



palliative care knowledge network



GP Kit

A bundle of evidence-based tools and resources to support GPs providing palliative care across the last months of life

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



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A bundle of evidence-based tools and resources to support GPs providing palliative care across the last months of life

- Assessing patients and carer needs
- Symptoms and their management
- Bereavement
- Planning and discussing care
- The dying patient
- Professional Practice

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Using the CareSearch GP Kit

GPs are critical in providing person-centred and coordinated care for people approaching the end of life. This kit brings together practical, evidence-informed tools and resources for you, and resources you can share with families.

The information in this Kit is organised around needs and issues as they arise in the last months of life. They relate to the comprehensive care framework available in the [CareSearch GP Hub](#). They include useful tools and materials from the [CareSearch](#) and [palliAGED](#) websites.

You can order resources for families or more GP Kits in the [GP Hub](#).

Check out
the GP Hub:



Assessing patient and carer needs

- *Supportive and Palliative Care Indicators Tool (SPICT)*: Validated tool to identify people whose health is deteriorating. Use to review unmet palliative care needs
- *Australia-modified Karnofsky Performance Scale (AKPS)*: Used as an overall measure of ability to perform activities of daily living. Eligibility score needed for Support at Home (End of Life Pathway) and AN ACC Class 1 entry to residential aged care
- *Needs Assessment Tool for Carers (Patient Carer Resource)*: Helps the family carer to self-identify concerns or needs they have

Planning and discussing care

- *Prompts for End-of-Life Planning (PELP) Framework*: Supports GPs provide proactive, person-centred care within a 12-month timeframe
- *Communication starters for difficult conversations*: Provide helpful ways to start conversations about end of life
- *Support at Home (End of Life Pathway)*: If a patient is over 65, consider if they are eligible to receive aged care services through this pathway
- *We all need a plan (Patient Carer Resource)*: Gently introduces patients and carers to the need for advance care planning
- *Palliative Care Support for Patients, Carers and Families (Patient Carer Resource)*: Booklet that explains what to expect and where to find help
- *What is palliative care? (Patient Carer Resource)*: Describes what palliative care is and how it can help

Symptoms and their management

- *CareSearchgp App*: Download this app to give you immediate access to care and symptom resources and prescribing guidance
- *Medicines tracking list (Patient Carer Resource)*: A simple sheet for patients and carers to manage their medications

The dying patient

- *GP checklist for supporting a planned home death*: Guides GPs through planning and supporting a person who wishes to die at home
- *PBS prescriber bag medicines*: Access to anticipatory medicines for urgent symptom relief
- *Support at Home (End-of-Life Pathway)*: Review the eligibility criteria for access to this pathway if the person is over 65
- *My emergency contact list (Patient Carer Resource)*: Simple form to help family and carers know who to contact

Bereavement

- *Bereavement care in general practice*: Provides practical guidance for follow-up and referral

Professional practice

- *MyMedicare for GPs providing palliative care*: Highlights how My Medicare can support palliative care
- *General Practice in Aged Care Incentive (GPACI)*: Consider how this incentive can support coordination and collaboration between the care team
- *About CareSearch*: Provides links to the GP Hub and other National Palliative Care Program resources





**The SPICT is used to help identify people whose health is deteriorating.
Review unmet palliative care needs. Plan current and future care with them.**

Look for any general indicators of poor or deteriorating health.

- Urgent or emergency hospital admission(s) or visits.
- Functional ability is poor or deteriorating, with limited reversibility.
(eg The person often stays in bed or in a chair for more than half the day.)
- Depends on others more for care due to increasing physical and/or mental health problems.
Person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of health condition(s).
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment;
or wishes to focus on quality of life.

Look for clinical indicators of life shortening conditions.

Cancer

- Functional ability deteriorating due to progressive cancer.
- Too frail for cancer treatment or treatment is for symptoms.

Dementia or frailty

- Unable to dress, walk or eat without help.
- Eating and drinking less; difficulty with swallowing.
- Urinary and faecal incontinence.
- Not able to communicate by speaking; little social interaction.
- Frequent falls; fractured femur.
- Recurrent febrile illnesses or infections; aspiration pneumonia.

Neurological disease

- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.
- Recurrent aspiration pneumonia; breathless or respiratory failure.
- Ongoing disability with worsening physical and/or mental health after a major stroke or multiple strokes

Heart or vascular disease

- Heart failure or extensive, untreatable coronary artery disease; breathlessness or chest pain at rest or on minimal effort.
- Severe, inoperable peripheral vascular disease.

Respiratory disease

- Severe, long term lung disease; breathlessness at rest or on minimal effort between exacerbations.
- Persistent hypoxia needing long term oxygen therapy.
- Has needed ventilation for respiratory failure or ventilation is contraindicated.

Other conditions

- Deteriorating with physical or mental illnesses, multiple conditions and/or complications that are not reversible; best available treatment has poor outcome.

Kidney disease

- Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.
- Kidney failure complicating other life shortening conditions or treatments.
- Stopping or not starting dialysis.

Liver disease

- Cirrhosis with one or more complications in the past year:
 - diuretic resistant ascites
 - hepatic encephalopathy
 - hepatorenal syndrome
 - bacterial peritonitis
 - recurrent variceal bleeds
- Liver transplant is not possible.

Review current care and care planning.

- Review current treatments and medication; minimise polypharmacy.
Shared decision making about treatment and care.
- Review holistic care – symptoms; emotional, social, financial, spiritual needs. Support families and carers.
- Ask for specialist advice or a review if symptoms or other problems are difficult to manage.
- Agree a current and future care plan with the person/family.
Discuss future decision making (e.g. Power of Attorney).
- Record, share, and review care plans.

For more on palliative care visit caresearch.com.au

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The Australia-modified Karnofsky Performance Scale (AKPS)

The Australia-modified Karnofsky Performance Scale (AKPS) is a measure of the patient's overall performance status or ability to perform their activities of daily living.

It is a single score between 10 and 100 assigned by a clinician based on observations of a patient's ability to perform common tasks relating to activity, work and self-care.

A score of 100 signifies normal physical abilities with no evidence of disease.

Decreasing numbers indicate a reduced performance status.

How to assess AKPS

01

Rate AKPS at the start

Use the AKPS definitions to determine the initial rating on admission or commencement of an episode of care.

02

Assess routinely

A minimum of daily in an inpatient setting, at each visit in a community setting or each consult.

03

Assess AKPS for changes and discharge

Assess whenever there is a phase change and at episode end when the patient is discharged.

04

Use only scores in multiples of 10

Record the rating as assessed (scores in increments of 10). In between scores such as 45, 55 or scores such as 50-60 are invalid.

AKPS ASSESSMENT CRITERIA

SCORE

Normal; no complaints; no evidence of disease	100
Able to carry on normal activity; minor sign of symptoms of disease	90
Normal activity with effort; some signs or symptoms of disease	80
Cares for self; unable to carry on normal activity or to do active work	70
Able to care for most needs; but requires occasional assistance	60
Considerable assistance and frequent medical care required	50
In bed more than 50% of the time	40
Almost completely bedfast	30
Totally bedfast and requiring extensive nursing care by professionals and/or family	20
Comatose or barely rousable	10
Dead	0

Examples of questions

Have there been any changes today with the patient's ability to attend to activities of daily living?

Is the patient requiring more physical care today?

How much time is the patient actually spending in bed?

Permission granted by Australian Health Services Research Institute; University of Wollongong; Palliative Care Outcomes Collaboration (PCOC)

Abernethy AP, Shelby-James T, Fazekas BS, Woods D, Currow DC. [The Australia-modified Karnofsky Performance Status \(AKPS\) scale: A revised scale for contemporary palliative care clinical practice \[ISRCTN81117481\]](#). BMC Palliat Care. 2005 Nov 12;4:7.

palliAGED is funded by the Australian Government Department of Health, Disability and Ageing and managed by CareSearch, Flinders University

October 2025



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.

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					
Practical 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 themselves					
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.

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Prompts for End-of-Life Planning (PELP) Framework

Quality care in the last 12 months of life

TRIGGER: Would you be surprised if this person were to die in the next 12 months?

Applicable to **ALL** care settings to encourage culturally safe and person-centred care

CLINICAL PROCESSES

Advance care planning (ACP) and person-centred care based on need

Transition focus of care needs from restorative to palliative

Terminal care needs

After-death care

PROGNOSIS

At risk of dying
<12 months; timing uncertain

Likely to die soon
medium term; timing uncertain

Dying
short term, likely hours, days, or week; timing uncertain

Bereavement

PROMPTS

- Acknowledge importance of individual needs, including lifestyle factors, and prognostic uncertainty
- If not already commenced, begin **ACP**
 - » Discuss end-of-life options and limitations of treatments
 - » Suggest completion of ACP documents including noting substitute decision-maker
- Consider ongoing disease-modifying treatments and a palliative approach
- Consider mentioning voluntary assisted dying for eligible patients, if jurisdictionally appropriate* and within scope of practice
- Review medicines and deprescribe if appropriate
- Monitor for indicators of deteriorating health
- Explore availability of carers
- Coordinate care across all services including respite care

- Review ACP and person-centred goal setting
- Prepare **person-centred medical goals of treatment plan** and document
 - » Include ceilings of medical treatments if acute deterioration
- Coordinate care across all services
 - » Establish GP as team leader, if available
 - » Include palliative care team members, as required
 - » Consider respite care
- Review medicines, consider
 - » Deprescribing
 - » Anticipatory prescribing
- Provide a palliative approach
- Explore bereavement needs of person and carers

- Review ACP and person-centred medical goals of treatment documents
- Prepare **terminal care management plan** for preferred place of death
 - » Provide interventions for symptom control including non-pharmacological strategies
 - » Consider anticipatory prescribing and deprescribing
 - » Ensure culturally appropriate care and spiritual, individual and carer needs are met
- Document the **plan** and share with carers and after-hours providers
- Provide checklist for immediate after-death care
- Consider bereavement care for all

- If required
 - » Arrange bereavement care for all significant others
 - » Refer to support services
 - » Ensure team members have access to peer support, debriefing and counselling

CLINICAL IMPROVEMENT

CLINICAL DETERIORATION



SCAN CODE FOR LINKS TO OTHER RESOURCES

caringathomeproject.com.au

*Specific requirements for voluntary assisted dying vary between each state and territory. Healthcare services should familiarise themselves with the [legislation in their jurisdiction](#) and ensure patients and their families have access to appropriate information.

Adapted from: 1. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: Essential elements for safe and high-quality end of life care. Sydney (AU) ACSQHC; 2023.
2. Alfred Health. End of Life Care Management Guideline. Melbourne (AU) Alfred Health; 2015. Prompt Doc No: AHG0068908 v10.1.
3. Reymond L, Cooper K, Parker D, Chapman M. End-of-life care: Proactive clinical management of older Australians in the community. AFP. 2016 Jan-Feb; 45(1): 76-8.



Definitions



Advance care planning	The process of preparing for likely scenarios near the end of life that usually includes assessment of, and discussion about, a person's understanding of their medical condition and prognosis, values, preferences and personal and family resources. Advance care planning supports a person in communicating their wishes about their end of life. ¹
Carer	A person who provides personal care, support and assistance to another individual who needs it because they have a disability, medical condition (including a terminal or chronic illness) or mental illness, or they are frail and aged. An individual is not a carer merely because they are a spouse, de facto partner, parent, child, other relative or guardian of an individual, or live with an individual who requires care. A person is not considered a carer if they are paid, a volunteer for an organisation or caring as part of a training or education program. ¹
Family	The family is defined as the people identified by the person as family. This may include people who are biologically related, however it may not. People who joined the family through marriage or other relationships, such as kinship, as well as the chosen family, street family for those experiencing homelessness, and friends (including pets) may be identified by the person as family. ¹
Goals of care	Goals of care are what a patient wants to achieve during an episode of care, within the context of their clinical situation. Goals may be clinical and personal and are determined in the context of a shared decision-making process. Identifying goals of care helps to organise and prioritise care activities and contributes to improved satisfaction, quality-of-life and self-efficacy for patients. ²
Palliative approach	An approach to treatment that improves the quality of life of patients and their families facing life-limiting illness, through the prevention and relief of suffering. It involves early identification, and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual). ³
Substitute decision-maker	Substitute decision-maker(s) are people appointed or identified by law to make substitute decisions on behalf of a person whose decision-making capacity is impaired. Substitute decision-maker(s) have legal authority to make decisions about health, medical, residential and other personal matters (but not financial or legal decisions); the relevant legislation varies between jurisdictions (states and territories). More than one substitute decision-maker may be appointed. ¹
Voluntary assisted dying	Voluntary assisted dying (VAD) refers to the assistance provided to a person by a health practitioner to end their life. It includes: <ul style="list-style-type: none"> • 'self-administration', where the person takes the VAD medication themselves and • 'practitioner administration', where the person is given the medication by a doctor (or in some Australian States, a nurse practitioner or registered nurse). <p>'Voluntary' indicates that the practice is a voluntary choice of the person, and that they are competent (have capacity) to decide to access VAD.⁴</p>

Sources: 1. Palliative Care Australia. National Palliative Care Standards for Specialist Palliative Care Providers. 5.1 ed. Canberra (AU) PCA; 2024.
2. Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. 2nd ed. Sydney (AU) ACSQHC; 2021.
3. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end of life care. Sydney (AU) ACSQHC; 2023.
4. End of Life Law in Australia: Voluntary Assisted Dying (Internet). Queensland: QUT; 2023 (Cited 2024 June 7). Available from: <https://end-of-life.qut.edu.au/assisteddying>.

Patients often expect doctors to start conversations about serious illness and future care. These prompts can support clear, compassionate communication with patients and their families.

Setting up the conversation

- Can we talk about your health and what matters to you.

Inviting dialogue while acknowledging difficulty

- This might not be what you were expecting to hear today. Can we talk about this together?
- This is a lot to take in. Let's talk about what's ahead.

Gauge understanding

- What is your understanding of where you are with your illness right now?
- It sounds like you may be feeling

Assess preferences for information

- How much would you like to know about what might lie ahead?

Getting the timing right

- This deserves time. We don't need to decide today. Let's talk again when you're ready.

Defining personal goals and priorities

- What matters most to you as we plan your care?
- If time is shorter than we'd hoped, what would you want to focus on? will be the most important thing you'd want to focus on?
- What are your biggest hopes or concerns about the future?

Involving others

- How much do the people closest to you know about your priorities and wishes for care?
- Have you chosen someone to decide for you if you can't?

Affirm support

- I'll support you and help ensure you get the best care.

Based on: Ariadne Labs. Serious Illness Conversation Guide: Patient-test language [Internet]. Boston, MA: Ariadne Labs; 2023 [cited 2024 Dec 6]. Available from: <https://www.ariadnelabs.org/wp-content/uploads/2023/05/Serious-Illness-Conversation-Guide.2023-05-18.pdf>.

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Support at Home: End-of-Life Pathway

The End-of-Life Pathway supports older people who have been diagnosed with 3 months or less to live and wish to remain at home by providing funding to access in-home aged care services. The aged care services complement services available under state and territory based palliative care schemes.

A total of \$25,000 is available per eligible participant over a 12-week period.



Eligibility criteria

An older person is eligible to access the End-of-Life Pathway if they meet the following criteria:

- A doctor or nurse practitioner advising estimated life expectancy of 3 months or less to live, and
- Australian-modified Karnofsky Performance Status (AKPS) score (mobility/frailty indicator) of 40 or less.

The End-of-Life Pathway form will be available on the Department's website from 1 November 2025.

What if someone is already in the Support at Home Program?

The End-of-Life Pathway is available to participants already accessing Support at Home services as well as older people not currently accessing services.

Funding for the End-of-Life Pathway is discrete from other Support at Home classifications.

If eligible, existing Support at Home participants can transition from an ongoing classification to the End-of-Life Pathway via a high-priority Support Plan Review. The End-of-Life classification replaces the previous ongoing classification and a budget of \$25,000 is allocated to the participant under the End-of-Life Pathway.

Planning Care

End-of-Life Pathway participants can access services from the Support at Home service list, determined on a needs basis in accordance with their high-priority aged care assessment or high-priority Support Plan Review.

A care plan should be developed for participants receiving services under the End-of-Life Pathway, in the same way as for ongoing classifications. The older person must also receive care management through a Support at Home provider, by a staff member known as a care partner.

Participant contribution arrangements apply for independence and everyday living services accessed under the End-of-Life Pathway.

The pathway period commences from the start date outlined on the Aged Care Entry.

How does someone exit from this pathway?

Exit from the End-of-Life Pathway may take place for one of the following reasons:

- the participant has passed away;
- the participant no longer wishes to, or is no longer able to, remain at home;
- the participant has a change in medical circumstances and services under the End-of-Life Pathway are no longer required;
- the period of funding for the End-of-Life Pathway has finished (maximum 16 weeks).

Where can I find out more?

The [Support at Home program manual](#) is a guide designed to assist registered providers to understand and comply with the Support at Home program rules, procedures and obligations. Section 14 deals with the End-of-Life Pathway.

The [Aged Care Quality and Safety Commission](#) has information on the reform agenda and all aspects of the pending changes.



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.

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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 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.

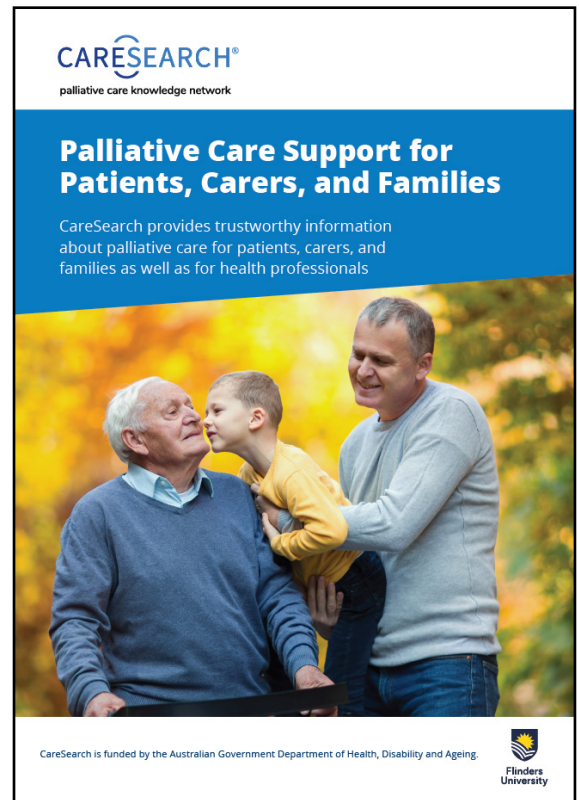
Some may have more complex needs and symptoms that need careful management. In this case there may be the continuing involvement of a specialist team and short or longer stays in a hospice or palliative care ward.

Palliative Care Support for Patients, Carers, and Families Booklet

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)

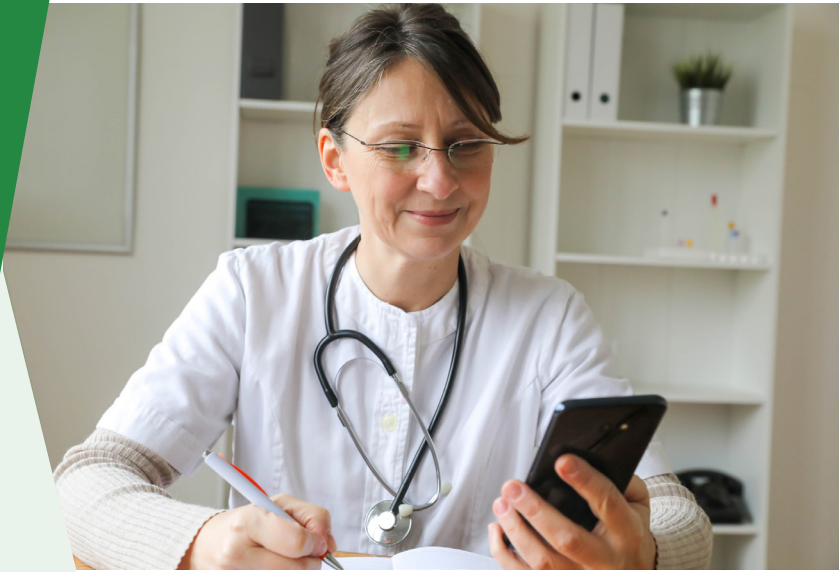
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Free palliative care app for GPs

Supporting you to care for your patients at the end of life

Easy to use

Evidence-based guidance and useful tools



Download now for free

The [CareSearchgp app](#) supports GPs in delivering quality palliative care across the life course. It brings together guidance on terminal prescribing for specific symptoms and evidence-based information on key care issues including:

- Advance care planning
- Recognising deterioration
- Engaging in palliative care case conferences
- Caring for the dying patient, and
- Assisting families through stages of bereavement.



The app also includes interactive features. GPs can create a list of links to quality resources tailored to the needs of individual patients. They can also curate their own collection of professional learning opportunities. The app also includes the Home Death Checklist which can be filled in and emailed when supporting an individual patient to die at home.

“
Something I would encourage all junior doctors and colleagues to utilise.
”

- Dr Liz Hawkins
Director of Medical Services,
Atherton Hospital, QLD

Explore our [GP Hub](#) to see more resources that can support your clinical decision-making:



The [CareSearchgp app](#) is available for free download from the [Apple Store](#) and [Google Play store](#).



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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.

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.



Supporting a planned home death: The GP's Checklist

The GP has a critical role in end-of-life care for patients who wish to die at home. This checklist guides GPs through decision-making, care of the patient and family, and identifying the need for appropriate supports early so that issues can be addressed ahead of time. GPs managing patients dying at home usually share care with other services, including palliative care and home nursing. This checklist can act as a planning tool for shared care, and a trigger to help clarify how care will be organised between those involved.

Patient name/ID

Date

1. Clarify expectations and support

Has the patient indicated they want to die at home?

Actions needed:

Do those who live with the patient know about and share that wish?

- Has the plan been discussed within the family?
- Consider - young children, others with care needs in the household

Actions needed:

Are there enough people to share the care?

- Consider practical, hands-on availability for round-the-clock care. Suggest a roster to support the carer and provide time out.
- Consider specific services that can support families e.g. night nursing services, Support at Home Program (End of Life Pathway), volunteers. The local palliative care service can advise.

Actions needed:

Review the patient's prognosis, in order to help the family plan ahead e.g. Is care likely to be needed for days, weeks, or months?

Actions needed:

Is there a back-up plan if either the patient or the family find it difficult?

- Clarify and document a plan and ensure that it is realistic, and understood by all involved. Where appropriate, provide a letter (or Ambulance Plan) describing the palliative goals of care in case of a triple zero call. Clearly state that the patient is dying and cardiopulmonary resuscitation is not appropriate, where agreed.

Actions needed:

2. Assess the home situation

Can the patient be cared for safely and comfortably in the home?

- Refer to home nursing services, and ask them to teach the family how to provide care safely (e.g. transferring and moving the person, eating and drinking, giving medicines). Confirm how much nursing support is available.
- Are there complex nursing needs that will be difficult to manage at home e.g. difficult wounds, fistulas, spinal analgesia?
- Consider equipment for nursing a bed-bound patient. They will need a hospital bed, mobility aids, commodes and personal care equipment, wheelchair, pressure mattresses, etc. Consider a palliative care referral for OT and/or physiotherapy assessment to advise on and organise equipment.
- Consider an in-dwelling catheter to reduce the care burden for a bed-bound patient.
- Discuss practical arrangements to make caring easier or safer – e.g. moving a patient's bed to a different room, or patient moving in with a family member. Remember that moving to a different address can disrupt eligibility for services – so do this early if possible.

Actions needed:

3. Plan for symptom management

Review long-term medications. Cease any that no longer contribute to the patient's comfort.

Actions needed:

Discuss with the family how the patient's symptoms will be reviewed and managed.

- How often GP visits will occur
- What the home nurses will do
- What the palliative care service will do
- Arrangements to provide prescriptions

Actions needed:

Plan for predictable, common symptoms that occur at the end of life:

- Dyspnoea/ terminal secretions
- Delirium
- Pain
- Nausea

Actions needed:

Ensure emergency medications are available in the house for when they are needed. This is best done well in advance as deterioration can be rapid and unpredictable.

- Remember – dying patients cannot take oral medications
- Subcutaneous medications are preferred to ensure continuing symptom control, with bolus medications via sc butterfly needle, and/or a syringe driver with a 24-hour infusion
- Family members should be taught how to give breakthrough doses by palliative or home nurses
- Check that medications are available at a community pharmacy, and that the carers have an adequate supply to get through after-hours and weekends in particular

Actions needed:

Consider whether a plan is needed for high-risk problems such as major bleeding, airway or bowel obstruction. If care needs are complex, or a high-risk problem exists, seek early advice from a palliative care specialist.

Actions needed:

4. Information that families need

Are the carers fully prepared for the fact that the dying person will be dependent and bedbound?

Actions needed:

Do carers need information about eating and drinking in the palliative care situation? Do they know that loss of appetite is a common and predictable feature of advanced disease? Are they aware that swallowing deteriorates with the approach of the terminal phase? Do they need ideas about what and how much to offer the patient to eat and drink, and how to do this safely?

Actions needed:

Do the carers need information about physical changes that occur as a person is dying, including:

- Changes in breathing patterns, including the possibility of terminal secretions ('death rattle')
- Changes in skin colour and temperature
- Changes in level of consciousness, including the possibility of terminal delirium

Actions needed:

Ensure that the family has access to 24-hour phone advice about symptoms or changes in the patient's condition. Make sure these contact numbers are accessible to anyone who might need them.

Actions needed:

Do the carers need information about what to do after the patient dies?

- Encourage them to think about choosing a funeral director
- Reassure them that there is no urgency to ring anyone straight away after death
- Do they know which doctor has agreed to certify death and how to contact them?

Actions needed:

Facility name:

Address:

For more information visit [CareSearch GP Hub](#)

Here you will find family resources you can order and give to patients and carers.

CareSearch
GP Hub:



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PBS Prescriber Bag medicines for terminal phase symptoms

These medicines are available through the PBS at no cost to prescribers. They can be provided free to patients during home visits for emergency use in managing symptoms or bridging the gap until a prescription is dispensed. Medicines shaded are part of the National Core Community Palliative Care Medicines List and are used to treat common symptoms in straightforward cases.

Medicine	Clinical uses in terminal phase	Strength and form	Pack size	Max qty (packs)
Adrenaline (Epinephrine)	Airway obstruction (nebulised), small volume malignant bleeding (topical)	1 in 1000 (1 mg/mL) injection	5 x 1mL	1
Clonazepam	Agitation, anxiety, distressing breathlessness, refractory distress, seizure	2.5 mg/mL drops	1 x 10mL	1
Furosemide	Oedema associated with heart failure	20 mg/2 mL injection	5 x 2mL	1
Haloperidol	Anxiety, delirium, nausea/vomiting, refractory distress, terminal restlessness	5 mg/mL injection	10 x 1mL	1
Hydrocortisone	Acute severe breathlessness/spinal cord compression, in place of dexamethasone	100 or 250 mg injection (reconstituted to 2mL)	1 x dual chamber vial	2 (100mg) or 1 (250mg)
Hyoscine butylbromide	Respiratory tract secretions, noisy breathing, managing cramps with bowel obstruction	20 mg/mL injection	5 x 1mL	1
Metoclopramide	Nausea/vomiting	10 mg/2 mL injection	10 x 2mL	1
Midazolam	Agitation, distressing breathlessness, refractory distress, seizure	5 mg/mL injection	10 x 1mL	1
Morphine	Distressing breathlessness (first line), pain	10, 15, 20, or 30 mg/mL injection	5 x 1mL	1
Naloxone	Reversing lifethreatening opioid overdose	400 microgram/mL injection	5 or 10 x 1mL	2

Based on: caring@home/Pharmaceutical Society of Australia. National Core Community Palliative Care Medicines List [Internet]. Brisbane, QLD: caring@home; 2024. Available from: <https://www.caringathomeproject.com.au/for-health-professionals/national-core-community-palliative-care-medicines-list>

The PBS Prescriber Bag for palliative care

People with palliative care needs may choose to be cared for and die at home. This may include their private dwelling or a residential aged care facility. The evidence encourages the prescribing of all terminal phase medicines in advance, known as anticipatory prescribing. While it should not be a substitute for good advance planning, the PBS Prescriber Bag provides a safety net for those who deteriorate rapidly and unexpectedly at the end of life. This ensures rapid symptom management when needed, though deterioration can occur suddenly.

Prescriber Bag supply order forms allow monthly ordering of medicines and can be requested from Services Australia:

<https://www.servicesaustralia.gov.au/pbs-and-rpbs-official-stationery?context=20>

Complete the form, sign it, and give it to a community pharmacist for dispensing.

Dosing information

For specific dosing advice, refer to the [CareSearchgp](#) or [palliMEDS apps](#) (free to download), Palliative Care Therapeutic Guidelines, or Australian Medicines Handbook. You can also consult your local pharmacist.

Notes on use of specific medicines

- Morphine: avoid repeated dosing in people with serious kidney failure.
- Clonazepam or midazolam: may help with breathlessness if anxiety is present. They may also help to relieve rigidity associated with endstage Parkinson's Disease if dopaminergic medication has ceased.
- Adrenaline in nebulised form may give temporary relief of stridor with breathlessness.

Practical tips

- Order your PBS Prescriber Bag medicines at the end of each month.
- Securely store S8 medicines (especially opioids) and follow local legislative guidelines.
- Consider carrying equipment to administer medicines subcutaneously.
- Limit subcutaneous injections to 1.5 mL to avoid causing pain at the injection site.

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			

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Bereavement care in general practice

General practitioners are often the first point of contact for people who are bereaved. Their ongoing relationships with patients, knowledge of personal and medical histories, and role in continuing care place GPs in a strong position to support healthy adjustment and to notice when grief may be becoming more complex or prolonged.

Grief as a natural response

Grief is a normal response to loss. In the weeks and months following a death, individuals may experience sadness, emotional pain, and disruption to daily life. For most, the intensity of grief eases over time without the need for formal intervention. GPs can provide valuable support to these patients by:

- Asking a practice nurse to follow up the family or carer with a phone call
- Acknowledging a bereaved patient's loss and asking how they are going during an appointment
- Offering an appointment to discuss the death, particularly if the GP cared for both the deceased and the bereaved
- Using routine visits to monitor the person's overall health and management of chronic conditions.

When to be concerned

In a small number of cases, grief persists and interferes with daily functioning. Prolonged Grief Disorder (PGD) is now recognised in the DSM-5-TR and ICD-11 as a distinct mental health condition affecting 3–10% of bereaved adults. Diagnosis is typically made between 6 and 12 months after a loss, depending on the criteria used.

Patients with PGD may experience persistent, preoccupation with the deceased, emotional distress, and a sense of meaninglessness. These symptoms can impair social, occupational, or personal functioning and are not better explained by depression or PTSD. Risk factors for PGD include:

- loss of a close person (e.g., partner or child)
- prior depression or trauma
- sudden or violent death
- limited social support
- disrupted mourning rituals
- older age or cognitive decline.

Assessment and clinical considerations

Recognising PGD in a busy clinical setting can be challenging. Brief, grief-specific self-report tools like the PG-13-R and TGI-SR+ can help initiate assessment and conversation. While these tools are practical, they are best used as screening aids rather than diagnostic tools.

Structured clinical interviews aligned with ICD-11 and DSM-5-TR are in development and awaiting further validation.

PGD may overlap with depression and PTSD but has distinct clinical features. Differentiating between these conditions can help guide appropriate care and referral pathways.

Grief responses vary across cultural groups. Considering the bereaved person's cultural norms, mourning practices, and access to support may assist in providing assessments appropriate to their context.

Referral pathways

Referral to a psychologist or psychiatrist with expertise in grief should be considered if symptoms such as a sense of meaninglessness and preoccupation with the deceased persist beyond 6–12 months or if symptoms interfere with daily function. This can be supported by preparing a GP [Mental Health Treatment Plan](#) under the Better Access Initiative.

Bereaved people may also be eligible for specialist bereavement support through the palliative care service that cared for their loved one.

If a GP does not have a list of preferred mental health providers, the [Find a Psychologist](#) online directory by Australian Psychological Society may be helpful.

Resources

- [Grief Australia](#) (includes the My Grief App)
- Bereavement for GPs: [CareSearchgp App](#)
- Grief and bereavement: [CareSearch Clinical Evidence Summary](#)

References used in this guide

Killikelly C, Smith KV, Zhou N, Prigerson HG, O'Connor MF, Kokou-Kpolou CK, Boelen PA, Maercker A. [Prolonged grief disorder](#). *Lancet*. 2025 May 3;405(10489):1621-1632. doi: 10.1016/S0140-6736(25)00354-X.

O'Connor M, Breen LJ. [General practitioners' experiences of bereavement care and their educational support needs: A qualitative study](#). *BMC Med Educ*. 2014 Mar 27;14:59. doi: 10.1186/1472-6920-14-59.



MyMedicare for GPs providing palliative care: A factsheet

What is MyMedicare?

MyMedicare is an Australian Government initiative designed to enhance patient-centred care by enabling patients to voluntarily register with a single general practice. The initiative improves continuity of care, especially for older people or those with complex or chronic health conditions. This includes people with palliative care needs who need ongoing, coordinated management.

Why this matters for palliative care

Palliative care patients often require regular follow-up to manage symptoms such as pain, breathlessness, and emotional distress. MyMedicare provides a framework for GPs to deliver consistent, ongoing care, offering reassurance to both patients and their families. It also encourages multidisciplinary collaboration, helping GPs coordinate with specialists, allied health providers, and community nurses to address patients' physical, psychological, and spiritual needs.

Key features of MyMedicare for GPs

The older person is eligible for the pathway if:

- **Voluntary patient registration:** Palliative care patients can register with a single GP practice, allowing consistent care until the end of life.
- **Continuity of care payments:** GPs receive financial support for managing registered patients with complex needs, incentivising regular follow-ups and proactive care.
- **Enhanced coordination:** MyMedicare promotes collaboration between GPs and palliative care specialists to ensure patients' evolving needs are met without service gaps.
- **Telehealth integration:** Telehealth enables GPs to monitor symptoms and provide consultations remotely, particularly for patients in advanced stages of illness or with mobility challenges.
- **Data sharing:** Digital platforms like My Health Record give palliative care providers immediate access to patient information, improving care coordination and care decisions.
- **Advance care planning (ACP):** Structured ACP discussions help document and respect patients' end-of-life preferences, reducing unnecessary hospital admissions or interventions.

Care coordination payments

GPs managing registered palliative care patients may receive care coordination payments, recognising the complexity of managing these cases. This financial support enables GPs to allocate time and resources to regular symptom reviews and coordination with home care, respite, and allied health services.

Implications for practice

- **Holistic and multidisciplinary management:** GPs act as central coordinators, ensuring care reflects the patient's comprehensive needs.
- **Support for GPs:** Financial incentives under MyMedicare empower GPs to provide high-quality, continuous care tailored to the changing needs of older patients and those approaching the end of life.
- **Improved continuity:** MyMedicare strengthens the GP-patient relationship, ensuring care adapts to evolving symptoms or circumstances, including emergency care or hospitalisation.

Further information

For more details on MyMedicare and patient registration, visit the Australian Government's [MyMedicare](#) website. You can also download plain language [fact sheets and introductory videos](#) to help patients and their families understand the program and its benefits.



General Practice in Aged Care Incentive (GPACI)

What is GPACI?

The General Practice in Aged Care Incentive (GPACI) aims to improve GP services in residential aged care homes. It provides financial incentives to encourage GPs to offer regular, comprehensive care, including palliative care, through structured payments and support.

Why this matters for palliative care

Residents in aged care homes with palliative care needs often require ongoing, complex care. GPACI promotes frequent and planned visits from GPs, ensuring better continuity of care, symptom management, and quality of life for people approaching the end of life.

Key features for GPs

- **Incentive payments:** GPs earn \$300 per year per patient under GPACI. Practices receive \$130 annually per patient. These payments supplement existing Medicare and DVA rebates.
- **Regular care planning:** GPs must provide two care planning services per year and visit patients as least twice per quarter. This helps manage symptoms and review end-of-life care preferences.
- **Service requirement:** GPs must deliver at least eight services annually to each registered patient. This ensures consistent care and symptom monitoring, particularly for palliative patients.
- **Collaboration:** GPACI promotes collaboration between GPs, aged care staff, and specialist providers, coordinating palliative care as part of a multidisciplinary team.
- **Telehealth services:** In rural and remote areas (MMM 4-7), GPs can use telehealth to provide care when in-person visits are difficult or not possible.

Record keeping and reporting

GPs must maintain detailed documentation of each visit, including care plans and symptom reviews, to meet GPACI compliance and improve communication between the GP and care team.

Preventive care focus

GPACI encourages GPs to focus on preventing hospitalisations by managing symptoms and planning care in advance, such as prescribing medications ahead of potential crises.

Support for family communication

Regular visits also help GPs engage with families, keeping them informed and involved in the care planning process, which is especially important in palliative care.

Further information

For more details on eligibility, payments, and the GPACI process, visit the Australian Government's [General Practice in Aged Care Incentive](#) webpage.

About CareSearch



palliative care knowledge network

CareSearch including palliAGED is a nationally funded palliative care project supported by the Australian Government. It provides evidence-based resources to health professionals, patients, and families across all care settings. CareSearch translates the latest research into practical, accessible tools to improve care at the end of life.

Most resources in this kit can be downloaded directly from the [CareSearch](#) or [palliAGED](#) websites, with many also available in print. To explore more tools and learning opportunities, visit the [CareSearch GP Hub](#) at <https://www.caresearch.com.au/Health-Professionals/General-Practitioner>

Check out
the GP Hub:



Further resources for GPs

In addition to CareSearch, a number of national palliative care programs provide tools, training, and information tailored to support general practitioners and their teams across aged, primary, and community care settings.

Advance Care Planning Australia



advancecareplanning.org.au

Provides advice and support for advance care planning across all Australian states and territories. Offers free training and education for health and care professionals.

Advance Project



theadvanceproject.com.au/

A free, evidence-based program with practical tools and training resources for GPs, general practice nurses, and aged care staff in community and residential settings. Supports conversations around advance care planning and the assessment of palliative and supportive care needs.

CarerHelp



carerhelp.com.au

Designed for people caring for someone approaching the end of life. Offers practical advice, tools, and multilingual resources to support carers in their role.

caring@home



caringathomeproject.com.au

Provides education and clinical resources for health professionals to support families and carers managing symptoms and pain at home. The palliMEDs app is also available to familiarise GPs with eight palliative care medicines endorsed by the Australian & New Zealand Society of Palliative Medicine (ANZSPM).

palliAGED



palliaged.com.au

An online evidence-based resource for health professionals and aged care staff, offering guidance on delivering quality palliative care in aged care settings.



palliative care knowledge network



Patient Carer Resource

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

[caresearch.com.au](https://www.caresearch.com.au)

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



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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.

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					
Practical 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 themselves					
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.

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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.

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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.

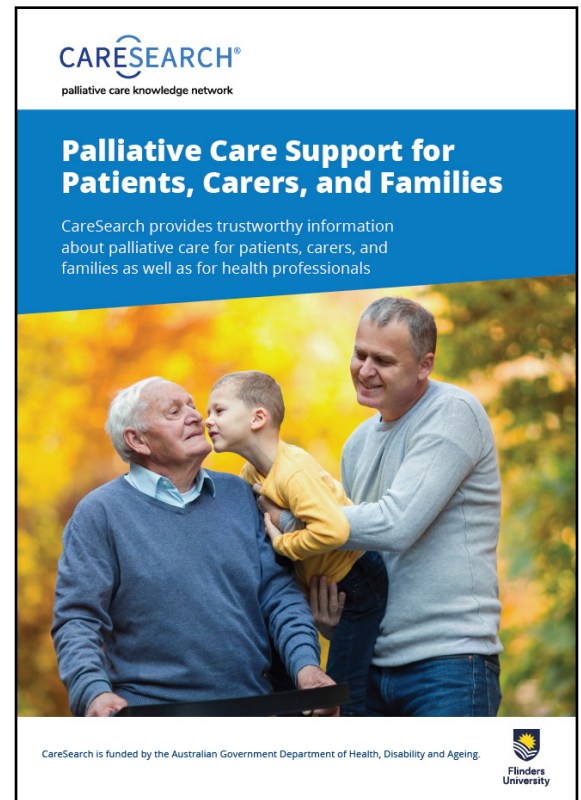
Some may have more complex needs and symptoms that need careful management. In this case there may be the continuing involvement of a specialist team and short or longer stays in a hospice or palliative care ward.

Palliative Care Support for Patients, Carers, and Families Booklet

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)

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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.

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			

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