of life care. For more information on palliative care services available in your local area, ask your GP, or visit

www.palliativecare.org.au/directory-of-services

Workplace and financial information

It's important to discuss your situation with your employer and negotiate any necessary changes. You may need more flexible working hours or time off. It's also important to know your rights as an employee, which can be found on our website www.carersnsw.org.au

Some carers may experience financial hardship. It can be difficult to juggle caring with paid work, and the extra costs related to illness and disability can be enormous. Financial support may be available through Centrelink and other organisations. For further information visit www.carergateway.gov.au/financial-help

Planning ahead

Preparing as much as you can and being aware of what can happen will help you focus on supporting the person you care for at this very important time. Your health care team can help you prepare and discuss the options available for end of life care.

When planning care, your wishes should also be considered. If you and the person you care for both want care to be in the home until they die, you'll need a good support network to help. This network may include friends, family, your GP, community nurses and other services that provide care in the home.

Knowing the wishes of the person you care for is called Advanced Care Planning. It can help reduce stress and anxiety when making decisions on their behalf. It starts with an open and honest conversation about the person's health and care choices. It may include appointing a substitute decision-maker and completing an Advance Care Directive. For further information visit www.advancecareplanning.org.au



“Contact service providers to discuss what can be provided to help you cope at home and what can be done if you are no longer able to care.”

Further information

- **CarerHelp** – provides a comprehensive range of information for carers of people approaching the end of life, including tips on how to physically care for someone at home and information about how to care at the end of life – www.carerhelp.com.au
- **Carer Gateway** – provides access to information, counselling and support for carers – 1800 422 737 or www.carergateway.gov.au
- **Carers NSW** – provides information and support to carers – www.carersnsw.org.au
- Talk to your **doctor**