



Primary Health Care

Practical tools and resources
supporting end-of-life care
in the community

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PHC pack contents

Primary health care is a key provider of care and support at the end of life. Ensuring that key palliative care steps are not missed, and processes are well documented is part of good practice.

If you are part of a general practice care team providing care at the end of life, these forms and checklists are for you.

CareSearch for GPs and primary care providers

A guide to the CareSearch GP and PHC Hubs and their resources

Communication starters: Tips for initiating difficult conversations

People often find discussions about end of life and deteriorating health difficult. However, a discussion initiated by you can help people to plan for their future. Prior to an appointment with your client, use this form to prepare for these necessary but difficult conversations.

Recognising changing needs: Tools to help you identify changes

If you see clients regularly, it can be difficult to notice subtle changes in their condition. The SPICT and NAT-PD forms help you systematically assess for deterioration in a person's health and to identify unmet supportive and palliative care needs.

Assessing carer needs: A form to guide discussions

Palliative care focuses on the quality of life for both patients and families. Carers often take on the role and demands of caring without consideration for their own health. This form can be given to the carer to complete and may be used to guide discussions on their own health and wellbeing at their next appointment.

Addressing unanticipated needs: The PBS prescriber bag

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

Supporting a planned home death: The GP's checklist

A checklist for GPs to help guide decision-making, provide support to the patient and family, and flag issues needing to be addressed ahead of time.

MBS items supporting a planned primary health care palliative care pathway

MBS items for GPs, nurse practitioners, and allied health professionals linked to patient palliative care pathways and activities in the home and residential aged care settings.

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Communication starters

Having some communication starters to discuss serious illness and deterioration can be very useful.

Future planning

- It's important for me to understand what matters most to you as we look ahead and make plans for your care. This helps me make sure you get the care that helps you reach your goals. Can we spend a little time talking about this?
- Have you thought about whom you would want to make decisions for you if you were ever unable to make decisions for yourself?
- I get a sense that this is not what you were expecting to hear today.
- Is it OK for us to talk about what this means?
- If it turns out that time is limited, what things would you want to do?
- As you think about the future, what are you worried about?
- This topic deserves time and attention. We don't need to make decisions today. Let's set up a time to talk again when you are ready. In the meantime, here is some material that you may like to review.
- What you just said really helps me understand the situation better.
- I wish we had a treatment that would cure you [make your illness go away].
- It sounds like you may be feeling (sad, angry, scared ...)

Based on the REDMAP framework (<https://www.spict.org.uk/red-map/>) and Physician Orders for Life Sustaining Treatment (POLST)

Discussing deteriorating health

- What do you know about your health problems and what do you think might happen in future?
- If you did get more unwell, what would be the most important things for you and your family?
- Is there anything that is particularly important for you or your family that we should know about?
- Sometimes people choose a family member or a close friend to make decisions for them if they get less well.....Is that something you've thought about? Have you talked to your family about it?
- I am glad you feel better, and I hope you will stay well, but I am worried about what might happen if
- Can we talk about how we might cope with not knowing exactly what will happen and when? What would be the best way for us to talk about that?
- I wish we had more treatment for.... could we talk about what we can do if that is not possible/is not going to help you?

Based on Using SPICTM <https://www.spict.org.uk/using-spict>

Serious illness communication guide

- Understanding: What is your understanding now of where you are with your illness?
- Information preferences: How much information about what is likely to be ahead with your illness would you like from me? (e.g. Some patients like to know about time, others like to know what to expect, others like to know both.
- Prognosis: Share prognosis, tailored to information preferences
- Goals: If your health situation worsens, what are your most important goals?
- Fears/Worries: What are your biggest fears and worries about the future with your health?
- Function: What abilities are so critical to your life that you can't imagine living without them?
- Trade-offs: If you become sicker, how much are you willing to go through for the possibility of gaining more time?
- Family: How much does your family know about your priorities and wishes?

Reference

Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. [Communication about serious illness care goals: a review and synthesis of best practices](#). JAMA Intern Med. 2014 Dec;174(12):1994-2003.



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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Supportive and Palliative Care Indicators Tool (SPICT-4ALL™)

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
<p>Physical symptoms</p> <ul style="list-style-type: none"> • 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? <p>Activities of daily living</p> <ul style="list-style-type: none"> • Is the patient having difficulty with toileting, showering, bathing, or food preparation? • Is there a caregiver to assist the patient? <p>Psychological</p> <ul style="list-style-type: none"> • 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? <p>Medication and treatment</p> <ul style="list-style-type: none"> • Is the patient able to manage complex medication and treatment regimes? <p>Spiritual/Existential</p> <ul style="list-style-type: none"> • 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? <p>Financial/Legal</p> <ul style="list-style-type: none"> • 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? <p>Sexual</p> <ul style="list-style-type: none"> • Does the patient have concerns about his/her sexual functioning or relationship? <p>Health Beliefs, Social and Cultural</p> <ul style="list-style-type: none"> • 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.) <p>Information</p> <ul style="list-style-type: none"> • 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
<p>Physical symptoms</p> <ul style="list-style-type: none"> • Are the patient's physical symptoms causing the caregiver or family distress? <p>Providing physical care</p> <ul style="list-style-type: none"> • Is the caregiver or family having difficulty coping with activities of daily living or practical issues such as equipment and transport? <p>Psychological</p> <ul style="list-style-type: none"> • 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? <p>Medication and treatment</p> <ul style="list-style-type: none"> • Is the caregiver or family having difficulty managing complex medication and treatment regimes? <p>Family and Relationships</p> <ul style="list-style-type: none"> • 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? <p>Information</p> <ul style="list-style-type: none"> • 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
<p>Physical and psychosocial</p> <ul style="list-style-type: none"> • 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? <p>Bereavement Grief (pre and post death)</p> <ul style="list-style-type: none"> • 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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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 & Burriddle 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](#).

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 carer and provide time out.
- Consider specific services that can support families caring for someone who is dying at home, e.g. night nursing services or 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 about how to provide care safely (transferring and moving the person, eating and drinking, giving medicines). How much nursing support is available? Specifically, how many visits can the patient have?
 - 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.
 - Discuss the option of an in-dwelling catheter to reduce the care burden for a bedbound patient.
 - Encourage the family to think about 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 though 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 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 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 caregivers 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 bleed, 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 the 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 wallowing 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 caregivers 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 the patient dies
 - Ensure that they know which doctor has agreed to certify death, and the arrangements for contacting them.

Actions needed: _____

Facility name: _____
Address: _____

For more information visit CareSearch GP Hub www.caresearch.com.au Here you will find family resources you can order and give to patients and carers.

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MBS items supporting a planned general practice palliative care pathway

This document uses the MBS items currently available to general practitioners to suggest a timeframe and care pathway for community patients with palliative care needs. A separate pathway is provided for [residential aged care patients \(144kb pdf\)](#)

Suggested timeframe	Medicare initiative	Activities	MBS Item	MBS Benefit 100% (as of 01/05/24)	
0 months	Over 75 years health assessment	An annual assessment of a patient's health and physical, psychological, and social function. Select relevant item based on complexity and Practice Nurse and GP time. An opportunity to initiate discussion of advance care planning or palliative care.	701 (<30 mins)	\$65.30	
			703 (30-45 mins)	\$151.80	
			705 (45-60 mins)	\$209.45	
			707 (>60 mins)	\$295.90	
2nd week	GP management plan (GPMP)	For managing terminal medical conditions by preparing, coordinating, reviewing, or contributing to chronic disease management plans. An opportunity to introduce advance care planning or to discuss palliative care.	721	\$158.80	
	Team care arrangement (TCA) coordination	Requires at least two collaborating providers, each providing a different kind of treatment (e.g., allied health services or medical practitioner).	723	\$125.85	
3rd week	GP Mental Health Treatment Plan	For preparing a mental health care plan for a patient with mental health care needs. Select relevant item depending on time and GP training.	No GP mental health training	2700 (20-40 mins)	\$78.95
				2701 (>40 mins)	\$116.20

Suggested Timeframe	Medicare initiative	Activities	MBS Item	MBS Benefit 100% (as of 01/05/24)
		As per the Diagnostic and Statistical Manual of Mental Disorders (DSM-V-TR)	GP mental health training	<p>2715 (20-40 mins) \$100.20</p> <p>2717 (>40 mins) \$147.65</p>
1st month	GP-organised and coordinated multidisciplinary care conference	An opportunity for an holistic informed approach to ongoing care. Covers organising, coordinating, and participating in a case conference involving the patient, family/significant others, and a minimum of two other health providers.	739 (20-40 mins)	\$133.10
2nd month	Domiciliary Medication Management Review (DMMR)	Referral to eligible pharmacist. Ensures optimal management of patients with multiple medications and/or complexity.	900	\$170.45
4th month	Level D or E consultation	An extended consultation for the purpose of managing palliative care and end-of-life care needs, discussing goals of care, advance care planning, or for completing an Advance Care Directive based on earlier discussions.	<p>44 (Level D: >40 mins) \$118.00</p> <p>123 (Level E: >60 mins) \$191.20</p>	
5th month	Review GP Mental Health Plan	4 weeks to 6 months after preparation of plan, review referral feedback and progress against goals.	2712	\$78.95
6th month	Review of GPMP or TCA	Discuss progress against goals and actions.	732	\$79.30
8th month	GP-led case conference	A real-time discussion of any changing needs and goals of care with patient, significant others, and the health care team.	735 (15-20 mins)	\$77.85
5 per year	Practice nurse care plan monitoring	Where a GPMP or TCA is in place.	10997	\$13.20

Based on: PHN North Western Melbourne. MBS remuneration to support planned palliative care for patients: A guide for health professionals working in general practice and residential aged care. Melbourne: NWMPHN; 2017 [cited 2024 May 27]. Available from: <https://nwmpnh.org.au/wp-content/uploads/2020/12/NWMPHN-Palliative-Care-For-GP-and-RAC5.pdf>

MBS items supporting a planned general practice palliative care pathway in residential aged care

This document provides a suggested timeframe and pathway for aged care residents with palliative care needs based on the current MBS items available to the general practitioner.

Suggested timeframe	Medicare initiative	Activities	MBS Item	MBS Benefit 100% (as of 01/05/24)
0 months	Comprehensive medical assessment	On admission, then annually. Identify who is appointed to assist with healthcare decisions for patients who do not have capacity for palliative care discussions. Select relevant item based on complexity and PN + GP time.	701 (<30 mins)	\$65.30
			703 (30-45 mins)	\$151.80
			705 (45-60 mins)	\$209.45
			707 (>60 mins)	\$295.90
	Residential Medication Management Review (RMMR)	GP participation in a medication management review for someone in a residential aged care facility. Candidates for this review include residents for whom quality use of medicines may be an issue, or those at risk of medication misadventure due to a significant change in their condition or medication regimen.	903	\$116.70
1st month	Care plan contribution	GP contribution to a multidisciplinary care plan prepared by a residential aged care facility for managing terminal medical conditions.	731	\$77.50
2nd month	GP-organised and coordinated multidisciplinary case conference	An opportunity for an holistic informed approach to ongoing care for the resident. Should involve the resident, the resident’s significant others, the GP, and at least two other health and/or care providers.	735 (15-20 mins)	\$77.85
			739 (20-40 mins)	\$133.10
			743 (>40 mins)	\$221.90

Suggested timeframe	Medicare initiative	Activities	MBS Item	MBS Benefit 100% (as of 01/05/24)
4th month	Long patient consultation (Level D or E)	Attendance and consultation at the residential aged care facility with the purpose of managing palliative care and end-of-life care needs, discussing goals of care, advance care planning, or for completing an Advance Care Directive based on earlier discussions.	90051 (Level D: 40-60 mins)	\$118.00
			90054 (Level E: >60 mins)	\$191.20
6th month	Care plan contribution	Review of the resident's multidisciplinary plan	731	\$77.50
8th month	GP-organised and coordinated multidisciplinary case conference	An opportunity for a 'real time' discussion of the resident's ongoing care involving the multidisciplinary team (GP + 2 others) and, where possible, the resident and the resident's family or significant others.	739 (20-40 mins)	\$133.10
After 12 months	Repeat comprehensive medication assessment, case conferences and care plan contributions where clinically required.		As above.	

Based on information from: PHN North Western Melbourne. MBS remuneration to support planned palliative care for patients: A guide for health professionals working in general practice and residential aged care. Melbourne: NWMPHN; 2017 [cited 2024 May 27]. Available from: <https://nwmpnh.org.au/wp-content/uploads/2020/12/NWMPHN-Palliative-Care-For-GP-and-RAC5.pdf>

MBS items supporting nurse practitioner palliative care provision

MBS Item	Activities	MBS Benefit 100% (as of 16/05/24)
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>	\$10.55
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>	\$23.05
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>	\$43.70
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>	\$64.50

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MBS items supporting allied health professional palliative care provision

MBS Item	Activity	MBS Benefit % (as of 16/05/24)
<p>Chronic disease management services</p> <p>These item numbers can be used for up to 5 services in a calendar year to patients with chronic conditions or complex care needs providing:</p> <ul style="list-style-type: none"> the patient is being managed by a medical practitioner under both a GP Management Plan and Team Care Arrangement the patient’s medical practitioner has contributed to a multidisciplinary care plan prepared by a residential aged care facility the service is recommended in the patient’s Team Care Arrangements or multidisciplinary care plan the service is > 20 minutes in duration and provided 1-to-1 (not in a group). <p>For services to patients who are of Aboriginal or Torres Strait Islander descent, see items 81300-81360. Telehealth: item 93048. Phone: item 93061.</p>		
10950	Aboriginal Health Workers or Aboriginal and Torres Strait Islander Health Practitioners	Fee: \$68.55 Benefit (85%): \$58.30
10954	Dietitians	
10956	Mental health workers	
10958	Occupational therapists	
10960	Physiotherapists	
10962	Podiatry	
10968	Psychologists	
10970	Speech pathologists	

MBS Item	Activity	MBS Benefit % (as of 16/05/24)
<p>Chronic disease multidisciplinary case conference participation</p> <p>Attendance by eligible allied health practitioner at a case conference as part of a multidisciplinary case conference team, organised by the referring GP or consultant physician and at least two other allied health practitioners.</p>		
10955	Community or residential aged care case conference (15-20 mins)	Fee: \$53.75 Benefit (85%): \$45.70
10957	Community or residential aged care case conference (20-40 mins)	Fee: \$92.20 Benefit (85%): \$78.40
10959	Community or residential aged care case conference (>40 mins)	Fee: \$153.45 Benefit (85%): \$130.45
<p>Mental health case conference participation</p> <p>Attendance by eligible allied health practitioner at a mental health case conference as part of a multidisciplinary case conference team, organised by the referring GP or consultant physician, and with at least three care providers in attendance.</p>		
80176	Mental health case conference (15-20 mins)	Fee: \$53.75 Benefit (85%): \$45.70
80177	Mental health case conference (20-40 mins)	Fee: \$92.20 Benefit (85%): \$78.40
80178	Mental health case conference (>40 mins)	Fee: \$153.45 Benefit (85%): \$130.45