

1 Getting Started



Factsheet 1: Questions for the healthcare team

Below is a list of questions based on common concerns that carers of people with advanced disease have. Use them as a starting point for a conversation when talking to the doctor and/or healthcare team.

Questions about the person you are caring for:

What are the symptoms I am likely to see in the person I am caring for? Can you tell me about the physical, emotional, and cognitive symptoms they might have in the future?

What is the prognosis? How long do you think the person has left to live?

What sort of care will the person require from now until their death?

Are there any changes to their treatment or care that I need to be aware of?
Is palliative care an option now?

How can I best help them have a good quality of life?

What kinds of discussions should I have with the person I am caring for? (such as setting up an advance care plan or getting their affairs in order)

Questions about where to provide care:

Is home care an option? If not, where is the best place for care to be provided?

Will I need any additional equipment for home care? Are there any changes or modifications at home that I will need to consider?

Who can help me to provide care at home?

If home care does not work out or becomes too hard, what are the other options?

Questions about who to call:

Who should I talk to if things are not going well?

Who should I call if it is after hours or on the weekend and I need help?

Who can I call in an emergency?

Questions about your own wellbeing:

How might caring impact on me?

Do I need to be available full time to care?

How can I set up support for me? What services are available to support me?

Am I eligible for carer payments or other financial assistance?



Factsheet 2: Financial Assistance

Below are information on types of payments and financial assistance available to carers and specific financial considerations around end of life. We also make some suggestions for managing your finances well to ensure that you have access to finances after the person you are caring for has died.

Costs of caring

Some carers find that caring for someone at the end of life has a financial impact. This can be due to:

- Reducing or stopping work to care for a person may reduce your income
- The cost of medications, services and hiring equipment
- The loss of the income of the person you are caring for
- Possible extra travel costs to regularly visit the person if they are being cared for outside the home
- The cost of the funeral
- Difficulty accessing money after the death of the person they were caring for.

Receiving financial assistance during this time can also reduce your financial burdens.

Here is what you need to know about financial assistance and some links to where you can get more information.

Remember that the social worker at the hospital or your health care team may be able to also talk you through some of this information. Social workers often will assist you to complete forms and apply for payments.

Carer payments – through Centrelink

You may be eligible for some financial assistance while caring, especially if you have stopped working or reduced your work hours in order to care. There is a lot of good information on carer payments and how to apply on the Australian Government Department of Human Services website.
www.humanservices.gov.au/individuals/carers

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Alternatively, you can call Centrelink directly (13 27 17) to help you work out whether you are eligible for a Carer Payment. Prepare to be on hold for a while, so have all your questions ready to go and have a good book or magazine to read while you wait.

Age Pension or Carer Payment?

In some cases, you may need to choose between a Carer Payment and an Age Pension.

There are pros and cons to each type of payment, depending on your personal situation. To see how they compare, visit the Department of Human Services website.

www.humanservices.gov.au/individuals/subjects/choosing-between-carer-payment-and-age-pension

NDIS – National Disability Insurance Scheme

The National Disability Insurance Scheme is a new way of supporting people under the age of 65 who have

a disability. The aim of the program is to help people with disability to remain independent. If the person you are caring for is under the age of 65 and has a disability then for more information please visit www.ndis.gov.au

www.carersaustralia.com.au/ndis-andcarers/support-for-families-and-carers/

My Aged Care

If the person you are caring for is aged 65+ (or 50+ for Aboriginal or Torres Strait Islander People) then you may be eligible for assistance from Australian Government funded aged care services.

They will fund additional services so that you do not need to pay for these services privately. Some services that they can provide include personal care or nursing care services in the home, physio and other care, modifications to the home, meals, cleaning, and equipment.

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They can provide short term help including respite if you need a break yourself or they can assist with care in an aged care home.

You can also call My Aged Care on 1800 200 422 (8am-8pm Mon-Fri and 10am-2pm Sat). Have the Medicare number of the person you are caring for handy. Once someone is registered they will get a My Aged Care number that you can use in any future contact.

www.myagedcare.gov.au/home-start-here

Preparing your finances for the future

It is also really important to prepare yourself financially for when the person you are caring for dies. Getting prepared from a practical and financial perspective can be difficult while caring for someone at the end of their life. You are probably very busy with day to day caring activities and you may feel emotionally overwhelmed.

You may feel like it is too hard to also take care of additional financial, legal

and other practical matters. However, updating legal documents, changing names on accounts, and ensuring you have access to income will make things a lot easier down the track.

If you have an accountant, it can be helpful to ask them to talk you through how to prepare financially for the death of your partner, relative or friend.

Bank accounts will not be accessible once the person dies, unless you are a joint holder of the account. Sometimes the process of finalising the estate can take months and during that time you will not have access to any money held in accounts of the person who has died.



For more information

Money Smart is a very useful website for financial matters and

has a good section to help people get their finances in order before they die. You may want to work through this with the person you are caring for as it will also be very useful for you:

www.moneysmart.gov.au

Knowing how to deal with the estate can be daunting. The Australian Taxation department have written a checklist which will be able to help: www.ato.gov.au

Your bank will have a support team who will be able to help you work through the requirements of completing a deceased estate, including claiming for immediate expenses.



Therefore, it is a good idea to ensure that you have your name on any accounts that you need access to after the person has died. This is also true of loan accounts, including home loans.

Again, it is a good idea to go through the process of adding your name as a joint account holder so that you have access to these accounts following the person's death. However, if you are named on a joint account when the person dies, you will also be responsible for paying any outstanding money or debts associated with that account. Please talk to your accountant about any tax implications of adding your name to loan, investment, or other accounts.

It is also good to know that banks will cancel any credit cards for the person who died if they were the primary card holder. That means if you are using a credit card, as the secondary card holder, it may be cancelled.

If this is the case for you, it may be worth applying for your own credit card and attaching it to your own bank account.

It is helpful to make sure that any superannuation accounts, life insurance, or other similar products, have a named person as the beneficiary in case of death. This will make it easier to access following the death of the person.

Most banks and superannuation funds have information on their website about what to do when a person dies. In some cases, they release funds from accounts to pay for funerals or pay outstanding invoices or debts.

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Factsheet 3: Helplines for carers

Sometimes, having someone to talk to can make a big difference. You might need information about practical matters, help with a concern about a specific disease, or you might need urgent emotional support. Knowing who to call matters.

Remember that the palliative care service and your health care team should always be considered when seeking information. However, the helplines below may also be useful sources of trustworthy information.

Need help now?

Call 000 for emergency services if you are experiencing an emergency and require urgent assistance.

Lifeline [13 11 14] offers 24-hour crisis support and suicide prevention services.

Helpful helplines

Beyondblue [1300 224 636] provides 24/7 telephone support with a mental health professional.

Cancer Council [13 11 20; Monday to Friday, 9am to 5pm] provides a telephone counselling service free of charge for support and information; this is available to cancer patients, their families, friends, and carers.

Carer Gateway [1800 422 737], an initiative of the Australian Government, has a helpline for carers to access support and advice; you can also request a call back through an online portal from Monday to Friday, between 8am and 6pm.

Carers Australia's Carer Advisory Service [1800 242 636; Monday to Friday, excluding public holidays] offers information, support and counselling to carers; translation services are also available.

Commonwealth Respite and Carelink Centres [1800 052 222 during business hours or 1800 059 059 for emergency respite support outside standard business hours] can give you information and access to respite care.

The Continence Helpline [1800 330 066; Monday to Friday, 8am to 8pm AEST] has continence nurse advisors available to provide information and advice about bladder and bowel problems.

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Factsheet 3: Helplines for carers

Dementia Australia's National Dementia Helpline [1800 100 500; Monday to Friday, 9am to 5pm, excluding public holidays] is a confidential information and support service you can access by phone or email.

The Dementia Behaviour Management Advisory Service [1800 699 799] is available 24 hours a day and can give clinical support to carers of a person with dementia who exhibits behavioural and psychological symptoms.

Department of Human Services financial assistance for carers and people with disability [132 717; Monday to Friday, 8am to 5pm]; call to find out more about whether you or the person you care for are eligible for any financial assistance from the Department of Human Services.

Department of Veterans Affairs [1800 555 254; Monday to Friday, 8am to 5pm] assists carers of veterans and carers who are veterans; call them to find out more about any assistance that may be available to you.

Grief Line [(03) 9935 7400, or 1300 845 745 by landline] offers both telephone and online counselling for persons experiencing loss and grief.

My Aged Care [1800 200 422] can give you information about and assistance with accessing aged care services if you are caring for an elderly person.

The National Relay Service has several options for assisting you to make calls if you are deaf or have a hearing or speech impediment [Speak and Listen number 1300 555 727; Teletypewriter calls number 133 677; SMS Relay number 0423 677 767].

The Translating and Interpreting Service [13 14 50] offers immediate telephone interpreting in a range of languages.

Wellways Helpline [1300 111 500; Monday to Friday, 9am to 9pm AEST, excluding public holidays] supports people experiencing mental health struggles, as well as their carers, family, and friends.

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Factsheet 5: Scheduling timetable



Keep track of all appointments with a weekly timetable.

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
07:00 – 08:00							
08:00 – 09:00							
09:00 – 10:00							
10:00 – 11:00							
11:00 – 12:00							
12:00 – 13:00							
13:00 – 14:00							
14:00 – 15:00							
15:00 – 16:00							
16:00 – 17:00							
17:00 – 18:00							
18:00 – 19:00							
19:00 – 20:00							
20:00 – 21:00							



Factsheet 7: Managing communications

It is important to be able to discuss and talk about your concerns and the things you need to prepare for as you care for your loved one. These can include sharing with family and friends how things are going, talking with the health care team, organising services and supports, and having discussions with the person needing care.

Communication tips

Be clear about what you want to say. Sometimes it can be helpful to make some notes about what needs to be discussed or decided.

Remember that listening is a very important part of good communication. Pay attention to what the other person is saying.

Ask questions if you are not sure what the other person means. If the topic is very difficult for you, ask if you can think about it for a little while. But make sure you do return to the conversation.

You have a right to share your feelings. Be honest about how you feel and what you need.

Sometimes you might need to start the conversation several times. It's ok to say "Perhaps we could talk about this later, when I am not so tired."

When making a point try explaining the effect something has on you rather than blaming the other person. "I" messages such as "I feel that I am not doing enough when you say something like that" may be more helpful than saying "You are always rude to me".

It can be hard to ask for help if you have always been independent but family and friends want to help. Don't be afraid to ask for specific types of help such as asking for helping with transport to appointments or to mow the lawn.

Important conversations

It can be hard to talk about difficult subjects such as finances, wills, advance care planning and funerals.

These can be quite emotional and confronting for both of you. But preparing and resolving issues can reduce future stress.

Communicating with doctors and nurses

Many carers attend health appointments. This can be important in making sure that you are getting key information about care and the future.

Be sure the health care team understands your role and what you are able to do and what you cannot do in the caring role. Make sure they are aware of your other commitments such as work or young children.

Don't be afraid to ask questions. Our Question List is a good way to make sure that you don't forget important questions. Make sure you write important information down. It is very easy to forget particularly if you are tired or stressed. If you have looked for information on the internet, you may want to talk about what you found with the healthcare team.

If you and the person you are caring for are not certain what you want to do, ask if the decision needs to be made today. If not, ask if you can discuss it at the next appointment.



It can be helpful to have one family member as the main contact for the health care team. This person will need to be able to clearly communicate care information and decisions.

Think about where to have conversations. You should have the whole attention of the doctor or the nurse. Conversations should be held in a private place, not in a corridor or in the waiting room.

You can feel awkward talking about costs and money but it can be helpful to discuss the costs of care with the team, particularly if illness is causing financial problems.

Speaking for your rights

Carers often have to speak out on behalf of the person they are caring for and represent their interests and needs. You may feel you need to develop your skills to do this. The following are some suggestions about how to manage this role:

- Understand as a carer and a health care consumer you have rights
- Identify what is the problem and what you would like to happen
- Find out who to speak to or what organisation is responsible for decisions
- There are support services that can help you such as Carers Australia
- Having a plan for discussion when you go to a meeting
- Be assertive. Make your points clearly and honestly. Listen carefully so that you can consider other views.
- Finally, remember you want to find a solution so negotiation can be important.



Factsheet 8: What to do in an emergency

If you are caring for your partner, relative or friend at home, it is important that you have a plan of what to do in an emergency situation. This doesn't always mean that you need to ring 000, it may mean that you are not sure what to do or how to handle the situation.

Some of these situations may include:

- Being concerned that some of the person's symptoms (such as pain, agitation) are getting worse and the normal medications are not helping
- The person seems very uncomfortable
- You are feeling extremely anxious, fearful, or overwhelmed
- Something unplanned comes up and you have to leave the house and no one else is available to come and be with the person you are caring for
- The person you are caring for has a serious fall.

Generally a good plan would be to have the names and phone numbers of the person's doctor, palliative care team, after hours contact (of the doctor) or nursing service you have been using. It would also have a few family and friends phone numbers (or a neighbour) who could help you in an emergency.

You can always call '000' if you are concerned and need assistance in an emergency.

Handling medications

- Some medicines need to be stored in specific ways. Your pharmacist will tell you how and where each medication should be stored.
- Always check the label on medicine boxes or containers to ensure that you are giving the right medicine at the right time to the right person.
- Not all medicines are taken orally (by mouth), so check first. Some medicines may need to be given by injection, via a skin patch, or by other means.
- Sometimes people are given a list of medicines, what they are for, and when to take them. If you haven't got a list and would like one, speak to your doctor or health care team about how to get one.
- Some medicines should be given at a certain time (each day) and others are 'as required'. For example, some pain medication should be taken only when the person gets pain, whilst others are given at specific times of the day and night (that is, regularly).
- If there are many tablets to be taken, consider using a pill box, which allows tablets to be put in compartments so that it is easier to remember which ones need to be given and when to give them. Pill boxes are available at the chemist and can be filled by you or the pharmacist.
- Another alternative is a 'webster' pack, which is a weekly pack of all medications made up by the pharmacist.
- If syringes and needles are being used, ask about safe disposal using a 'sharps disposal container', available from the chemist or local council.
- It is common for medicines to change. When a medicine is no longer needed, it should be discarded to avoid accidental use.
- Unused medication should be returned to the chemist for safe disposal. If there is a chance the medicine may need to be used in the future, store it in a safe, cool and dry place, away from the medicines you are using regularly.
- If you only have a small amount of a medicine left, speak to the doctor or health care team to arrange another prescription. Try to avoid having to do this on the weekend.
- If swallowing is difficult for the person you are caring for, check with the pharmacist or your doctor if it is okay to crush the medicine first.
- If you feel unsure or have questions about a medicine, the medication box or container will have written instructions on it. If you are still unsure or you are worried, please speak to a pharmacist for advice.