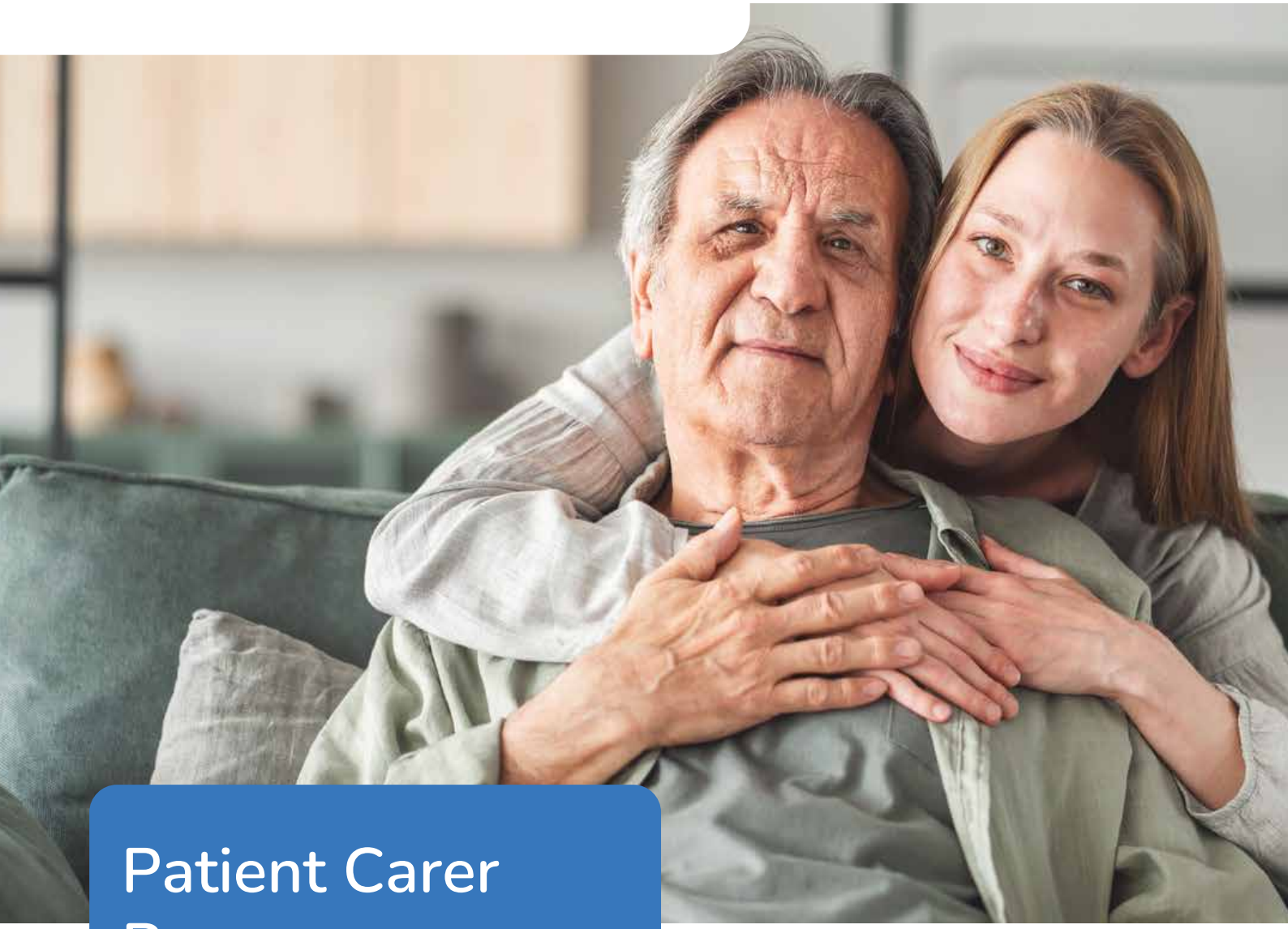
CARESEARCH®

palliative care knowledge network



Patient Carer Resource

Evidence-based resources to support patients and carers through the end of life

caresearch.com.au

CareSearch is funded by the Australian Government Department of Health, Disability and Ageing

Flinders University

This page is intentionally left blank

CARESEARCH®

palliative care knowledge network

Needs Assessment Tool for Carers of People with a Chronic Condition (NAT-CC)

What is the NAT-CC?

Caring for someone with a chronic condition is important but can be demanding, affecting your health and wellbeing. The NAT-CC helps you identify concerns about your health that you may wish to discuss with your GP, who can support your well-being.

How does the NAT-CC work?

The NAT-CC helps you highlight health issues important to you. It also allows you to note which topics you want to discuss with your GP today or later. It serves as a conversation-starter and a plan to improve and maintain your health.

How is my privacy protected?

What you discuss with your GP is confidential. Without your consent, it cannot be shared with anyone, including the person you care for.

How can I help my GP address my concerns?

- Complete the NAT-CC before your appointment.
- Book a longer appointment with the GP for ample time.
- If you have several concerns, your GP may suggest a follow-up visit.

Information for your GP

- The NAT-CC outlines common carer concerns about their health and well-being.
- It identifies your patient's priorities and when they wish to discuss them, which may not always be today.
- The patient can complete it alone or with your help.
- You can flag issues that might be sensitive for the patient to address.
- If your patient raises multiple concerns, prioritise the most important and suggest a follow-up for the others.

CARESEARCH®
palliative care knowledge network

Needs Assessment Tool for Carers of People with a Chronic Condition (NAT-CC)

The topics below are often a concern for people close to someone with a chronic condition.

Please rate how concerned you are NOW about each issue, by selecting your level of concern:

None, Some, A lot

Then MARK IN THE COLUMNS ON THE RIGHT the topics you want to discuss with the GP, nurse or other health provider - either now or at some stage in the future.

Date _____ **Name** _____

Information Issues	Level of concern			Topics to discuss	
	None	Some	A lot	Now	Later
1. Finding general information about the chronic condition	☐	☐	☐	☐	☐
2. Finding specific information to give to the ill person	☐	☐	☐	☐	☐
3. What to expect during the illness	☐	☐	☐	☐	☐
4. How to plan for the unexpected things relating to the illness	☐	☐	☐	☐	☐
5. How to plan for my future	☐	☐	☐	☐	☐
6. Ways to care for the person at home, e.g. techniques or equipment	☐	☐	☐	☐	☐
7. Managing financial matters, e.g. getting Centrelink allowances and other benefits	☐	☐	☐	☐	☐
8. Legal matters, e.g. preparing or updating a will	☐	☐	☐	☐	☐
9. Now knowing who to go to with my questions	☐	☐	☐	☐	☐
10. My ability to give information to the ill person	☐	☐	☐	☐	☐
Pratical issues					
11. My ability to look after myself	☐	☐	☐	☐	☐
12. My ability to look after the ill person	☐	☐	☐	☐	☐
13. My medical conditions limit my ability to do things I have to do	☐	☐	☐	☐	☐
14. The ill person's symptoms limit their ability to function	☐	☐	☐	☐	☐
15. The ill person is having difficulty looking after themself	☐	☐	☐	☐	☐
16. My skills limit what I want to do for the ill person	☐	☐	☐	☐	☐
17. Other issues limit my ability to do what I want to do	☐	☐	☐	☐	☐

Needs Assessment Tool for Carers of People with a Chronic Condition (NAT-CC)

Personal health and well-being issues	Level of concern			Topics to discuss	
	None	Some	A lot	Now	Later
18. My own physical health is a concern	☐	☐	☐	☐	☐
19. I have problems with tiredness or lack of energy	☐	☐	☐	☐	☐
20. Being a caregiver impacts on my choices	☐	☐	☐	☐	☐
21. Being a caregiver impacts on my happiness	☐	☐	☐	☐	☐
22. Being a caregiver impacts on my self-confidence	☐	☐	☐	☐	☐
Relationship issues					
23. I have problems in close/intimate relationships with the ill person	☐	☐	☐	☐	☐
24. I have problems in other relationships	☐	☐	☐	☐	☐
25. My ability to communicate with the ill person is limited	☐	☐	☐	☐	☐
26. My ability to communicate with others is limited	☐	☐	☐	☐	☐
27. The ill person has problems in close/intimate relationships	☐	☐	☐	☐	☐
28. The ill person has problems in other relationships	☐	☐	☐	☐	☐
29. The ill person has limited ability to communicate with others	☐	☐	☐	☐	☐
Meaning issues					
30. The illness and its effects are challenging my beliefs and values	☐	☐	☐	☐	☐
31. The illness and its effects are challenging the ill person's beliefs and values	☐	☐	☐	☐	☐
32. The illness and its effects are challenging because of my culture, or the person's culture	☐	☐	☐	☐	☐
Are there other types of concerns? Please list here.					

Adapted with permission from Mitchell G, Girgis A, Jiwa M, Sibbritt D, Burridge L. The University of Queensland 2012.

This page is intentionally left blank

CARESEARCH®

palliative care knowledge network

We all need a plan

How many of us have taken the time to stop and think about what we would want to happen if we became seriously ill or if someone close to us was seriously ill what they would want?

What is advance care planning?

Advance care planning is about documenting your wishes to communicate on your behalf when you are no longer able to do so. This will help your family and friends to make decisions about your care if you cannot. Advance care planning generally covers three things:

- thinking and talking about your healthcare values and preferences
- appointing a substitute decision maker
- completing a document such as an advance care directive.

Why do we need a plan?

We all make plans in our life for today and the future. We will all die one day so we should plan for that too. Having a plan can help us, our family and the health professionals who care for us to know what we want. You can start having a conversation at any age about what you want if something unexpected were to happen.

Making a plan becomes more important as you are getting older or if you learn that you have a serious illness. Being informed about what will happen can help in making preparations and can make decisions easier. When making plans and decisions you need to let people know what you have decided. This includes your family and friends. You should also tell your health professionals.

Remember health professionals will not know what you want if you don't tell them what is important to you. You may have particular beliefs or traditions that need to be taken into account in providing care.

Helpful resources

Advance Care Planning Australia has a range of resources including learning modules and factsheets.
Palliative Care Australia's Starting to Talk Discussion Starter can help you talk about your wishes and preferences for your care at the end of life.

This page is intentionally left blank

CARESEARCH®

palliative care knowledge network

What is palliative care?

Palliative care is person-centred care and support for people with a life-limiting illness. This includes support for their family and carers. The aim is to help people live their life comfortably and as fully as possible by supporting their physical, emotional, social, and spiritual needs. Palliative care enhances quality of life. It intends neither to hasten or postpone death.

Examples of the care required might include:

- psychological and spiritual support
- a support system to help patients and family live as actively as possible until death
- support to help the family cope during the person's illness and in their own bereavement relief from distressing symptoms including:

  > pain
  > depression
  > fatigue (tiredness)
  > nausea
  > breathlessness (dyspnoea)
  > anxiety.

Who is palliative care for?

Palliative care is for people of any age with a life-limiting illness and their families.
A life-limiting illness is one likely to cause death in the foreseeable future. This includes:

- cancer
- neurological disease
- dementia
- advanced kidney, heart, liver, and lung disease.

Family can include partners, relatives, friends, or anyone who is considered as family by the patient (including pets).

When is palliative care provided?

Palliative care can be provided at any time depending on a person's needs. It is now accepted that combining palliative care with active treatment improves symptom control, quality of life, and family satisfaction. When you receive palliative care is a decision for you and your family.

Who provides palliative care?

Palliative care can be provided by many different health and care professionals. In a hospital setting care it is provided by doctors, palliative specialists, nurses, and allied health professionals. In the community the palliative care team might include the person's GP, community and aged care nurses, visiting allied health professionals, careworkers, and support workers. Family, friends, neighbours, and acquaintances will also provide important support.

Where is it provided?

Palliative care may be provided in hospitals or the community setting. This includes:

- private homes
- residential aged care
- accommodation for people experiencing mental illness
- accommodation for people living with a disability
- correctional facilities
- general practices
- community palliative care clinics and day centres
- hospitals.

Not all people with a life-limiting illness need specialist palliative care. Many people can be cared for at home and see specialist palliative care staff only when there is a need.

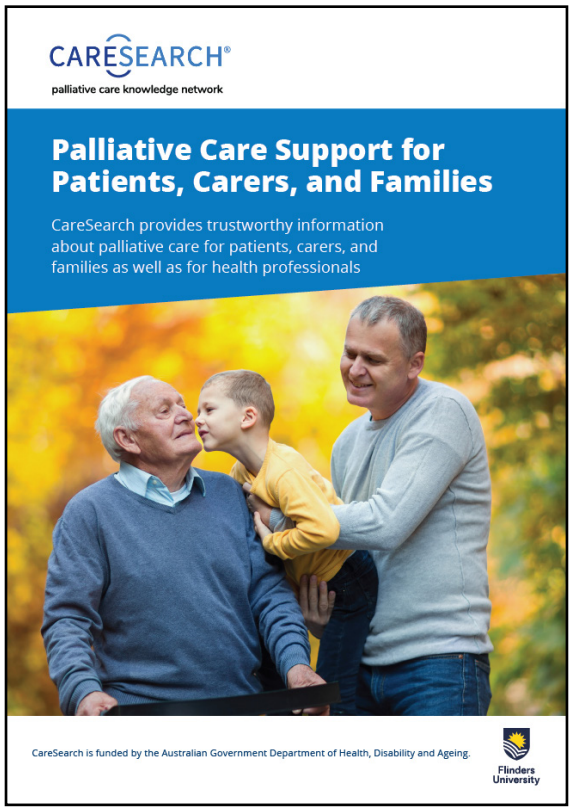
Being able to stay at home with a serious illness usually requires the help of family members or friends. Older people may be receiving palliative care alongside a homecare package or within a residential aged care facility.

Some may have more complex needs and symptoms that need careful management. In this case there may be the continuing involvement of a specialist team and short or longer stays in a hospice or palliative care ward.

Palliative Care Support for Patients, Carers, and Families Booklet

CARESEARCH®
palliative care knowledge network

This booklet provides a helpful starting point to learn about palliative care and the support available. It guides patients, carers, and families on what to expect and where to find help throughout the palliative care journey.



Helpful topics include:

- *About palliative care*: Understanding what palliative care is and the role of the care team that can support you.
- *Diagnosis and prognosis*: What happens from diagnosis through to end of life.
- *Caring and support*: Information and guidance for both patients and carers, including practical things you can do.
- *Symptoms*: Common physical and emotional symptoms patients may experience.
- *Medicines*: Tips for managing medicines and the discussion with your doctor or pharmacist.
- *Last days*: How to prepare for the end
- *Bereavement*: Even if death is expected after a long illness, it can still be deeply emotional. Understand everyone reacts and grieves differently.
- *Talking about death and dying*: Resources to help start important conversations, including books, music, and films.

Order free copies

To order free copies of the Palliative Care Support for Patients, Carers, and Families booklet, scan the QR code or visit https://bit.ly/GP-Kit

A downloadable PDF version (4.45MB pdf) is also available.

Order free copies

Download (4.45MB pdf)

This page is intentionally left blank

CARESEARCH
palliative care knowledge network

Medicines list:
Helping you to keep track of your medicines

My name: _____

My allergies or previous problems:

_____

_____

_____

My emergency contact(s):

_____

_____

_____

My GP/specialist contact details:

_____

_____

_____

My pharmacy: _____ Pharmacy phone number: _____

Other members of my care team:

Name _____ Contact details _____

Name _____ Contact details _____

Name _____ Contact details _____

Reminders:

- Ask a member of your care team to help you fill out this form.
- Bring this form to future medical appointments.
- List non-prescription medicines (including over-the-counter herbal and natural).
- Keep this list with you in case of an emergency.

CARESEARCH
palliative care knowledge network

Medicine name and strength	What it looks likes	How much and when	How to take it	Date started	What the medicine is for
e.g., paracetamol 500mg	e.g., round, blue, white liquid	e.g., one capsule per day	e.g., by mouth, with food, by injection	dd/mm/yy	e.g., pain

Learn more about your medicines from your GP, pharmacist, or use the NPS Medicinewise Medicine Finder: nps.org.au/medicine-finder

CareSearch is funded by the Australian Government Department of Health, Disability and Ageing.

My Emergency Contact List:

Helping you keep track of your team

Insert name of your organisation

My name: _____

Reminder:
Put this list on your fridge or somewhere where it can be found

Relationship/ Role	Name	Phone Number	Contact at time of death? (Y/N)
Partner/friend/ family member			
Partner/friend/ family member			
Partner/friend/ family member			
Partner/friend/ family member			
Substitute Decision-maker			
Specialist			
General Practitioner (GP)			
Nurse			
Pharmacist			
Other			

This page is intentionally left blank