



www.carerhelp.com.au



Factsheet 1: Tips for caring for someone at the end of life

We at CarerHelp recognise the needs of people caring for someone facing the end of life. You play an important role and at times it will be challenging. Here is some information that we hope can make the caring role easier for those living in country regions of Australia. Further general information can be found in the CarerHelp Information Pack or on the CarerHelp website.

Travelling for health care

You may need to travel to regional or metropolitan hospitals for health care. It is important to frequently remind health professionals that you are from a rural area and need to travel a significant distance. Find out what options are available and ask for what you need to make things easier for yourself.

“Travelling the 5 hours required planning. It was important to find accommodation suitable, affordable and close to the hospital.”

Some suggestions include:

- Can they schedule appointments together (to reduce the number of trips) or schedule appointments at certain times of the day (to make travel more convenient and avoid accommodation costs)? Peak-hour travel can be stressful, so you may like to avoid these times.
- Are there opportunities to reduce travel and use telehealth or is it possible to see your local GP instead (depending on the issue)? Specialists are often more than happy to have some of the appointments via telehealth after an initial face-to-face appointment.



- Is there someone who can assist with organising accommodation and travel, such as a hospital social worker or care coordinator? Alternatively you might like to use Medistays to find subsidised accommodation. Call 1300 085 036 or email contact@medistays.com.au.
- What financial assistance is available for travel and accommodation? Every state has a Patient Assisted Travel Scheme (PATS) as explained in the [National Rural Health Alliance factsheet](#). In all states and territories except Victoria, this service will bulk bill accommodation.
- If you are very rural or remote, the Flying Doctors Service may also be able to assist you with travel. Discuss this with your health provider.
- If you are Aboriginal or Torres Strait Islander, ask the hospital if there is an Aboriginal Hospital Liaison Officer who can greet you on arrival at the hospital.

“We relied on our local GP in between visits to Melbourne. I made sure I had phone numbers for our Melbourne health professionals and made sure I had plenty of supplies before I left.”

Look after yourself

Many country people pride themselves on their resilience and self-reliance. These are such great traits, but in a long-term or intense caring situation, they can lead to carer burnout, distress and physical illness.

You play such an essential role in looking after your friend or family member. You need to ensure you stay well to continue providing that level of care. It is important to ask for and accept help from others and also let people know if you are finding aspects of caring difficult. Health professionals are there to support you and the person you are caring for. Your general practitioner is a good initial person to talk to if things are becoming very difficult for you.

Check out our [Tips For Staying Well factsheet](#).

Factsheet 1: Tips for caring for someone at the end of life

Important conversations and planning ahead

It is important for anyone facing the end of life to consider some big questions and plan ahead. It is even more important to plan ahead if you are residing in a rural area. You may find it challenging to talk about end of life choices but things always run more smoothly if you have thought about them ahead of time and made a plan of action.

It may be helpful to talk to the person you are caring for about:

- What is most important to them? This will inform their care at the end of life, including where they would like to be when they die.
- If you have to travel suddenly for health care or for an emergency, who will look after other family members/pets/farm?
- If there is an emergency, would they want to be transported to a hospital, or remain at home?

“I had to really advocate for him by showing them his Advanced Care Directive and telling them to stop with all the tests and extra medicines.”





Top tips

1. Look for services in your area. Check out our [Finding Services to Support You factsheet](#).
2. Where possible, make health care appointments so they are convenient for you.
3. Get signed up early (My Aged Care, Carer Gateway, Government financial assistance, NDIS).
4. Ask for and accept help from friends and neighbours. Check out our [Community Supports factsheet](#).
5. Stay connected (helplines, online support, local supports). Check out our [Helplines for Carers factsheet](#).
6. Seek information online on the [CarerHelp website](#).
7. Look after yourself by going to your regular health appointments, taking breaks, and catching up with a friend.
8. Express your cultural, spiritual and individual needs (you are unique, and so are your needs).
9. Have important conversations with the person you are caring for and consider an Advance Care Plan or Advance Care Directive. Check out our [Important Conversations factsheet](#).
10. Develop a list of contacts which includes phone numbers in case of an emergency.

“Pack a hospital bag just in case and leave it near the front door. Pyjamas, toiletries, medical history and medicines list (and medicines), advanced care plan, and personal mementos.”



Emergency Contact Numbers

Make sure you know what to do in an Emergency. Keep emergency numbers somewhere easy to find.

Call 000 in all states and territories across Australia to be connected to emergency services in your local area.

If you are in a very remote location and do not have access to a local hospital visit [RFDS Emergency Royal Flying Doctor Service](#) to find emergency contact numbers and satellite phone numbers for your state/territory.

Additional Contacts

One of the biggest concerns for people caring for someone who is seriously ill is knowing who to call when they need advice or help. Whenever you see a health professional, it can be a good idea to ask them who the best person or service to call is if you need advice or assistance and for what type of circumstance. Create a list of 'Contacts' so that you have these at hand when you need them. Specifically, ask which contacts are available after hours.

If the person you are caring for has been discharged from a hospital, there may be a discharge plan that includes a phone number to call if you need advice or help. Check you have contact numbers before you leave the hospital.

Accessing local health and community services

In your local area, there will be a range of services that can assist you in providing care. Sometimes, these are obvious, but other times, you may have to call them and see what they offer. You may have a social worker or care coordinator who was assigned to the person you are caring for who can advise what is available in your local area. Let people know that the person you are caring for has a life-limiting illness (or terminal illness) so that they can offer you the most appropriate services.

"We hired some in-home nursing services but it was hard to get someone to travel so far and expensive. So we made a private arrangement with a local nurse who was fabulous."

Kat registers for aged care services through My Aged Care. A Home Care Package will enable Georgina to access services from providers in her area (there may be a co-contribution for these services).

Kat calls the local council who offers to provide temporary in-home cleaning. Some local councils are also aged care home care providers and can provide personal care services, Meals on Wheels programs, or respite activities.

Kat speaks to her local Pharmacist when picking up Georgina's medicine. The Pharmacist offers home delivery and also stocks incontinence products, skin care products, bandages for pressure areas, and useful equipment.

Georgina's General Practitioner organises a post-discharge follow up appointment for Georgina and Kat at the local clinic and suggests local services to approach for help. GPs can offer a palliative care approach and are supported by Medicare to have longer consultations to discuss complex issues.

Kat is caring for her elderly mother who is living with dementia, Georgina, and they live together in a rural town. Georgina is being discharged from the regional hospital. The geriatrician at the hospital confirmed that Georgina's dementia is progressing and that her cognitive and physical abilities are declining and she may not be alive in 12 months.

The hospital has referred Georgina to their local Community Palliative Care Service. The nurse visits the house and helps with complex symptom management and discusses Kat and Georgina's goals for the coming months. They talk through the type of practical care Georgina will need and offers equipment that will be necessary.

Kat calls Carer Gateway and they connect her with a carer support group run through her local community health service and counselling in her local area.



As Georgina's condition declines, Kat has to call the Ambulance to assist during a minor emergencies (a fall resulting from delirium). Because the paramedic service had been informed of Georgina by the community palliative care team, they were able to assist without the need for an emergency admission.

Factsheet 2: Finding rural services to support you

Further support

Check out our [Helplines for Carers factsheet](#) which has a list of helplines that may be useful for you as a carer.

Below is a list of additional free resources available to help farmers prevent distress and cope through tough times:

- [National Centre for Farmer Health](#) has many free programs to support farmers' health, wellbeing, and safety. You can even access a psychologist through this organisation.
- [Rural Aid](#) provides support including water, groceries, fodder (hay), workers, financial and counselling assistance to help farmers cope. Call the Counselling Intake Line at 1300 175 594 Monday to Friday, 9am to 5pm.
- [Australian Red Cross](#) offers information on managing stress in tough times, downloadable tip sheets, and links to other resources.
- [The Salvation Army](#) has a network of rural chaplains who will visit you and offer support and also financial assistance to those in crisis. Check online for your nearest Salvation Army or call 13 72 58.

- Rural Financial Counselling Service (RFCS) DAFF offer a free and confidential service that provides farmers with financial and business decisions. [Find a rural financial counsellor](#) in your area or call 1300 771 741.
- [WellMob](#) is a directory of social and emotional wellbeing resources made for Aboriginal and Torres Strait Islander peoples. Resources include other websites, apps, podcasts, videos, social media, and online counselling.

Key websites/organisations

- [Palliative Care state and territory organisations](#) will have information in your state or territory about palliative care services, how to access them and palliative care events that you might find useful.
- [Carer's state and territory organisations](#) will have state and territory-based information, supports, and events for carers.
- [Healthdirect](#) is a government-funded service. It has a service finder on the website to help you find services in your area. There is also a 24-hour number (Nurse on call) for health information and advice. Call 1800 022 222.

State based helplines

Many states have a helpline for patients and their families to receive palliative care advice:

- SA: Palliative Care Connect – Phone: 1800 725 548 (Mon to Fri, 8:30am to 4pm)
- VIC: Palliative Care Advisory Service – Phone: 1800 360 000 (daily 7am to 10pm)
- WA: Palliative Care WA Helpline – Phone: 1800 573 299 (business hours)
- QLD: Pal Assist – Phone: 1800 772 273 (daily 7am to 7pm)
- TAS: After-hours helpline run by GP Assist – Phone: (03) 6165 2348 (daily 6pm to 7:45am)
- NSW, ACT, and NT: Health Direct helpline – Phone: 1800 022 222 (24-hour number)

Emergency contact details	Phone
Emergency services – across all of Australia	000
Emergencies in very remote parts of Australia Royal Flying Doctor Service	
Key specialist doctors and hospital	Phone
Treating specialist doctor	
Treating specialist doctor	
Regional hospital	
After hours	
Hospital social worker or care coordinator	
State based organisations and helplines	Phone
Palliative care member organisation	
Carer member organisation	
Healthdirect (Nurse on call)	1800 022 222
Palliative care advice line	

Local services	Phone
General Practitioner	
Local Council	
Community Health Service	
Palliative Care Australia Service directory	
Aboriginal Health Centre	
Pharmacy	
Aged Care Services	1300 459 190
Carer Gateway	1800 422 737
Community Palliative Care Service	



www.carerhelp.com.au



Asking for and receiving support from your community

It is so important that you have support as a carer. You do not need to do it alone.

Often people think of dropping off a meal as a way to show their support. There are lots of ways for people in the community to support you and often people are wanting to know how they can help you. People in your community may be very willing to help with shopping, providing meals, driving to appointments, cleaning or gardening, or sitting with the person you are caring for while you go out or take a break. Often people want to help but are just waiting to be asked and given direction.

Carers also often report feeling isolated and lonely, so having someone to talk to, to provide some support over a cuppa can be invaluable.

"I remember feeling quite alone at times. People tended to stay away, but I would have liked people to come and just hang out with me."

In addition to family and friends, other options to explore include:

- Ask your local church group whether they have volunteers that can come assist you.
- Ask community organisations such as Country Women's Association, Rotary, Lions Club and cultural centres if they run any programs or have volunteers that may be helpful to you.
- If you own a larger property, you may find there are other people in your community who have particular skills who will help out on the property while you are unable to do so.
- You or a family member who can use 'social media' may already know of a local Facebook or similar group that can tap into connections and those who can provide assistance.
- Often, the nearest post office, library, local council, pharmacy or local store may provide a community notice board that already keeps you connected and abreast of local services to help.

The HELP APP – Technology can help others to help you

You may like to have a look at the [HELP app](#) which can help you to coordinate practical and emotional support. It facilitates the difficult process of asking for help, and enables people in your community know what types of support you would find helpful. You could even ask someone to set it up and coordinate it for you.

You can set up group chats in the HELP APP, or in WhatsApp or Messenger to keep everyone up to date with the person's progress or request assistance.

“Did you know? Other people actually get benefit from helping you.”



Consider placing people and services on the below diagram to help you see all your supports





www.carerhelp.com.au



Rural Patient (and Carer) Information Card

Patient and carer information

Name of patient

Patient preferred language

Name of carer

Carer preferred language

We live in

which is _____ hours drive from

I identify as Aboriginal Torres Strait Islander Prefer not to say

Local services information

GP name

GP contact details

Local pharmacy name

Local pharmacy contact details

Appointment preferences

- Monday
- Tuesday
- Wednesday
- Thursday
- Friday

- Morning
- Middle of the day
- Afternoon
- Avoid peak hour traffic



Patient information and values

Health status summary

- Pain issues
 - Mobility issues
 - Visual/hearing impairment
 - Other
-

Patient wishes/values/priorities

- Maximum time with family
 - Maximum time at home
 - Comfort and pain management
 - Other
-

Carer information and values

My priority or main area of concern

When we travel for appointments,
we need more support with

- Parking
- Accommodation
- Finances
- Getting patient into appointment

I want more information about

- The illness
 - The caring role
 - Medicines
 - Options for place of care
 - Planning ahead
 - Preparing for dying
 - Financial assistance
 - Home care
 - Other
-