palliAGED

PALLIATIVE CARE AGED CARE EVIDENCE

Home Care Resources

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

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The online palliative care evidence and practice information resource for the aged care sector

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Oct 22

palliAGED
PALLIATIVE CARE AGED CARE EVIDENCE

Practical help to assist you to support older people at the end of life at home

Home Care Pack Contents

Home care providers are a critical part of support for older people at the end of life. Ensuring that key palliative care steps are not missed, and processes are well documented is part of good practice.

To help you and your team to support older people living in their home, we have brought together this pack of resources.

Self-Care Plan - Aged Care Team

To care for others, you need to take care of yourself. This worksheet helps you to plan activities to maintain your balance in life.

- Self-care plan for the Aged Care Team.

Recognising changing needs - forms to help you identify changes

If you see clients regularly, it can be more difficult to notice subtle changes in their condition. These forms can be used to systematically assess for deterioration in a person's health and to identify unmet supportive and palliative care needs.

- SPICT Tool
- SPICT4ALL Tool.

Symptom control

Pain is one of the most common symptoms in palliative care. You can use this form to monitor for changes in pain status, and to track use of breakthrough medicines.

- Abbey Pain scale
- Breakthrough medicines.

Organising a palliative care case conference

A series of practical checklists and forms to guide and document case conferences.

- Using the palliAGED conference forms
- Case Conference Checklist - home care
- Invitation to attend a case conference - GPs
- Confirmation of a case conference - GPs
- Information about case conferences and palliative care
- Invitation to attend a case conference - person and family
- Confirmation for you and your family
- Staff Communication Form
- Case Conference Summary - home care.

Supporting older people and their family

You can give these forms to clients to help them keep track of emergency contacts, medicines, and to develop self-care plans for their well-being.

- My Emergency Contact List
- My Medicines List
- Self-care plan for Family Carer.

End of life care

Practical lists of medicines that can be used for responding to unanticipated needs in the terminal phase and a checklist to guide an at home death.

- Medicines from the PBS prescriber's bag for terminal phase symptoms
- Helping Patients and Families Plan for an Expected Home Death: The GP's Checklist.

MBS Remuneration

- MBS items for nurse practitioners
- MBS Remuneration to Support a Planned General Practice Palliative Care Pathway (Home).

To obtain further copies of this pack:
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Flinders University

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Self-Care Plan:

Aged Care Team

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 (continued)

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:

Adapted with permission from ReachOut Australia

Self-Care Plan (continued)

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:

Adapted with permission from ReachOut Australia

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THE UNIVERSITY of EDINBURGH

Supportive and Palliative Care Indicators Tool (SPICT™)

CARESEARCH® palliative care knowledge network

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. ☐

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. ☐

Other conditions

- Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome. ☐

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 family carers. ☐
- Plan ahead early if loss of decision-making capacity is likely. ☐
- Record, communicate and coordinate the care plan. ☐

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT™, April 2019

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THE UNIVERSITY of EDINBURGH

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

CARESEARCH® palliative care knowledge network

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 or worsening health?

- Unplanned (emergency) admission(s) to hospital. ☐
- General health is poor or getting worse; the person never quite recovers from being more unwell. (This can mean the person is less able to manage 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 lost a noticeable amount of weight over the last few months; or stays underweight. ☐
- 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 and getting worse. ☐

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 bowel. ☐

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, 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 bad 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. ☐

Kidney problems

Kidneys are failing and 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. ☐

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. ☐

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

- Start talking with the person and their family about why making plans for care is important. ☐
- 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. ☐

For more on palliative care visit www.caresearch.com.au

Please register on the SPICT website (www.spict.org.uk) for information and updates.

SPICT-4ALL™, June 2017

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Abbey Pain Scale

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

In the following, for each of the following six areas enter pain scores:

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

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.

Chart of Breakthrough medicines

Patient details

Surname.....

Title.....

Given names.....

DOB..... MRN.....

Address.....

Suburb.....

Postcode.....

About Breakthrough Medicines

Breakthrough symptoms occur for many reasons in people with palliative care needs. This includes symptoms like pain, nausea, breathlessness, and anxiety. Sometimes these symptoms 'break through' the stable control of symptoms that you might usually experience. Your prescriber may prescribe additional medicines to be used as a 'rescue dose' in case this happens.

It is important that you follow the advice given to you about treating breakthrough symptoms. Letting your care team know how much and how often breakthrough medicine is needed helps with management of your symptoms. You can use this chart to keep track of any breakthrough medicine that you or the person you are caring for takes.

1. **Medicine Name:**

   Strength:

   How much and how often to be given:

   Reason for taking:

Date							
Time							
Dose							
Time							
Dose							
Time							
Dose							
24-hour Total Dose							

2. **Medicine Name:**

   Strength:

   How much and how often to be given:

   Reason for taking:

Date							
Time							
Dose							
Time							
Dose							
Time							
Dose							
24-hour Total Dose							

3. **Medicine Name:**

   Strength:

   How much and how often to be given:

   Reason for taking:

Date							
Time							
Dose							
Time							
Dose							
Time							
Dose							
24-hour Total Dose							

My Emergency Contact List:

Helping you keep track of your team

Organisation:

My name: _____

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

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

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Medicines List:

Helping you keep track of your medicines

My name:

My allergies or previous problems:

My emergency contact(s) details:

My GP/specialist contact details:

My pharmacy:

My pharmacist(s):

My palliative care team (eg, careworker, nurse):

Organisation:

Reminders:

- Ask a member of your care team to help you fill out this form.
- Bring this form to any future medical appointments.
- Include non-prescription medicines.

Name of medicine	What it looks like	How much and when	How to take it	Date started	What the medicine is for
Example only	eg, round, red, blue, white liquid	eg, one capsule per day	eg, by mouth, with food, by injection	dd/mm/yy	eg, pain

Self-Care Plan:

Family Carer

Name: .....

Caring for someone at home at the end of life is complicated and you may find it challenging. The intensity of the caring situation can be hard to deal with. You might find it hard to sleep, feel anxious or worried. Your friends may not visit as often. 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. Here we suggest a few things that you could try, but what you choose will depend on what suits you best.

Home self-care - Activities to help you at home
Some examples **Have** someone to help with the care so that you can get time for yourself **Share** an online calendar with family and friends so that they know when you might need help or company **Find** out about respite services in your area that can be accessed for a few hours or a few days Join a support or training group for carers **Attend training programs for carers**
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 (continued)

Psychological self-care - Activities that help you to feel clear-headed and able to engage with personal challenges
Some examples **Keep** a reflective journal **Seek** regular meetings with the palliative care team **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:

Self-Care Plan (continued)

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
Some examples **Prioritise** close relationships in your life eg. with partners, family and children **Attend** the special events of your family and friends
My Activities:

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Using the palliAGED Palliative Care Case Conference forms

A case conference or family meeting between the person, their family and care providers can help to explain what is happening and to plan care. The palliAGED forms can help.

1. Use the palliAGED Case Conference Checklist for residential care or Case Conference Checklist for home care to organise a palliative care case conference. Tick off items as they are completed.

2. Speak with the person and their family about the need for a case conference. Provide Information on palliative care and case conferences.

3. Involving the person's GP is important. Use the GP invitation to invite them to attend, and/or to suggest a suitable time.

4. Closer to the date of the Case Conference send a letter confirming details to the person and their family, and send confirmation to the GP.

5. To guide the meeting and to make sure that all steps following the conference are completed use the palliAGED Case Conference Summary for residential care or Case Conference Summary for home care sheet.

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Palliative Care Case Conference

Planning Checklist - Home Care

Organisation:

Full name of resident: DOB (dd/mm/yy):

Date of case conference (dd/mm/yy): Time:

Venue: Room booked: ☐

Dial-in telephone number: Code:

Case conference facilitator:

Goals of case conference:

Family Participants

Name	Role/Relationship	Contact Details

Health and Care Professionals

Name	Role/Relationship	Contact Details

Document (tick as appropriate)	Sent	Accepted/Declined	N/A
Client & family information	☐	A ☐ D ☐	☐
Client & family confirmation	☐	A ☐ D ☐	☐
GP invitation	☐	A ☐ D ☐	☐
GP confirmation	☐	A ☐ D ☐	☐

	Needed	Obtained	N/A
Clinical record (including most recent medication chart)	☐	☐	☐
Advance care planning document (legal or non-legal)	☐	☐	☐
Carer document e.g. NAT-C needs assessment form	☐	☐	☐
Other (specify)	☐	☐	☐

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GP Invitation

Palliative Care Case Conference

Organisation:

To:	**Email/fax number:**
From:	**No. of pages:** (including this page)
Subject: Palliative Case Conference	**Date sent: (dd/mm/yy):**

Dear Dr,

A Palliative Care Case Conference is being organized for (Resident/client name):

Resident/client DOB (dd/mm/yy):

Proposed date (dd/mm/yy): **Start time:**

Expected duration: **Venue:**

As an important member of the care team for our resident/client, you are invited to participate.

Reason for case conference:

Please indicate availability to participate in this case conference by ticking one of the options below:

☐ Attending in person ☐ Unable to attend

☐ Attending via teleconference
Please provide your telephone number:

☐ Please reschedule so I can attend.
Proposed alternative date: (dd/mm/yy): and Time:

Please email/fax this back to (insert email/fax number):

Yours sincerely (name):

Role: **Organisation:**

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GP Confirmation

Palliative Care Case Conference

Organisation:

To:	**Email/fax number:**
From:	**No. of pages:** (including this page)
Subject: Palliative Case Conference	**Date sent: (dd/mm/yy):**

Dear Dr,

Following our recent correspondence with you a Palliative Care Case Conference has been organized for: (Resident/client name):

Resident/client DOB (dd/mm/yy):

Case conference date (dd/mm/yy): **Start time:**

Expected duration: **Venue:**

If you are joining by teleconference, please dial in using the following telephone number and code:

Telephone: **Code:**

Reason for case conference:

Yours sincerely (name):

Role: **Organisation:**

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Information for you and your family

Organisation:

Palliative care case conferences

It has been suggested that a case conference be held to discuss how you, or your family member might benefit from palliative care. The following explains what this is and why it is important.

Case conference: Case conferences or family meetings are an opportunity to discuss a person's care needs. They ideally include the person (if able to attend), their family and/or their substitute decision-maker, and members of the care team including the doctor.

Palliative care: Palliative care is person- and family-centred care that supports a person to live the best life they can with a life-limiting illness. A life-limiting illness means that the person has little or no prospect of cure and is expected to die. The focus is on quality of life.

Life-limiting illnesses include dementia, advanced heart, kidney, lung or liver disease, cancer, and motor neurone disease.

People can receive palliative care for days or weeks, or for months to years. Older people coming to the end of their life without illness may have some of the same care issues. They can also benefit from the approaches to care taken in palliative care.

Common care issues in palliative care include:

- pain
- dyspnoea (breathing difficulty)
- dysphagia (difficulty with swallowing)
- constipation/incontinence (bowel and/or bladder management)
- depression
- delirium (sudden confusion)
- anxiety
- nausea (feel that you want to vomit)
- fatigue (tiredness).

Who should attend a case conference?

Staff in residential aged care facilities and providers of home care often meet with families. If possible, the person receiving care should attend, their GP, and any concerned family members or friends.

Your contact for this case conference is:

Name of staff member: _____ **Role:** _____

Telephone: _____

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Invitation for you and your family

Organisation:

Palliative Care Case Conference

A palliative care case conference has been organised for:

Name of resident/client: _____

Resident/client date of birth (dd/mm/yy): _____

Case conference date (dd/mm/yy): _____ **Start time:** _____

Location: _____

Please let us know if you can attend. If you would like to join by telephone, let us know and provide a suitable number to contact you.

Your contact for this case conference is:

Name of staff member: _____

Role: _____

Telephone: _____

On the next page you will find information on palliative care and palliative care case conferences

Invitation for you and your family

Palliative Care Case Conference (continued)

Case conference: Case conferences or family meetings are an opportunity to discuss a person's care needs. They ideally include the person (if able to attend), their family and/or their substitute decision-maker, and members of the care team including the doctor.

Palliative care: Palliative care is person- and family-centred care that supports a person to live the best life they can with a life-limiting illness. This means that the person has little or no prospect of cure and is expected to die. The focus is on quality of life.

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- fatigue (tiredness).

Who should attend a case conference?

Staff in residential aged care facilities and providers of home care often meet with families. If possible, the person receiving care should attend, their GP, and any concerned family members or friends.

Confirmation for you and your family

Organisation:

Palliative Care Case Conference

A palliative care case conference has been organised for:

Name of resident/client: _____

Resident/client date of birth (dd/mm/yy): _____

Case conference date (dd/mm/yy): _____ **Start time:** _____

Location: _____

Your involvement in planning care is important. If you are unable to attend in person but would like to join by telephone, please dial in using the following telephone number and code.

Dial-in telephone number: _____ **Code:** _____

Your contact for this case conference is:

Name of staff member: _____

Role: _____

Telephone: _____

Please write down if there are any issues you want to talk about and remember to bring this form with you to the meeting so that this can be included.

On the next page you will find information on palliative care and palliative care case conferences

Confirmation for you and your family

Palliative Care Case Conference (continued)

Case conference: Case conferences or family meetings are an opportunity to discuss a person's care needs. They ideally include the person (if able to attend), their family and/or their substitute decision-maker, and members of the care team including the doctor.

Palliative care: Palliative care is person- and family-centred care that supports a person to live the best life they can with a life-limiting illness. This means that the person has little or no prospect of cure and is expected to die. The focus is on quality of life.

Life-limiting illnesses include dementia, advanced heart, kidney, lung or liver disease, cancer, and motor neurone disease.

People can receive palliative care for days or weeks, or for months to years. Older people coming to the end of their life without illness may have some of the same care issues. They can also benefit from the approaches to care taken in palliative care.

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- anxiety
- nausea (feel that you want to vomit)
- fatigue (tiredness).

Who should attend a case conference?

Staff in residential aged care facilities and providers of home care often meet with families. If possible, the person receiving care should attend, their GP, and any concerned family members or friends.

Staff Communication Sheet:

Palliative Care Case Conference

Organisation:

A palliative care case conference has been organised for:

Name of resident/client: _____

Case conference date (dd/mm/yy): _____ **Start time:** _____

Location: _____

As valuable members of the care team your contribution to the case conference is important. Please list below any issues, concerns or suggestions you would like mentioned. Common issues include review of symptoms (e.g. pain, dyspnoea), concerns with nutrition or hydration, family issues, emotional concerns of the resident. If you are available and would like to attend the case conference, please contact the Case Conference Facilitator:

Name of Facilitator: _____

Issue, concern or suggestion. Please be as specific as possible.	Designation

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Palliative Care Case Conference

Summary - Home Care

Organisation:

Full name of client:

DOB (dd/mm/yy):

Purpose of Case Conference:

Client consent/substitute decision-maker (SDM) consent

My care provider has explained the purpose of a case conference and I give permission for my care provider to prepare a case conference. I give permission to the providers listed below to participate in the case conference and discuss my/my family member's medical history, diagnosis, and current needs.

Signature:

Date:

Dial-in telephone number: **Code:**

Client in attendance? Yes ☐ No ☐ **If no, give reason:**

Family Members		
Name	**Relationship**	**Attending in person (P) or teleconference (T)**
		☐ P ☐ T
		☐ P ☐ T
		☐ P ☐ T
		☐ P ☐ T
		☐ P ☐ T

Health and Care Professionals		
Name	**Discipline/Position**	**Attending in person (P) or teleconference (T)**
		☐ P ☐ T
		☐ P ☐ T
		☐ P ☐ T
		☐ P ☐ T
		☐ P ☐ T

Palliative Care Case Conference

Summary - Home Care (continued)

Start time: _____

Need (as appropriate): _____

Key Issues	Description
Advance care plan Does this need to be reviewed? Does the person understand their diagnosis/prognosis?	
Symptoms For example: fatigue, anorexia, pain, nausea, dyspnoea, dysphagia	
Social/psychological needs For example: isolation, anxiety, depression What supports are being provided? What supports are needed?	
Assessments/investigations Can the client manage ADL's (Activities of Daily Living)? Do they need additional support?	
Carer/Family issues or needs For example: has a Needs Assessment Tool for Carers (NAT-C) been completed?	
Other For example: general issues, housing issues, financial issues	

Palliative Care Case Conference

Summary - Home Care (continued)

Agreed Action Plan

Goal	Actions	Key Person(s) Responsible	Description

Palliative Care Case Conference

Summary - Home Care (continued)

Time completed:

General Practitioner: _____

Tick appropriate box

- ☐ Original placed in the client's clinical notes
- ☐ Copy provided to all participants
- ☐ Copy sent to GP
- ☐ Client's care plan and assessment reviewed and updated

Palliative Care Case Conference Facilitator

Name: _____ **Position:** _____

Signature: _____ **Date (dd/mm/yy):** _____

palliAGED
PALLIATIVE CARE AGED CARE EVIDENCE

Medicines from the PBS Prescriber's 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 injection	400 microgram/mL	5 x 1 mL	2	10
	OR	OR			
11233F	Naloxone 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 September 2022. See www.pbs.gov.au for more.

Medicines from the PBS Prescriber's 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's 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; and
- See the person through until a prescription can be dispensed.

A prescriber bag supply order form 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 prescribers' 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. For severe hyperactive delirium with agitation see response to Agitation.

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 then 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, 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; and
- 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
- palliAGED symptoms and medicines
- palliAGEDgp smartphone app, and your local pharmacist

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Helping Patients and Families Plan for an Expected 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 is designed to guide the GP through decision-making about care, to help them support the patient and family, and to identify the need for appropriate supports early. It flags issues which may need to 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 involve.
- 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

☐ Will the patient be able to 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, e.g.:

- 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, for instance:

- That loss of appetite is a common and predictable feature of advanced disease?
- That swallowing deteriorates with the approach of the terminal phase?
- Do they need ideas about what , and how much, to offer the patient to eat and drink, and how to do this safely?

Actions needed: _____

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

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

Actions needed: _____

☐ Ensure that the family has access to twenty four hour phone advice about symptoms or changes in the patient's condition, which everyone providing care knows how to contact.

Actions needed: _____

☐ Do the caregivers need information about what to do after the patient dies? E.g.

- 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

There are family resources you can order and give to patients and carers.

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MBS Items for Nurse Practitioners

Note: This webpage aims to provide clear guidance on the remuneration that Nurse Practitioners can obtain for palliative care services for patients within the community.

MBS	Medicare Initiative	MBS Benefit 85% (as of 21/12/2022)
82200	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.	$8.65
82205	Professional attendance by a participating nurse practitioner lasting less than 20 minutes and including any of the following: taking a history; undertaking clinical examination; arranging any necessary investigation; implementing a management plan; providing appropriate preventive health care, for 1 or more health related issues, with appropriate documentation.	$18.85
82210	Professional attendance by a participating nurse practitioner lasting at least 20 minutes and including any of the following: taking a detailed history; undertaking clinical examination; arranging any necessary investigation; implementing a management plan; providing appropriate preventive health care, for 1 or more health related issues, with appropriate documentation.	$35.70
82215	Professional attendance by a participating nurse practitioner lasting at least 40 minutes and including any of the following: taking an extensive history; undertaking clinical examination; arranging any necessary investigation; implementing a management plan; providing appropriate preventive health care, for 1 or more health related issues, with appropriate documentation.	$52.70

There are also a number of MBS Telehealth items (video and phone services) for a range of (out of hospital) consultations.

Source: https://www.servicesaustralia.gov.au/organisations/health-professionals/services/medicare/bulk-billing- nurse-practitioners-and-midwives. Accessed 20/05/2021

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MBS Remuneration to Support a Planned General Practice Palliative Care Pathway (Home)

The aim of this webpage is to support multidisciplinary practice by describing a palliative care pathway which clearly shows remuneration for palliative care services.

Suggested Timeframe	Medicare Initiative	Activities	MBS Item	MBS Benefit 100% (as of 21/12/22)
0 months	Over 75 Year Health Assessment	Select relevant item based on complexity and Practice Nurse and GP time. Introduce a discussion about Advance Care Planning or palliative care.	701	$62.75
			703	$145.80
			705	$201.15
			707	$284.20
2nd week	GP Management Plan (GPMP)	For patients with chronic disease, include discussion about Advance Care Planning or palliative care approach.	721	$152.50
	Team Care Arrangement (TCA)	Requires at least 3 providers, including GP, to collaborate on care. Entitles the patient to Medicare allied health services (5 per calendar year).	723	$120.85
3rd week	GP Mental Health Treatment Plan	Select relevant item depending on time and GP training. As per - diagnostic and Statistical Manual of Mental Disorders (DSM - 5) criteria.	2700	$75.80
			2701	$111.60
			2712	$75.80
			2713	$75.80
			2715	$96.25
			2717	$141.80
1st month	Case Conference	Opportunity for holistic informed approach to ongoing care for providers, carers and family. Organised by the GP, 20-40 minutes long; requires GP and at least 2 other providers (e.g. Palliative Care Specialist) in 'real' time.	739	$127.85

Suggested Timeframe	Medicare Initiative	Activities	MBS Item	MBS Benefit 100% (as of 21/12/22)
2nd month	Domiciliary Medication Management Review ('HMR')	Referral to eligible pharmacist; ensures optimal management of patient with 5 of more medications and/or complexity.	900	$163.70
4th month	Level D consultation	To complete Advance Care Plan, following earlier discussions.	44	$113.30
5th month	Review GP Mental Health Plan	4 weeks - 6 months after preparation of plan, review referral feedback and progress against goals.	2712	$75.80
6th month	GPMP Review	Discuss progress against goals and actions.	732	$76.15
	TCA Review	Discuss progress with team members. Can claim item 732 twice in the same day if services are separate and times noted.	739	$127.85
8th month	Case Conference	Organised by GP; 15-20 minutes long; GP + 2 other providers in 'real' time.	735	$74.75
5 per year	Practice Nurse care plan monitoring	Where a GP Management Plan is in place.	10997	$12.70

Source: Based on information from: PHN North Western Melbourne, MBS Remuneration to Support Planned End-of-Life and Palliative Care for Patients, A guide for Health Professionals working in General Practice and Residential Aged Care. Sept. 2019.