



palliative care knowledge network



Nurses

Information and resources
to support quality palliative
care at the end of life

caresearch.com.au

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Nurses pack contents

With increasing numbers of people with chronic illness and older people approaching the end of their life, all health professionals will need to help with palliative care. Often this will be in the community setting.

To help nurses provide community-based palliative care, we have brought together this pack of resources.

A guide to using CareSearch for Nurses

Relevant CareSearch information for nurses working in the community.

Recognising the need for palliative care: Tools to help you identify changes

It can be more difficult to notice subtle changes in a regular client's condition. Use these tools to assess for deterioration and to identify unmet supportive and palliative care needs:

- SPICT Tool
- SPICT4ALL Tool
- NAT-PD Tool

Communication with patients, carers, and families

Communication with patients at end of life is essential for planning and decision-making. It can also be hard. This sheet has tips on what to say and how.

Abbey Pain Scale

Pain is one of the most common symptoms in palliative care. This scale can help you monitor changes in pain status when caring for people with dementia or patients unable to state their needs.

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

A form to help carers to identify their own care needs to discuss with their GPs.

Medicines from the PBS prescriber bag for terminal phase symptoms

A practical list of medicines that can be used for responding to unanticipated needs in the terminal phase.

Responding to grief, bereavement, and loss

A set of tips for nurses on recognising and responding to grief and loss reactions.

Personal and professional practice

- Self-care plan for nurses
- MBS items for nurse practitioners

Use the QR code to download or order additional copies of these resources

caresearch.com.au/resourcepacks



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A guide to using CareSearch for Nurses

People with a life-limiting illness and/or approaching death often look to nurses for support. The [CareSearch Nurses Hub](#) provides nurses with evidence-based information and resources.

Here are some ways the Nurses Hub can help

1. Talking about end of life can be hard. [Communication with patients, carers, and family](#) provides guidance on what you can say.
2. [Communication within the care team](#) has practical tips for case conferences, handovers, and interdisciplinary team meetings.
3. Managing symptoms is an important part of palliative care. You can find information on how to recognise, assess, and manage [ten commonly experienced symptoms and issues](#). Each symptom page has a My CPD reflection form for you to record your learning.
4. The [Planning and coordinating care](#) pages provide practical information on end-of-life nursing care.
5. Careful [assessment](#) is key to [recognising deterioration in a person's health](#). CareSearch has information and interactive versions of validated tools to help.
6. Palliative care represents a unique population and off-label use of medicines is common. The Nurses Hub [Medicines management](#) section can help and, for terminal phase prescribing, [visit our palliAGED section Symptom Management](#).
7. A syringe driver is often used when a person can no longer swallow. For information including on using syringe drivers visit the [Syringe drivers](#) page.
8. Good [end-of-life care](#) supports someone to have a good and dignified death. It also involves caring for the family during the terminal phase and providing respectful [after-death care](#).
9. [Loss](#) is a universal part of the experience of life-limiting illness and old age. This section can help you recognise and respond to needs at this time.
10. This repository of [forms, checklists and tools](#) can assist you in providing and documenting palliative care. These may be downloaded for free.

Visit the [CareSearch Nurses Hub](#)



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The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health.

- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (eg. The person stays in bed or in a chair for more than half the day.)
- Depends on others for care due to increasing physical and/or mental health problems.
- The person's carer needs more help and support.
- Progressive weight loss; remains underweight; low muscle mass.
- Persistent symptoms despite optimal treatment of underlying 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 one or multiple life-limiting conditions.

Cancer

Functional ability deteriorating due to progressive cancer.

Too frail for cancer treatment or treatment is for symptom control.

Dementia/ 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 episodes 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.

Persistent paralysis after stroke with significant loss of function and ongoing disability.

Heart/ vascular disease

Heart failure or extensive, untreatable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe, chronic lung disease; with 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 other conditions, multiple conditions and/or complications that are not reversible; any treatment available will have a poor outcome.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting 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 treatment and medication to ensure the person receives optimal care; minimise polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, share, and review care plans.

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The SPICT™ helps us to look for people who are less well with one or more health problems. These people need more help and care now, and a plan for care in the future. Ask these questions:

Does this person have signs of poor health or health problems that are getting worse?

- Unplanned (emergency) admission(s) to hospital.
- General health is poor or getting worse; the person never quite recovers from being more unwell. (This means the person is less able to manage day to day life and often stays in bed or in a chair for more than half the day).
- Needs help from others for care due to increasing physical and/ or mental health problems.
- The person's carer needs more help and support.
- Has clearly lost weight over the last few months; or stays too thin.
- Has troublesome symptoms most of the time despite good treatment of their health problems.
- The person (or family) asks for palliative care; chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Does this person have any of these health problems?

Cancer

Less able to manage usual activities; health getting poorer.

Not well enough for cancer treatment or treatment is to help with symptoms.

Dementia/frailty

Unable to dress, walk or eat without help.

Eating and drinking less; difficulty with swallowing.

Has lost control of bladder and bowels.

Not able to communicate by speaking; not responding much to other people.

Frequent falls; fractured hip.

Frequent infections; pneumonia.

Nervous system problems

(eg Parkinson's disease, MS, stroke, motor neurone disease)

Physical and mental health are getting worse.

More problems with speaking and communicating; swallowing is getting worse.

Chest infections or pneumonia; breathing problems.

Severe stroke with loss of movement and ongoing disability.

Heart or circulation problems

Heart failure or has had attacks of chest pain. Short of breath when resting, moving or walking a few steps.

Very poor circulation in the legs; surgery is not possible.

Lung problems

Unwell with long term lung problems. Short of breath when resting, moving or walking a few steps even when the chest is at its best.

Needs to use oxygen for most of the day and night.

Has needed treatment with a breathing machine in the hospital.

Other conditions

People who are less well and may die from other health problems or complications. There is no treatment available or it will not work well.

Kidney problems

Kidneys not working well; general health is getting poorer.

Stopping kidney dialysis or choosing supportive care instead of starting dialysis.

Liver problems

Worsening liver problems in the past year with complications like:

- fluid building up in the belly
- being confused at times
- kidneys not working well
- infections
- bleeding from the gullet

A liver transplant is not possible.

What we can do to help this person and their family.

- Start talking with the person and their family about any help needed now and why making plans for care is important in case things change.
- Ask for help and advice from a nurse, doctor or other professional who can assess the person and their family and help plan care.
- We can look at the person's medicines and other treatments to make sure we are giving them the best care or get advice from a specialist if problems are complicated or hard to manage.
- We need to plan early if the person might not be able to decide things in the future.
- We make a record of the care plan and share it with people who need to see it.

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NEEDS ASSESSMENT TOOL: PROGRESSIVE DISEASE (NAT: PD) USER GUIDE

Purpose of the NAT: PD

- Used in both generalist and specialist settings, the Needs Assessment Tool: Progressive Disease (NAT: PD) can assist in matching the types and levels of need experienced by people with progressive chronic diseases (eg cancer, heart failure, COPD) and their caregivers with the most appropriate people or services to address those needs.
- In generalist settings (eg general practice, oncology and cardiology), the NAT: PD can be used to determine which needs may be met in that setting and which needs are more complex and may be better managed by specialists.
- In specialist settings (eg specialist palliative care services), the NAT: PD can assist in determining when complex needs have been met and act as a discharge planning tool, or to identify the need for ongoing support.
- The NAT: PD is an important tool for facilitating communication between primary and specialist care providers about patient needs and actions taken to address these.

Completing the NAT: PD

The NAT: PD is a one-page assessment tool that can be completed by health professionals across a range of disciplines. When completing the NAT: PD, the following steps should be followed:

1. ASSESS patient/caregiver level of concern FOR EVERY ITEM, using the response options: "none", "some/potential for" or "significant".
2. CONSIDER the range of issues within each domain that apply to a person at this stage of their illness. Prompts are provided on a separate page to help you.
3. ACT on each need where you identified some concern ("some/potential for" or "significant"). Your actions may include: directly managed by you, managed by another member of your care team, or referral to someone outside your care team. Record your action on the NAT: PD.
4. REFER if required by completing the referral section at the bottom of the tool, ensuring that information regarding the type of referral, the priority of the referral and client knowledge of the referral is included.
5. INFORM other members of the care team of the outcomes of the needs assessment by:
 - a. Filing one copy of the NAT: PD in the patient's medical file.
 - b. Sending a copy to the person's GP/oncologist/cardiologist/other specialist.
 - c. If a referral is required, forwarding a copy to the referee.
6. REASSESS needs by completing the NAT: PD approximately monthly or when the patient's or family's situation, or functional status changes.

NEEDS ASSESSMENT TOOL : PROGRESSIVE DISEASE (NAT: PD)

COMPLETE ALL SECTIONS

PATIENT NAME: _____

DATE: _____ DIAGNOSIS: _____

PATIENT/ADDRESS LABEL

SECTION 1: PRIORITY REFERRAL FOR FURTHER ASSESSMENT

	Yes	No	If dotted boxes are ticked, consider assessment by SPCS
1. Does the patient have a caregiver readily available if required?		*	
2. Has the patient or caregiver requested a referral to a specialist palliative care service (SPCS)?	*		
3. Do you require assistance in managing the care of this patient and/or family?	*		

SECTION 2: PATIENT WELLBEING (Refer to the prompt sheet for assistance)

	Level of Concern			Action Taken		
	None	Some/Potential	Significant	Directly managed	Managed by other care team member	Referral required (complete referral section below)
1. Is the patient experiencing unresolved physical symptoms (including problems with pain, breathlessness, sleeping, appetite, bowel, fatigue, nausea, oedema or cough)?						
2. Does the patient have problems with daily living activities?						
3. Does the patient have psychological symptoms that are interfering with wellbeing or relationships?						
4. Does the patient have concerns about how to manage his/her medication and treatment regimes?						
5. Does the patient have concerns about spiritual or existential issues?						
6. Does the patient have financial or legal concerns that are causing distress or require assistance?						
7. Does the patient have concerns about his/her sexual functioning or relationship?						
8. From the health delivery point of view, are there health beliefs, cultural or social factors involving the patient or family that are making care more complex?						
9. Does the patient require information about: (tick any options that are relevant)	<input type="checkbox"/> The diagnosis <input type="checkbox"/> Treatment options <input type="checkbox"/> Financial/legal issues <input type="checkbox"/> Advance directive/resuscitation order <input type="checkbox"/> The prognosis <input type="checkbox"/> Medical/health/support services <input type="checkbox"/> Social/emotional issues <input type="checkbox"/> Other:					

COMMENTS: _____

SECTION 3: ABILITY OF CAREGIVER OR FAMILY TO CARE FOR THE PATIENT (Refer to the prompt sheet for assistance)

Who provided this information? (please tick one) <input type="checkbox"/> Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Both	Level of Concern			Action Taken		
	None	Some/Potential	Significant	Directly managed	Managed by other care team member	Referral required (complete referral section below)
1. Is the caregiver or family distressed about the patient's physical symptoms?						
2. Is the caregiver or family having difficulty providing physical care?						
3. Is the caregiver or family having difficulty coping?						
4. Is the caregiver or family have difficulty managing the patient's medication and treatment regimes?						
5. Does the caregiver or family have financial or legal concerns that are causing distress or require assistance?						
6. Is the family currently experiencing problems that are interfering with their functioning or inter-personal relationships, or is there a history of such problems?						
7. Does the caregiver require information about: (tick any options that are relevant)	<input type="checkbox"/> The diagnosis <input type="checkbox"/> Treatment options <input type="checkbox"/> Financial/legal issues <input type="checkbox"/> Advance directive/resuscitation order <input type="checkbox"/> The prognosis <input type="checkbox"/> Medical/health/support services <input type="checkbox"/> Social/emotional issues <input type="checkbox"/> What to do in event of patient's death					

COMMENTS: _____

SECTION 4: CAREGIVER WELLBEING (Refer to the prompt sheet for assistance)

Who provided this information? (please tick one) <input type="checkbox"/> Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Both	Level of Concern			Action Taken		
	None	Some/Potential	Significant	Directly managed	Managed by other care team member	Referral required (complete referral section below)
1. Is the caregiver or family experiencing physical, practical, spiritual, existential, sexual or psychological problems that are interfering with their own wellbeing or functioning?						
2. Is the caregiver or family experiencing grief over the impending or recent death of the patient that is interfering with their own wellbeing or functioning?						

COMMENTS: _____

IF REFERRAL REQUIRED FOR FURTHER ASSESSMENT OR CARE, PLEASE COMPLETE THIS REFERRAL SECTION

1. Referral to: (Name) _____

2. Referral to: (Specialty) ☐ General practitioner ☐ Social worker ☐ Psychologist ☐ Specialist palliative care service ☐ Physiotherapist
☐ Community nurse ☐ Oncologist ☐ Cardiologist ☐ Occupational therapist ☐ Other: _____

3. Priority of assessment needed: ☐ Urgent (within 24 hours) ☐ Semi-Urgent (2-7 days) ☐ Non-Urgent (next available)

4. Discussed the referral with the client. ☐ Yes ☐ No

5. Client consented to the referral. ☐ Yes ☐ No

6. Referral from: Name: _____ Position: _____ Signature: _____

PATIENT WELLBEING

Physical symptoms

- Does the patient present with unresolved physical symptoms such as drowsiness, fatigue, dyspnoea, vomiting/nausea, persistent cough, pain, oedema, constipation, diarrhoea, sleep problems or loss appetite?

Activities of daily living

- Is the patient having difficulty with toileting, showering, bathing, or food preparation?
- Is there a caregiver to assist the patient?

Psychological

- Is the patient experiencing sustained lowering of mood, tearfulness, guilt or irritability, loss of pleasure or interest in usual activities?
- Is the patient experiencing feelings of apprehension, tension, anger, fearfulness or nervousness, hopelessness or a sense of isolation?
- Is the patient requesting a hastened death?

Medication and treatment

- Is the patient able to manage complex medication and treatment regimes?

Spiritual/Existential

- Is the patient feeling isolated or hopeless?
- Does the patient feel that life has no meaning or that his/her life has been wasted?
- Does the patient require assistance in finding appropriate spiritual resources or services?

Financial/Legal

- Are there financial concerns relating to loss of income or costs of treatment, travel expenses, or equipment?
- Is the family socio-economically disadvantaged?
- Are there conflicting opinions between patient and family relating to legal issues such as end-of-life care options and advance care plans?
- Is the patient or family aware of the various financial schemes available and do they need assistance in accessing these?

Sexual

- Does the patient have concerns about his/her sexual functioning or relationship?

Health Beliefs, Social and Cultural

- Does the patient or family have beliefs or attitudes that make health care provision difficult?
- Are there any language difficulties? Does the patient or family require a translator?
- Is the family preventing information about prognosis from being disclosed to the patient?
- Is the patient or family feeling socially isolated?
- Does the family live more than 50km from the primary service provider?
- Is the patient of Aboriginal or Torres Strait Islander descent?
- Is the patient over 75 years of age? (NB: older patients are under-represented in SPCSs.)

Information

- Does the patient want more information about the course and prognosis of the disease and treatment options?
- Is the patient aware of the various care services available to assist them and do they need assistance in accessing these?

ABILITY OF CAREGIVER OR FAMILY TO CARE FOR PATIENT

Physical symptoms

- Are the patient's physical symptoms causing the caregiver or family distress?

Providing physical care

- Is the caregiver or family having difficulty coping with activities of daily living or practical issues such as equipment and transport?

Psychological

- Is the caregiver or family having difficulty coping with the patient's psychological symptoms?
- Is the caregiver or family requesting a hastened death for the patient?

Medication and treatment

- Is the caregiver or family having difficulty managing complex medication and treatment regimes?

Family and Relationships

- Is there any communication breakdown or conflict between patient and family over prognosis, treatment options or care giving roles?
- Is the patient particularly concerned about the impact of the illness on the caregiver or family?

Information

- Does the caregiver or family want more information, eg about the course and prognosis of the disease and treatment?
- Is the caregiver or family aware of the care services available to assist them and do they need assistance in accessing these? (eg respite, financial and legal services, psychological services, support groups, pastoral care.)

CAREGIVER WELLBEING

Physical and psychosocial

- Is the caregiver experiencing physical symptoms eg fatigue, physical strain, blood pressure/heart problems, stress related illness, or sleep disturbances?
- Is the caregiver feeling depressed, hopeless, fearful, nervous, tense, angry, irritable or critical of others, or overwhelmed?
- Does the caregiver have spiritual/existential issues that are of concern?
- Does the caregiver have concerns about his/her sexual functioning or relationship?

Bereavement Grief (pre and post death)

- Is the caregiver or family experiencing intrusive images, severe pangs of emotion, denial of implications of loss to self and neglect of necessary adaptive activities at home or work?

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Communication with patients, carers, and families in palliative care includes supporting people through caring tasks and the development of a therapeutic relationship to build trust and a sense of solidarity and empowerment. The following tips are to get you started.

Knowing when a discussion is needed

Triggers indicating the need for discussion include:

- When a life-limiting advanced progressive illness is diagnosed.
- When a treatment decision needs to be made.
- When there is a change in the person's condition, or when the person, carers, or a health professional perceive a change.
- When family or carers are distressed or overwhelmed.
- Requests or expectations that are inconsistent with clinical judgement.

Building relationships to understand and exchange information

- Actively listen and allow the person to express themselves; this may involve periods of silence.
- Ask open-ended questions, for example:
 - *'What troubles you the most?'*
 - *'With what you know about your illness, what's most important to you?'*
- Paraphrase and summarise to check that you have understood correctly:
 - *'What I hear you saying is that you have been experiencing ... which has been making you feel ... Have I understood that correctly?'*

Emotions and uncertainty

- Ask what information the person and their support network want to receive:
 - *'Do you want to know the details of the [diagnosis] [care plans]?'*
 - *'Would you prefer that I talk with someone in your family?'*
- Ask about the impact of any symptoms and what other factors influence this impact them:
 - *'How have you been coping with these experiences?'*
 - *'I can see you are really concerned about ... Can you tell me more about that?'*
 - *'What are you (most) worried about?'*
 - *'Is it ok for us to talk about what this means for you?'*

- Ask whether there are any other practical issues that might influence the choice of treatment, including cultural, spiritual, and geographical factors.
- Ask the person about their current and intended place of care.
 - *'Can you please help me to understand what I need to know about your beliefs and practice to take the best care of you?'*
 - *'Is there someone else you would like me to involve or speak to?'*

Acknowledging and involving patients, carers, and family when delivering care

During care you should be aware of both verbal and non-verbal signals that you are communicating.

Verbal communication tips

- Introduce yourself and others in the room there to help and explain what team members are going to do.
- Ask permission before you begin and invite the person to ask questions.
- Ask about and acknowledge their needs and goals, and any concerns.
- Acknowledge the role of carer(s).
- Speak with a caring voice tone and avoid speak too loudly or quickly.
- Use teach-back method: Give information in small chunks and ask them to tell you what they have understood. Clarify as needed.

Non-verbal communication tips

- Respect the person's privacy and dignity e.g. draw a curtain, close the door as appropriate.
- Give the person your full attention and use eye contact where appropriate.
- Nod your head to show you are listening and do not interrupt the person.
- When talking with the person, if possible, position yourself at their level.
- A person's health literacy level should guide communication. Assume low health literacy, use plain language, and avoid clinical jargon and acronyms.
- Document what is discussed and said so that all providers of care are informed.

Useful tools

- SPICT and SPICT4ALL for recognising deterioration.
- SPIKES for delivering bad news.
- The NURSE mnemonic for responding to emotional cues.

Visit the [CareSearch Nurses Hub](https://www.caresearch.com.au/CareSearch-Nurses-Hub)



CareSearch. Communication with Patients, Carers, and Family [Internet]. Adelaide SA: CareSearch, Flinders University; [updated 2022 Oct 13; cited 2024 Jun 25]. Available from: <https://www.caresearch.com.au/Health-Professionals/Nurses/Communication/Communication-with-Patients-Carers-and-Family>

Abbey Pain Scale

Enter pain scores for each of the following six areas:

Absent = 0; Mild = 1; Moderate = 2; Severe = 3

Patient details

Surname.....
 Title.....
 Given names.....
 DOB..... MRN.....
 Address.....
 Suburb.....
 Postcode.....

Enter date:					
Enter time:					
Sign entry:					
1. Vocalisation e.g. whimpering, groaning, crying.					
2. Facial Expression e.g. looking tense, frowning, grimacing, looking frightened.					
3. Change in body language e.g. fidgeting, rocking, guarding part of body, withdrawn.					
4. Behavioural change e.g. increased confusion, refusing to eat, alteration in usual patterns.					
5. Physiological change e.g. temperature, pulse or blood pressure outside normal limits, perspiring, flushing or pallor.					
6. Physical changes e.g. skin tears, pressure areas, arthritis, contractures, previous injuries.					
Total scores					
Circle the range that matches the total pain score 0-2 No pain 3-7 mild 8-13 moderate 14+ severe	No pain Mild Moderate Severe	No pain Mild Moderate Severe	No pain Mild Moderate Severe	No pain Mild Moderate Severe	No pain Mild Moderate Severe

Tick the box which matches the type of pain: Acute ☐ Chronic ☐ Acute on chronic ☐

About Abbey Pain Scale

Purpose: Developed to detect pain in elderly residents with dementia and inability to communicate verbally. It is a 6-item 3 point scale tool.

Description: The Abbey Pain Scale was developed for use in aged care and dementia care. The tool is best used as part of an overall pain management plan. As the tool does not differentiate between distress and pain measuring the effectiveness of any interventions is essential. Use the form to collate recordings across an extended period to facilitate monitoring of responses. The Australian Pain Society recommends using the tool as a movement-based assessment and conducting a **second evaluation one hour after any intervention taken**. Repeat hourly until a score of mild pain is reached and then 4 hourly for 24 hours with treatment for pain as required. Contact the GP or pain team if there is no improvement.

Acknowledgement: Abbey J, et al. The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia. Int J Palliat Nurs. 2004 Jan;10(1):6-13.

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

What is the NAT-CC?

Being a carer for someone with a chronic condition is important. It can also be demanding and affect your own health and well-being. GPs have knowledge and experience to help carers with their own health problems. The NAT-CC can help you to identify any concerns that you may have so that your GP may be able to discuss them with you. Your GP cares about your health and well-being.

How does the NAT-CC work?

For you, the NAT-CC helps to name the issues which are important to you about your own health and well-being. Your GP can help you do this. It also helps you to note which of these you would like to discuss with your GP, and whether you would like to do this today or at another time. For you and your GP, the NAT-CC is like a conversation-starter, to help guide what you discuss today. It is also like a planner, to help improve and maintain your own health.

How are my health concerns protected?

Your privacy is important, and what you discuss with your GP is confidential. Without your permission, it will not be discussed with anyone else, including the person that you are caring for.

How can I work with my GP to deal with my concerns?

- Complete the NAT-CC before you see the GP, so that they have a chance to read it before seeing you.
- It will be helpful if you book a long appointment with the GP.
- If there are several issues which you would like to discuss soon, your GP might suggest that you make a further appointment to continue on from today's visit.

Information for GPs

- The NAT-CC lists the common concerns of carers regarding their health and well-being.
- The completed NAT-CC identifies your patient's concerns about the person's health and well-being.
- It also ranks the relative importance of these concerns, and indicates when the patient would like to discuss them. That may not necessarily be today.
- It can be completed by the patient, or with your help.
- You may wish to flag with the patient any issues of concern that they may not wish to discuss.
- If your patient identifies several concerns to discuss today, you may wish to discuss those of most importance to the patient, and suggest another appointment to complete the rest.

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			Helpful to discuss with my GP, nurse or health provider	
	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			Helpful to discuss with my GP, nurse or health provider	
	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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Medicines from the PBS Prescriber bag for terminal phase symptoms

PBS Item Code	Pharmaceutical benefit and form	Strength	Packet size	Max qty (packs)	Max qty (units)
3451P	Adrenaline (Epinephrine) injection	1 in 1000 (1 mg/mL)	5 x 1mL amps	1	5
3478C	Clonazepam oral liquid	2.5 mg/mL (0.1 mg/drop)	1 x 10mL	1	1
3466K	Furosemide (Frusemide) ampoule	20 mg/ 2 mL	5 x 2mL	1	5
3456X	Haloperidol ampoule	5 mg/mL	10 x 1mL	1	10
3470P	Hydrocortisone Sodium Succinate injection*	100 mg (reconstituted to 2mL)	Single injection	2	2
	OR	OR			
3471Q	Hydrocortisone Sodium Succinate injection*	250 mg (reconstituted to 2mL)	Single injection	1	1
3473T	Hyoscine Butylbromide ampoule	20 mg/mL	5 x 1mL	1	5
3476Y	Metoclopramide ampoule	10 mg/ 2 mL	10 x 2mL	1	10
10178Q	Midazolam ampoule	5 mg/mL	10 x 1mL	1	10
10862Q	Morphine ampoule	10 mg/mL	5 x 1mL	1	5
	OR	OR			
3479D	Morphine ampoule	15 mg/mL	5 x 1mL	1	5
	OR	OR			
10868B	Morphine ampoule	20 mg/mL	5 x 1mL	1	5
	OR	OR			
3480E	Morphine ampoule	30 mg/mL	5 x 1mL	1	5
10786Q	Naloxone hydrochloride injection	400 microgram/mL	5 x 1 mL	2	10
	OR	OR			
11233F	Naloxone hydrochloride injection	400 microgram/mL	10 x 1 mL	1	10

Based on the emergency practice concept proposed by Seidel et al 2006 Aust Fam Physician. 2006 Apr;35(4):225-31. Information from PBS listings current as of March 2024. See www.pbs.gov.au for more.

Medicines from the PBS Prescriber bag for terminal phase symptoms

Many people with palliative care needs, choose to be cared for and die at home.

Prescribing medicines in advance (anticipatory prescribing), ensures prompt response when symptoms occur. Yet, people can deteriorate suddenly and rapidly.

In Australia, some medicines are provided without charge to prescribers, who can supply them free on home visits. The Pharmaceutical Benefits Scheme (PBS) prescriber bag list includes medicines which can be useful in caring for the dying, in the home environment. These can be administered immediately to manage symptoms or to see the person through until a prescription can be dispensed.

Prescriber bag supply order forms can be ordered online from [Services Australia](#). The forms allow monthly ordering of medicines. They must be completed, signed, and given to a community pharmacist for dispensing.

The PBS prescriber bag is a safety net for those who deteriorate suddenly at the end of life. It is not a substitute for good advanced planning.

Symptoms common in the terminal phase

Agitation, or terminal restlessness:

Characterised by anguish (spiritual, emotional, or physical), restlessness, anxiety, agitation, and cognitive failure. Sublingual clonazepam, subcutaneous midazolam and subcutaneous haloperidol may be used.

Delirium: Haloperidol is commonly used to reduce distress due to delirium.

Dyspnoea: Subcutaneous morphine is the gold standard. Avoid repeated dosing in people with serious kidney failure. Because there may be an anxiety component, sublingual clonazepam or subcutaneous midazolam may also

have a role. Nebulised adrenaline may give temporary relief if stridor is present.

Nausea and vomiting: For onset of new nausea or vomiting in the terminal phase, when the cause is unknown, haloperidol or metoclopramide are usually used as first-line therapy.

Oedema associated with heart failure: Intravenous or subcutaneous furosemide (frusemide) can be adjusted against the oral dose until symptoms are controlled.

Pain: Subcutaneous morphine can be used in most people with pain. Avoid repeated dosing in severe renal failure. naloxone can be used for opioid poisoning.

Respiratory tract secretions: The inability to clear secretions from the oropharynx or trachea causes pooling of fluids in the throat. This results in rattly breathing. This may be more distressing for the people around than for the person themselves. Hyoscine butylbromide can be used.

Rigidity associated with end-stage Parkinson disease: If dopaminergic medication is ceased, subcutaneous midazolam or sublingual clonazepam may help to relieve rigidity.

Palliative care emergencies: A sudden and life-threatening change in a person's condition. Some emergencies may be unexpected. Some can be foreseen, based on the nature and location of the disease.

These may include:

- superior vena cava obstruction
- catastrophic haemorrhage
- airway obstruction
- seizures
- spinal cord compression.

Morphine and midazolam, administered subcutaneously in the home, can reduce distress.

Subcutaneous hydrocortisone may be used in place of dexamethasone, where an anti-inflammatory is useful (e.g. bowel obstruction, spinal cord suppression, and airway obstruction).

***Note:** The final volume of the hydrocortisone, once reconstituted, is 2mL which may limit the dose that can be comfortably administered.

In managing a bowel obstruction, hyoscine butylbromide is helpful in managing the cramping pain, while haloperidol is preferred for nausea and vomiting. Topical use of adrenaline is suggested for small volume superficial malignant bleeding.

Practical tips

In addition to carrying medicines, bring equipment to administer them.

Order your PBS prescriber bag medicines at the end of the month.

Lock medicines up in a secure place. You are responsible for their security and must adhere to legislative requirements around secure storage of S8 medications such as opiates.

Keep a recording book for administering, supplying, or discarding medications.

The maximum volume generally accepted for a subcutaneous injection is around 1.5mL - larger volumes are more likely to be associated with pain at the injection site. See hydrocortisone and volume considerations above.

Speak with the community pharmacist about stocking these medicines, so the ongoing prescription can be dispensed immediately.

For specific dosing advice, refer to:

- [Australian Medicines Handbook](#)
- [Palliative Care Therapeutic Guidelines](#)
- [CareSearchgp app](#).

Tips for nurses responding to grief, bereavement, and loss

Nurses can play an important role by recognising and supporting the needs related to grief and loss of people with advanced illness, family members and carers. The following tips are to get you started with recognising and managing those needs.

What are we talking about?

- Grief or mourning is a response to loss.
- Anticipatory grief is the grieving prior to loss. It can include grief for the loss of identity, the loss of future plans, or loss of relationship.
- Bereavement is the period of grieving experienced by a person in response to the death of someone close to them.
- Complicated and prolonged grief are terms for a prolonged, intense response to bereavement that negatively affects a person's life including their relationships and employment.
- Disenfranchised grief describes a grief reaction where there is no social recognition that the person has the right to grieve or receive social sympathy or support.

How to recognise grief

Reactions that are common in normal grief include:

- Physical: hollowness in stomach, tightness in the throat or chest, over-sensitivity to noise, loss of appetite, breathlessness, dry mouth, muscle weakness, lack of energy, susceptibility to illness.
- Behavioural: crying, sighing, sleep disturbance, over- or under-activity, absentmindedness, social withdrawal, dreams of the deceased, avoiding reminders, searching and calling out, visiting places associated with the deceased, carrying reminders.
- Cognitive: disbelief, denial, confusion, preoccupation.
- Emotional: anxiety, fear, sadness, anger, guilt, inadequacy, hurt, relief, loneliness.

How to manage bereavement

Good quality bereavement care includes communicating with the family and providing support to them when the person approaches their death; this can impact positively on bereavement after the person has died.

Formal bereavement support might be provided by a multidisciplinary team of nurses, social workers, counsellors, doctors, and chaplains.

It might also help the person if nurses:

- Recognise that for some people, grief may be accompanied by feelings of relief and freedom along with guilt over having these feelings.
- Acknowledge the loss and the person's feelings and take time to listen to their experience and feelings. When a person is talking about a loss, they may not need answers or advice; listening to them may give the greatest comfort.
- Ask about their main concerns for themselves or others (e.g. children, siblings) and other current stressors (e.g. other losses, caring responsibilities, financial strain).
- Provide information and reassurance about grief.
- Recognise that someone may benefit from financial support at this time. In this case, you can direct them to the Australian Government page on What help there is when an adult dies.
- Acknowledge that the bereaved often are exhausted from caring for the deceased. You can suggest that the bereaved person meets their GP particularly if the GP knows them well.
- Encourage them to identify and use existing or new support networks.

Visit the [CareSearch Nurses Hub](https://caresearch.com.au)



Self-care plan:

Health professionals

Name:

Caring for others can be rewarding. However, staff working in aged care look after many people who die. You might find this loss hard to accept. You might find it hard to sleep, no longer enjoy your work, or feel tired. This can affect you and your family. Self-care is what we do to maintain balance in our life.

A self-care plan based on what you like to do can help. We have suggested a few things that you could try, but what you choose will depend on you.

Workplace self-care: Activities to help you at work

Some examples

Regular meetings with supervisors or a more experienced colleague

Join a support group with the people you work with

Attend training programs

My activities:

Physical self-care: Activities that help you to stay fit and healthy

Some examples

Develop a regular sleep routine

Aim for a healthy diet

Take lunch breaks and go for a walk

Get some exercise before/after work regularly

My activities:

Self-care plan

Psychological self-care: Activities that help you to feel clear-headed and able to engage with workplace and personal challenges

Some examples

Keep a reflective journal

Seek regular meetings with supervisors or a more experienced colleague

Turn off your email and work phone outside of work hours

Make time to be with friends and family

My activities:

Emotional self-care: Allowing yourself to safely express your emotions

Some examples

Develop friendships that are supportive

Write or think of three good things that you did each day

Play a sport and have a coffee together after training

Talk to your friends about how you are coping with work and life demands

My activities:

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Self-care plan

Spiritual self-care: Develop a sense of perspective beyond the day-to-day of life which can include religion, but it is not always about religion

Some examples

Engage in reflective practices like meditation

Go on walks to connect with nature

Go to church/mosque/temple

Do yoga

My activities:

Relationship self-care: Maintain healthy, supportive relationships, and ensure that you are not only connected to work people

Some examples

Prioritise close relationships in your life eg, with partners, family and children

Attend the special events of your family and friends

Arrive to work and leave on time every day

My activities:

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MBS items supporting nurse practitioner palliative care provision

MBS Item	Activities	MBS Benefit 100% (as of 01/08/24)
82200	<p>Brief attendance</p> <p>Professional attendance by a participating nurse practitioner for an obvious problem characterised by the straightforward nature of the task that requires a short patient history and, if required, limited examination and management.</p> <p>Telehealth: Item 91192. Phone: Item 91193.</p>	\$14.20
82205	<p>Short attendance (<20 mins)</p> <p>Includes any of the following: taking a history; undertaking clinical examination; arranging any necessary investigation; implementing a management plan; or providing appropriate preventive health care, for one or more health related issues, with appropriate documentation.</p> <p>Telehealth: Item 91178. Phone: Item 91189.</p>	\$31.05
82210	<p>Detailed consultation (>20 mins)</p> <p>Includes any of the following: taking a detailed history; undertaking clinical examination; arranging any necessary investigation; implementing a management plan; or providing appropriate preventive health care, for one or more health related issues, with appropriate documentation.</p> <p>Telehealth: Item 91179. Phone: Item 91190.</p>	\$58.85
82215	<p>Extensive consultation (>40 mins)</p> <p>Includes any of the following: taking an extensive history; undertaking clinical examination; arranging any necessary investigation; implementing a management plan; or providing appropriate preventive health care, for one or more health related issues, with appropriate documentation.</p> <p>Telehealth: Item 91180. Phone: Item 91191.</p>	\$86.80

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