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## Providing end of life and palliative care for someone at home

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### Summary

- Providing end of life and palliative care for someone at home can be demanding. Support and advice is available.
  - Carers often find their role rewarding, despite the demands.
  - Family carers have varied roles. You can choose what role to take on.
  - You have rights and options as a carer.
  - Everyone involved in providing care for someone needs to understand their role.
  - Know when to contact the palliative care service or your doctor.
  - There are no silly questions when seeking support or advice.
  - There are organisations that offer support and advice.
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End of life and palliative care services can provide you and your relative with home-based care and support. Many people needing end of life and palliative care choose to remain at home. They know their surroundings and may feel they have more privacy and freedom.

However, not everyone will prefer to be cared for at home, and you should not be 'talked into' home-based care if it is not right for you or your loved one.

Community palliative care services offer support including home visits and (in most areas) 24-hour telephone support. Despite the availability of these services, the demands on a carer at home can still be overwhelming.

As a carer you may get frustrated, tired, angry and down at times. This is normal. It is important to seek advice about help that is available to lessen the burden if things are getting too much.

### What do family carers at home usually do?

Some family members or friends providing care like to help with meals, medications and transporting their loved one to medical and other appointments. Others like to provide emotional support – by being there to listen and to comfort their relative. Some carers want to be involved in the more intimate aspects of care such as personal hygiene or bathing, grooming and skin care.

You are not required to take on any of these roles unless you feel comfortable in doing so. If you are not sure, ask the community palliative care team or your doctor for guidance.

Caring for someone requiring end of life and palliative care can be very hard. It can be physically and emotionally draining. Some carers have said they feel like they are on a roller coaster with emotional highs and lows. Some say they get little time for themselves and feel tired. Others have said that they found it hard to get enough sleep and at times felt overwhelmed. These are all normal responses.

### The benefits of being a carer

Carers often talk about very positive outcomes from helping a relative needing end of life and palliative care. Some describe being part of the end of life of a loved one as rewarding and a privilege.

Seeing the benefits can be hard when things are not going so well. Carers may find they feel better when they 'look for the positive' in difficult times.

### Your rights and options when providing end of life and palliative care for someone at home

It is important that you are aware of your rights and options as a carer. These include:

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- accessing information to assist you
- accessing palliative care support and advice
- respite – taking a break from caring
- saying ‘no’ to things you are not comfortable doing
- deciding that you can’t continue with your caring role
- making a formal complaint about unsatisfactory services.

### **Support and care from other family members and friends**

If other family members, friends, or a paid carer are helping, it is important that everyone understands their roles and responsibilities. This will help avoid misunderstandings.

It’s a good idea for you and others involved in providing care to:

- communicate openly and honestly with each other and the palliative care team
- seek to be valuable members of the care team
- have a plan for what to do in a crisis
- create an **advance care plan** with your loved one, if one is not already completed
- discuss and review the advance care plan, if required
- record relevant health-related events
- ask the healthcare team about further support arrangements.

It’s also a good idea for families and carers to:

- undertake disease-specific education and skills training (where relevant)
- consider their own health and wellbeing and seek help as required.

How much support you get and the type of care you receive from your family or friends will depend on your immediate needs, availability of others and what tasks you are all comfortable with doing.

A valuable role some family carers undertake is providing emotional support or help to the primary carer. Have an open and honest conversation with your family or friends about what you are comfortable with. You can decide together on the best plan for your loved one’s care.

### **Caring for someone at home – information about the person’s illness**

A person’s medical history is a private matter but often in our lives we don’t mind sharing this information with people we trust such as a spouse, partner, parent or other relative.

If you are going to be the main carer for your relative, having their written permission to give and receive information about their medical situation will make it easier for you and assist in providing care for your loved one.

Your relative may already have a legal ‘**enduring medical power of attorney**’ in place to enable this. If they don’t, get your relative to state in writing who they will allow to access their medical information, and ask them to sign it and have someone sign as a witness. This will make communication easier when you need to speak to nurses, doctors and other health professionals about your relative’s condition.

For further information on legal matters see the section Planning and decisions for end of life [insert link].

### **When should I contact the palliative care service or GP?**

It’s a good idea to write down questions or issues that are important to you. Then ask yourself, do I want to contact the palliative care team about this issue? Or our GP? It may depend what the issue is, whether it is urgent and if you need an answer in normal business hours or after-hours.

If you are unsure, phone the palliative care team and speak to a nurse, who will help decide if the doctor needs to be contacted. Sometimes there may be more than one doctor or specialist involved in your relative’s care.

Some GP's are happy to provide you with an out-of-hours contact number. Some use a locum service (a temporary substitute GP) when the usual GP is not available. You may want to establish this and the following questions early on in your caring role:

- What is our GP's availability, especially after hours and at weekends?
- Will the GP do home visits?
- What locum does our GP use when they are not available?
- What is the GP's end of life and palliative care experience?

It does not have to be an emergency situation to make a phone call to the palliative care service or GP. However, after hours calls are usually limited to more urgent matters. The palliative care service is there to support you and your loved one, so don't delay in getting further advice if something is concerning you. An early phone call may save you hours of worry.

Don't ever think your question is silly – the palliative care team is used to hearing all types of questions and will always give you a response.

Sometimes questions may not be answered with absolute certainty by health professionals. Supporting someone who needs end of life and palliative care can be complex. Different approaches sometimes need to be tried. This can occur especially if treatment for another condition is active at the same time as palliative care treatment.

It can help to have a plan of action to deal with the issues of concern. You might feel concerned if you need to keep changing your plan, but don't worry – this is very common.

### **Further support**

Being a carer can be a demanding role and it is important to remember that help is always available. Talk to your palliative care team or your local GP. Further information, resources and support are available at the organisations listed below.

For more information on support for carers see the page [\*\*Looking after yourself\*\*](#).

### **Carers Victoria advisory line**

Carers Victoria provides counselling and practical resources to support you in your caring role.

Contact the [\*\*Carers Victoria advisory line\*\*](#) on 1800 242 636 from anywhere in Victoria between 8.30 am – 5.00 pm Monday to Friday (except for public holidays).

Carers Victoria can arrange interpreting services with the national Translating and Interpreting Service ([\*\*TIS National\*\*](#)) if English is not your preferred language.

### **Palliative care guidebook for carers**

Palliative Care Victoria has published a useful guidebook for carers called Supporting a person who needs palliative care: a guide for family and friends.

The book is provided free of charge by [\*\*Palliative Care Victoria\*\*](#).

### **Where to get help**

- Your GP
- Your palliative care provider
- [\*\*Palliative Care Victoria\*\*](#), Tel. (03) 9662 9644

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