



palliAGED Practice Tips for Careworkers in Aged Care

Introduction & Care Provider Issues

Decision-Making & Communication

Care Issues







Introduction

The following collection of palliAGED Practice Tip Sheets has been developed to support people providing palliative care to older people approaching the end of life. Palliative care is an approach to care that emphasises quality of life when providing support for people with a life-limiting illness and their family and carers. A life-limiting illness is one that will cause a person to die sooner than they would have without the illness. Commonly encountered life-limiting illnesses include dementia, cancer, chronic obstructive pulmonary disease (COPD), and advanced stages of heart, liver, kidney, and lung disease.

Palliative care may also be relevant to the older person approaching their natural end of life without a life-limiting illness but experiencing similar care issues.

The palliAGED Practice Tip Sheets for careworkers have been developed for careworkers and personal attendants providing palliative care support. Each Tip Sheet highlights a different care issue and provides information to support the provision and improvement of care. Through recognition of needs and awareness of what might be done, care providers can actively support the older person's quality of life and sense of dignity.

The palliAGED Practice Tip Sheets also support care provider personal development, encouraging staff to develop capacity and gain confidence in providing palliative care.

The information is of a general nature, and health and care professionals should use their best clinical judgement in the way in which it is used and seek professional medical care and advice as required.

The online versions of palliAGED Practice Tip Sheets are regularly updated to reflect new evidence and best practice. It is recommended that you check for updates to the information in this booklet by visiting www.palliaged.com.au

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Using palliAGED Practice Tip Sheets

The palliAGED Practice Tip Sheets for careworkers in aged care are suitable for independent learning and in-house training of careworkers (personal attendants) who support older people with palliative care needs. This is part of a companion series, with a second collection of related content also available for educators and nurses new to palliative care. The aim is to develop capacity and foster further development of skills by individuals and within teams. The following describes the palliAGED Practice Tip Sheets for careworkers.

To facilitate selection of the most relevant palliAGED Practice Tip Sheets the collection has been divided into:

- 1. Introduction & care provider issues
- 2. Decision-making & communication issues
- 3. Care issues.

There is no recommended order for working through the series. Each palliAGED Practice Tip Sheet can be used on its own or as part of a group, with other relevant Tip Sheets indicated on the second side. For those interested, within the online version the evidence and references used to develop the palliAGED Practice Tip Sheets are also listed.

The first side of each palliAGED Practice Tip Sheet includes a description of:

- What it is
- · Why it matters
- · What I need to know.

For careworkers this is then followed with tips as to what to **Note** and what to **Do**. The second side of each palliAGED Tip Sheet provides an opportunity to reflect on what the information presented means in terms of current and future care. Completion of the reflection questions might be useful to demonstrate professional development and/or staff training.

They might also help to identify gaps at an organisation and/or individual level in the understanding and provision of palliative care, and thus highlight opportunities for care improvement. Reflection points could also be used as a group activity to initiate co-worker discussions.

The palliAGED Practice Tip Sheets complement the palliAGED Introduction Modules and the palliAGED Practice and Evidence Centres available at www.palliaged.com.au. Health and care professionals looking to gain more detailed information on providing palliative care are strongly encouraged to access the palliAGED website for evidence-based guidance and knowledge resources about palliative care in aged care. The palliAGED website content and the palliAGED Practice Tip Sheets have been reviewed by experts in aged care, palliative care, and evidence. Their knowledge and practical experience have contributed greatly to the rigour and applicability/suitability of these resources to contemporary aged care in Australia.



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Introduction & Care Provider Issues



Tips for Careworkers: Aged Care Access and Assessment



What it is: The aged care system provides support for older Australians living in their own home or residential aged care. Access to government-funded aged care starts with an assessment of the person's needs. The older person is asked questions about what they would like help with to keep them as independent as possible, safe, and connected with their community. This is used to recommend the type and level of care that will best meet their needs.

Why it matters: Sometimes care decisions and what care people expect can be a source of worry for the person. It might also result in arguments in the family or with care providers. Understanding how access to aged care works means that you can better support people to receive the care they need. It can also help to manage what they expect of you.

What I need to know: Aged care assessment has a focus on client needs. It also aims to support wellness and reablement where appropriate. The amount of funding provided depends on the level of care approved. This will affect the type and amount of care provided.

After approval and allocation of funds, the aim is to arrange services according to the person's needs and what is important to them.

My Aged Care is there to answer any questions relating to assessment or eligibility for government-funded services.

An older person or their representative can register with MyAgedCare for an assessment, or they can be referred by a health professional. Assessment can take place at the older person's home, or in a hospital. There is a process in place for review of the assessment outcome if requested.

If you care for a client who requires more support than their current package allows, they can apply through My Aged Care to be reassessed. Speak with your supervisor if you notice an increased need for care.

Note

If clients or families have any questions about access to aged care, refer them to your supervisor and/or My Aged Care at www.myagedcare.gov.au

Anyone with consent can register an older person with My Aged Care for screening. They can also be referred from a hospital, or by a GP or other health professional with patient consent.

Do

Visit the palliAGED 'For Community' section for information on access to aged care for older Australians www.palliAGED.com.au

How can aged care assessment help an older person?

My notes:

See related palliAGED Practice
Tip Sheets:
Advance Care Planning
Frailty
Palliative Care







Tips for Careworkers: Palliative Care

What it is: Palliative care is an approach that improves the quality of life of people and their family and carers who are facing concerns associated with a life-limiting illness. This means that the person is expected to die in the foreseeable future and before they would have without the condition. This can be true for people at any age including older people.

Why it matters: The number of older people requiring palliative care is increasing in Australia. Careworkers in aged care often spend a lot of time with older people and may learn of their likes, concerns, and experiences. They have an important role in caring for the person and reporting this information to nurses/supervisors.

What I need to know: Dementia, cancer, and advanced heart and lung disease are all examples of life-limiting chronic conditions.

Palliative care provides pain relief and manages symptoms as well as providing spiritual, emotional, and social support. The timing of the start of palliative care depends on the individual and the condition. Care plans may change.

Older people coming to the end of their life without illness can also benefit from a palliative approach to care. Common care issues in people needing palliative care include:

- pain
- dyspnoea (breathing difficulty)
- dysphagia (difficulty with swallowing)
- constipation/incontinence (bowel management)
- anxiety
- · dry mouth
- fatigue (tiredness)
- depression.



Note

As a person's needs change, palliative care helps with care planning, declining health, dying, and bereavement.

Note

Some common signs that may indicate things are changing and palliative care needed are:

- less interest in doing things they enjoyed before
- changes in how they act and talk
- less interest in food and eating
- weight loss
- not as physically active as previously
- getting slower and less mobile
- difficulty with toileting
- problems swallowing.

Report what the person enjoys and what gives them satisfaction; recognise what they do well and 'what works'.

Let nursing/supervisory staff know if you notice any signs that a person may need palliative care.

Ask nursing/supervisory staff about SPICT4ALL, a tool to identify when a person's health is declining.

What are some of the illnesses an older person might have that suggest a need for palliative care?

Why is palliative care important?

What do I do to communicate with older people in my care?

My notes:

See related palliAGED Practice
Tip Sheets:
Advance Care Planning
End-of-Life Care Pathways
Pain Management





Tips for Careworkers: Self-Care



What it is: Self-care is a range of information, skills, and attitudes that careworkers can use to maintain mental and physical wellbeing.

Self-care can include understanding your strengths, weaknesses, thoughts, beliefs, motivation, and emotions. In palliative care, self-care can also include grief and bereavement support, and understanding how to recognise and prevent burnout.

Why it matters: Caring for others can be rewarding. However, staff working in aged care look after many people who die. As a result, they may experience repeated grief.

Grief over the death of residents or clients is not unusual and may contribute to stress or burnout. Self-care is important to maintain balance in life.

What I need to know: It is helpful to be a member of a team that provides support, reflection, and debriefing. A team may be your work colleagues or a network of people outside of work.

Team meetings, debriefing or regular supervision can provide support.

- Po Report to nursing/supervisory staff if you see signs that suggest a person is not coping. These can include:
 - physical and emotional exhaustion
 - poor sleep
 - headaches
 - negativity or feeling useless
 - lack of enjoyment
 - not working effectively
 - absence from work.
- Acknowledge your grief and recognise that it is a normal reaction to loss.
- Talk to your supervisor and colleagues about what you are experiencing and request their help or support from a professional counsellor if needed.
- Do Develop a self-care plan and strategies that promote your physical and emotional wellbeing. Self-care strategies may be different for everyone; select ones that work for you.
- Do Visit the ELDAC Self-care room.

What support does my organisation provide for self-care?

Have I created a self-care plan and, if so, does it need to be reviewed?

My notes:

See related palliAGED Practice
Tip Sheets:
Grief and Loss among Staff
Talking Within the
Aged Care Team



Decision-Making & Communication







What it is: Advance care planning (ACP) is where a person plans for their future care by discussing and/or recording their preferences and values. An Advanced Care Directive (ACD) is a written advance care plan. In different states of Australia an ACD may have a different name. An ACD may include care preferences and values, and instructions about future treatment. What can be included and the forms to be used depends on the relevant state or territory law. An older person can name someone to make decisions for them if later they are unable to. This person is called a substitute decision-maker (SDM). Some states and territories include this in an ACD.

Why it matters: Advance care planning helps people receive the care that they would want to receive. Writing down preferences is important because if a person can no longer make or express decisions, the people around them will know what they would want. Careworkers can support older people and their families by referring questions about ACDs to nursing/supervisory staff.

What I need to know: A person does not have to plan or have an ACD. An ACD is only used if the person cannot make or express decisions.

ACDs can be changed whenever the person wants to change them or when their health or circumstances change.

A person may choose to refuse treatment. This is not giving up and does not mean that care will stop. It means the focus of care will be on comfort, dignity and the support of the person and their family and carer(s).

- Make sure that a current ACD accompanies the older person moving to or from hospital or place of care.
- Make sure you have the contact details of the:
 - substitute decision-maker
 - person to contact in case of an emergency.

These may not be the same person.

- Do If someone wants to discuss health planning, tell nursing/supervisory staff.
- Visit Advance Care Planning Australia's online learning modules for aged care.

Can an Advanced Care Directive (ACD) be changed?

What should I do when an older person is moved to a new place for care?

Have I thought about advance care planning for myself or my family?

My notes:

See related palliAGED Practice
Tip Sheets:
After-Death Choices
Palliative Care
Talking about Dying









What it is: Care of an older person and their family does not end when the person dies. There are arrangements that need to be made in line with their wishes.

Why it matters: The person may have written down their wishes in an Advance Care Directive (ACD) but some decisions may need to be taken by members of the family. Planning can assist the family with their grief and bereavement. Support from careworkers can also help.

What I need to know: The Registered Nurse (RN)/supervisor needs to speak with all relevant people and make sure all special needs at the time of death are attended to.

Families may wish to spend time with the person's body.

An authorised person needs to make sure the person is dead, and a document signed to officially confirm the death. After this, a funeral company can take the body into their care.

There may be requirements for reporting a death to the coroner. Relevant legal requirements are not the same across Australia.

Respect and support the family members who may:

- need time to accept the death
- need time to travel to the site of death
- want to sit with the deceased.

Report to nursing/supervisory staff any needs including religious and cultural practices that may be important for the family.

When and what to tell others following the death of an older person in your care.

It is important to have a plan in place, because if an authorised person is not available to verify a death, then the police need to be called and the coroner involved.

When a person dies, who should speak with relevant people and take control?

Staff working in aged care look after many people who die. What can I do for my own self-care?

My notes:

See related palliAGED Practice
Tip Sheets:
Advance Care Planning
End-of-Life Care Pathways
Grief and Loss among Older People,
Families and Residents









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

Why it matters: A palliative care conference can:

- help the person and family members to understand the goals of care
- discuss options for future care
- share information
- help families to deal with distress.
- plan responses to emergencies or crises.

What I need to know: Knowing who you can share information with is important.

Staff in residential aged care facilities and providers of home care often meet with families. This is to talk about routine care, or when the older person's health status is changing, or death is expected within days.

You may be invited to attend a family conference. As you are likely to know the day-to-day care needs of the person, this can be very helpful.

Note

Family meetings are different to case conferences. Family meetings focus on the care goals of the person and their family.

Do

Look out for and report to nursing staff, any changes in a person's:

- mood
- normal daily activity
- ability to swallow, move, or breathe.

Do

Report to nursing staff comments that the person may make about their health or future wishes.

Do

Support the person and family before and after a case conference and refer any concerns or questions to nursing/ supervisory staff.

What is the difference between a case conference and a family meeting?

What are some of the changes in a person I should report to nursing/supervisory staff?

My notes:

See related palliAGED Practice
Tip Sheets:
Advance Care Planning
Continuity of Care
Palliative Care









What it is: Continuity of care has three main parts:

- 1. The care provider knows and follows the care of a person, client or resident.
- 2. There is good exchange of relevant information between different care providers.
- 3. Different care providers cooperate so that care is connected care.

Why it matters: Continuity of care helps care providers to be aware of a person's preferences and care needs. It also helps with the smooth coordination of a person's care. It is particularly important for the care of a person who may be at the end of life. It also helps care providers to have the information they need so that the person's choices are respected.

What I need to know: Continuity of care can:

- avoid unnecessary hospitalisations
- ensure the older person receives uninterrupted care for their needs
- make sure that important treatments continue when a person is moved to or from a care setting (home, hospital, residential aged care)
- make sure that a person's preferences and needs are considered.

Do Know the signs of dying.

Talk clearly with the family, carers, nurses and management to ensure you and others are aware of any new goals of care.

Report to nursing/supervisory staff any changes that you notice in the person or requests made by the older person or their family.

Ask your supervisor about the SPICT4ALL tool. This helps you to identify people who are declining in health and might benefit from better supportive and palliative care.

How do I report to nursing/supervisory staff any changes that I notice or any questions that family members may have?

My notes:

See related palliAGED Practice
Tip Sheets:
Advance Care Planning
End-of-Life Care Pathways
Talking within the Aged Care Team

Flinders University



Tips for Careworkers: Culturally Responsive Care -Communication

What it is: Culture describes the beliefs and behaviours that are part of social groups.

Culturally responsive care pays attention to the social and cultural characteristics of people from culturally and linguistically diverse (CALD) backgrounds.

It is a form of person-centred care and how we talk with people is important.

Why it matters: Health care that respects a person's cultural and spiritual heritage can positively impact overall health.

What I need to know: Many older Australians were born in a non-Englishspeaking country.

Across all cultures, what is normal to one person may not be normal to another. This may also be true for people within the same cultural group or even the same family. The only way to know is to ask.

Providing culturally responsive care at the end of life requires:

- careworkers to be aware of the influence of their own cultural beliefs on their practice
- · sensitivity to the cultural practices and beliefs of others.

A person may prefer another family Note

member or community member with them when possible and/or to speak on their behalf.

- Do Respect the rules about what part of the body you can and cannot touch.
- Build rapport and trust by: Do listening actively
 - showing empathy and respect.
- Ask the family what the illness means to the person and to the family.
- Be open and ask the older person: Do
 - how they would like to be called
 - what is appropriate physical contact
 - what special days are important to them
 - what food is culturally appropriate to eat.
- Do Let nursing/supervisory staff know if English is not a person's first language. Professional interpreting services can help with discussions where lots of information is shared.

How many of the people I care for speak a language other than English? How many of the people I work with speak a language other than English?

What are some of the ways that help me communicate well with people from a CALD background?

My notes:

See related palliAGED Practice
Tip Sheets:
First Australians - Communication
People with Specific Needs
Person-Centred Care









What it is: A care pathway is a tool to plan best care for a person with a disease or condition where we know what to expect. End-of-life care pathways guide the care you will provide to the person who is dying.

Why it matters: Care pathways aim to:

- guide clinical decisions
- start care as soon as possible
- make sure everyone works to the same plan
- prevent unnecessary emergency treatments
- · make care more efficient
- give you confidence that you are providing the right care.

What I need to know: A care pathway is different from a care plan. A care pathway represents the ideal way to manage most people with a specific problem or long-term condition. A care plan is made for an individual person and might not be the same as a care pathway.

The Residential Aged Care End of Life Care Pathway (RAC EoLCP) guides the provision of good quality terminal care in residential aged care.

Care pathways use documents, sometimes flowcharts, to outline the steps of care to be followed by members of multidisciplinary teams.

Do

Look out for changes in a person's physical condition and mental and emotional state.

Do

Report to nursing/supervisory staff any changes in the person's

- skin, eyes, ear, nose, throat
- mobility
- eating, sleeping, or toilet habits
- odours, discharge, itching, swelling, burning
- hands or feet (if numb or cold)
- mood or behaviour (agitation, restlessness).

Do

Discuss regularly with nursing/supervisory staff what you should do to support the person on their care pathway.

Name two aims of care pathways.

What changes in a person should I report to nursing staff?

My notes:

See related palliAGED Practice
Tip Sheets:
Advance Care Planning
Case Conferences
Continuity of Care





Tips for Careworkers: First Australians - Communication



What it is: Appropriate care for Aboriginal and Torres Strait Islander peoples includes talking with them in a culturally sensitive way. It also includes cultural safety. This is about recognising, respecting, and nurturing their cultural identity.

Culturally appropriate care for Aboriginal and Torres Strait Islander peoples:

- has people and their needs at the centre
- includes the context of their family, community, and culture.

Why it matters: Aboriginal and Torres Strait Islander people have high risk of life-limiting conditions. This includes advanced heart, kidney, and lung disease, and dementia. Being able to talk with the person and their family is important.

What I need to know: For Aboriginal and Torres Strait Islander peoples, 'family' members may not be related by blood but through traditional kinship or cultural groupings.

To build good relationships, introduce yourself and begin with a relaxed conversation. This is sometimes known as 'having a yarn'.

Acceptable terms to describe Aboriginal and Torres Strait Islander peoples are Aboriginal person, Torres Strait Islander person, and First Australian.

Note Post-death practices or requirements will differ across communities. Only certain people can touch or move a dead body.

Ask the person if they want to hear information about their care; or whether they prefer you to talk to family members instead.

Ask who has the right to make decisions on behalf of the person; this may not be the 'next-of-kin'.

You might like to ask:

'Are there cultural or spiritual practices that affect the way you wish to be cared for?'

'Are there other people we should include in talks about your care?'

Do Tips for talking together:

- · don't talk too fast or be too direct
- some people avoid eye contact;
 this doesn't mean they aren't listening
- listen, ask questions rather than giving answers
- avoid questions requiring a 'yes' or 'no' answer.

When I first meet with an older Aboriginal or Torres Strait Islander person what could I do to make them feel comfortable?

What are important things to remember when talking with First Australians?

My notes:

See related palliAGED Practice
Tip Sheets:
Culturally Responsive Care Communication
People with Specific Needs
Person-Centred Care





Tips for Careworkers: People with Disability Communication



What it is: Here, we mean talking with people with an intellectual or developmental disability or limited communication.

Why it matters: Many older people with an intellectual disability have more than one medical condition or advanced illness requiring palliative care.

Many people with intellectual disability are cared for by family carers and as they age, may need more support. In some cases, people with intellectual disability may be admitted to aged care because of:

- · increasing care needs
- ageing carers or death of a family carer
- previous arrangements no longer providing enough support
- a lack of appropriate local services or accommodation.

What I need to know: Older people with intellectual disability:

- often have poorer health due to other illnesses like epilepsy and diabetes
- · may show signs of early ageing
- often have depression and dementia
- may have difficulties with hearing, eyesight and mobility
- may find it difficult to join in a usual activity program
- may have limited access to disability services once in residential aged care
- may have difficulty with communication, speaking, and understanding what is said.

Always give the person your full and complete attention and make sure that you have their attention before speaking.

Do not talk over the person as though they are not there.

Use language that fits with the person's communication level.

Look at the person not the disability.

Use pictures and diagrams to clarify explanations if this is an appropriate way to communicate with the person.

Do I speak to people with disability in an age-appropriate way?

What can I do when speaking with a person with disability to help them understand what I am saying?

My notes:

See related palliAGED Practice
Tip Sheets:
People with Specific Needs
Person-Centred Care
Talking about Dying









What it is: Person-centred care is about dignity, worth and human rights. Sometimes called 'patient-centred care'; it involves treating people the way they want to be treated and listening to their needs and preferences. This supports quality of life. It helps people to live a meaningful life based on what they value.

Why it matters: Quality care is more than good symptom control and emotional support. It is about helping the older person to live well and maintain control over their life, relationships, and social connections.

What I need to know: Palliative care is focused on quality of life. Being treated with dignity and respect is essential to quality of life. Being compassionate and valuing people as the person they are, rather than just the illness they have promotes a sense of dignity.

Helping people retain dignity as they die includes:

- symptom control
- psychological and spiritual support
- attending to privacy, respect and choice
- care of the family.

Always introduce yourself and give the person your full and complete attention.

Do Respect a person's need for privacy.

When speaking with the person try to be seated at the person's eye level when possible.

Address people by their preferred name and avoid pet names or generic terms like 'love' or 'dear'.

Do Ask questions such as:

'What should I know about you as a person to help me take the best care of you that I can?'

'What are the things at this time in your life that are most important to you or that concern you most?'

'Who else should we get involved at this point, to help support you through this difficult time?'

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What could I do when speaking with an older person that would make them feel valued and listened to?

What situations have I observed that have not been person-centred? What could I do to improve things, so this doesn't occur again?

My notes:

See related palliAGED Practice
Tip Sheets:
Advance Care Planning
Case Conferences
People with Specific Needs





Tips for Careworkers: Quality of Life with Change and Deterioration



What it is: Quality of Life (QoL) is how a person feels about their life in relation to their goals, hopes, fears, values, and beliefs. So, QoL will mean different things to different people. It often includes:

- · feeling valued and respected
- being comfortable and pain-free
- being able to socialise or spend time with family and friends
- · being as independent as possible
- not feeling like a burden
- feeling supported.

Why it matters: QoL is part of palliative care. As a person's illness deteriorates their QoL can worsen. Their ability to do what is important to them can change.

What I need to know: QoL is personal. What the older person values as part of QoL may not be the same as other people.

As their disease progresses, their QoL can change. The disease might stop them from doing their usual activities. It might mean they cannot socialise in the same way or form relationships with others. Changes in QoL may be slow with diseases like dementia that progress slowly (over a longer period).

Other people might not register a change in QoL. They may adapt to what is currently possible and not compare it to what they could do before.

Do Talk with the person and family

- Regularly ask what is now important to the older person and their family
- Talk with the older person to set individual goals and support them with activities that are meaningful to them
- If families are concerned, ask your supervisor to help you support family members with information about the changes
- Help the older person to stay connected with family and friends
- If language is a barrier, ask your supervisor if there are staff who speak their language.

Support the older person to maintain their spiritual perspectives and spiritual connections.

Do Encourage them to remain active with tasks that they can manage.

- If tasks become more difficult offer help rather than doing it for them
- Help the person to adapt personal interests and activities as functional ability changes.

What tools are used in my organisation to measure QoL?

How often do I re-assess what is important to the people I care for?

My notes:

See related palliAGED Practice
Tip Sheets:
People with Specific Needs
Person-Centred Care
Recognising Deterioration





Tips for Careworkers: Supporting Families



What it is: Family can still be unprepared for decline and death even when the older person is becoming frailer and less active. They need support to understand what is happening (including what happens as a person is dying), share experiences, make care decisions, and cope with loss.

Why it matters: Supporting carers and family members is part of palliative care. For an older person, family is part of who they are. They provide physical and emotional support and help.

What I need to know: Carers and family often look for support to understand the disease and symptom management, and end-of-life planning. Frequent, short conversations with small amounts of information can help. Family members might need your help with emotional issues including:

- Guilt and/or relief if they are unable to continue caring and the older person needs to move into residential aged care
- Sadness and distress at the older person's deteriorating condition
- Anticipatory grief before the older person's death
- Grief due to loss of a loved one, an end to their role as carer, and changes to their daily routine
- Distress if the family think:
 - The person's dignity and identity are not being maintained
 - the family is not seen as a partner in providing care
 - the care provided is 'cold' and 'clinical'
 - o not enough care is being provided.

Welcoming family as partners in providing care will help them to feel respected.

Identify the substitute decision-maker and the key contact. Let your supervisor know.

Note

Frequently provide small 'chunks' of clear and honest information about the person's condition and any deterioration. Be sensitive and show empathy, but do not give false hope.

Support decision-making by asking what they understand. Refer to what family have discussed previously with the person.

Do

Tips for talking:

- Actively listen to the older person and their family
- Be available to talk with family members
- Let your supervisor know if they need more information
- Ask them what they think before offering your own thoughts.

Do

Acknowledge grief that starts before death.

Acknowledge cultural needs of the person and family.

Would my family members be happy to receive the level of care I provide to the older people I care for?

What do I do to support relatives of people in my care? What guides my choices?

My notes:

See related palliAGED Practice
Tip Sheets:
Case Conferences
Grief and Loss among Older People,
Families and Residents
Talking About Dying



Flinders University







What it is: Talking about death and dying is not easy for everyone.

Why it matters: It can be hard to tell someone that care will be about comfort, not cure. But these conversations can help the person and their family to make decisions about future care and to improve the care that the person receives.

Acknowledging the role of family and talking with them can improve the care of the person, their family and carers. Careworkers can support the person and their family and let nursing/supervisory staff know when they have questions.

What I need to know: Effective communication or talking:

- allows staff to identify a person's needs and to provide care for that person
- may reduce agitated behaviour in older people with impaired cognition (poor understanding).

When a resident or older person dies, other residents or older people may be sad, fear that they will be next, become angry or withdrawn. Listening to their concerns can help them feel comfortable again.

Developing effective communication skills requires training, reflective learning, practice and a supportive working environment. Note

When talking with people, remember to:

- be aware of sensory impairment and make sure the person is wearing their glasses and/or hearing aid if needed
- make appropriate eye contact
- keep your face in view
- speak slowly or as loudly as needed.

Do

Take the time to listen to people. This helps people feel that they are valued and treated as an individual.

Do

Report to nursing/supervisory staff a person's likes, dislikes, behaviours and responses to care. Their preferences can then be respected when they can no longer communicate.

Do

Consider a person's culture before talking about dying. Not all cultures talk about dying and death in the same way.

Before talking about dying with a person what should I consider?

What can I do to help people feel more comfortable when talking about death?

Who can I call on to help me with difficult discussions about death and dying or if people in my care have questions that I cannot answer?

My notes:

See related palliAGED Practice
Tip Sheets:
Advance Care Planning
Palliative Care
Spiritual Care







What it is: Talking with members of the care team taking care of an older person. The team caring for a person with palliative care needs may include people with different skills including nurses, carers, GPs, allied health, and spiritual care practitioners.

Why it matters: Good communication (talking) between careworkers and other staff helps the quality of palliative care provided to clients or residents. It means everyone involved in the care of a person knows what to do and why. It also helps people to feel confident that staff know and understand what to do, and that they are providing appropriate care.

What I need to know: Written records are a common way for teams to communicate. Case conferences are another way to communicate. Often the Registered Nurse (RN)/supervisor will pass information between team members, management, the older person and their family.

Effective communication is:

- · open, honest, accurate
- respectful and sensitive
- may be formal (team meetings) or informal (casual meetings in the work area or staff room).

Effective communication:

- supports understanding between the sender and receiver of information
- is part of good teamwork.

Technology including electronic care records, email communication, telehealth meetings, and social media are changing the way people communicate. These new technologies need to be used carefully and in line with policies at your organisation.

Note

Know with whom you can share information.

Do

Check what needs to be reported or recorded.

Do

Ask questions if you are not sure of something.

What are two ways that information about a person I am caring for could be communicated?

What should I do if I'm not sure of something relating to the care of someone in my care?

My notes:

See related palliAGED Practice
Tip Sheets:
Case Conferences
Continuity of Care
Talking about Dying



Care Issues



Tips for Careworkers: Advanced Dementia



What it is: Dementia is a group of diseases affecting the brain. Over time the person loses everyday skills.

Why it matters: There is no cure for dementia. It is a life-limiting illness. Palliative care is needed with advanced dementia. The focus is on quality of life. When a person with dementia enters a care facility, they often have advanced dementia.

Careworkers can take an active role in supporting the person with dementia to express their wishes and report any changes in the person's condition. Getting to know the person well will assist in providing care.

People with dementia often have other diseases like heart disease, high blood pressure, and chest disease. Frailty and pain are common. They may need palliative care before they reach an advanced stage of dementia.

What I need to know: Dementia is most common in people over 65 years of age, but not all old people have dementia. Dementia can affect younger people.

A person with dementia may experience loss of:

- memory
- good sense and judgement
- ability to talk
- · social skills
- · physical functioning.

As dementia advances people have difficulty with:

- going to the toilet, washing, eating and drinking, walking
- making decisions
- being able to remember recent events
- thinking things through.

At all stages, the person with dementia still has their own likes and dislikes. Remember that even if a person with dementia is unable to speak, they may still sense the presence of loved ones and experience fear and loss.

It can be difficult to know when a person with dementia is approaching the end of their life.

Do

Check for signs of deterioration such as changes in:

- level of pain
- alertness
- care needs
- behaviour e.g., agitation and distress
- oral intake
- sense of comfort or discomfort.

Report changes to nursing/supervisory staff.

What other diseases might a person with dementia have?'

What tasks might a person with dementia have difficulty with? How can I help?

My notes:

See related palliAGED Practice
Tip Sheets:
Advanced Dementia
Behavioural Changes
Palliative Care
Recognising Deterioration





Tips for Careworkers:
Advanced
Dementia –
Behavioural Changes

What it is: People with advanced dementia may show behaviour that is very different to how they usually are. If this is related to their dementia, then it is known as behavioural and psychological symptoms of dementia (BPSD). BPSD commonly appears as aggression, agitation, anxiety, depression, or apathy.

Why it matters: Most people with dementia experience BPSD. This has a negative impact on their quality of life. It also affects carer quality of life.

What I need to know: Common BPSD symptoms include:

- being easily upset or worried
- repeating questions
- · arguing or complaining
- · physical aggression
- searching for or hoarding things
- inappropriate screaming or sexual behaviour
- refusing care (such as not wanting to have a shower or to get dressed)
- wandering or shadowing (following a carer).

Creating supportive relationships with the person to promote trust can help. Personcentred care based on activities that the person enjoys can also help. For example, music therapy where the person can choose the music and take part in the activity. Ask the person or their family what things they do or do not like. Usually, antipsychotic medications are not recommended. But they may be needed if the person has severe BPSD and could harm themself or others.

Do

If you notice symptoms of BPSD let your supervisor know. Look for – and try the following:

- unmet needs such as pain, hunger, need to go to the toilet
- worries about family or staff interactions
 take time to talk one-to-one
- lack or loss of supportive social relationships or meaningful activity – be a friend for them, help them to focus on what they can do and to make choices such as what to do or wear
- communication difficulties use communication cards or an interpreter if appropriate
- physical environment problems such as privacy, noise, or light levels – knock before entering their room, find a quiet place for them to be including for meals if wanted, ask if they want lights on or off
- things that have changed for them such as staff, their routine, or physical ability – gently talk with them about this
- patterns in behaviours e.g. time of day, a certain activity – be prepared to provide more support at these times.

Do

Keep the person physically active if appropriate.

Do

Watch for body language signs indicating that they agree (smiling, laughing) or disagree (agitation, resisting activity, restlessness).

What ways have I tried to deal with behavioural and psychological symptoms of dementia?

What worked well and what could have been done better?

What supports does my organisation offer staff and families to manage BPSD? What would be useful?

My notes:

See related palliAGED Practice
Tip Sheets:
Advanced Dementia
Anxiety
Person-Centred Care









What it is: Feeling anxious means a person feels scared or worried about something. This is normal, and usually goes away.

Anxiety is when these feelings don't go away.

Why it matters: Many older people experience anxiety. Anxiety can be more common when people have a serious illness or at the end of life.

In an older person anxiety can be difficult to see because it is often associated with loneliness, depression and/or dementia.

When a person experiences anxiety and depression together, their symptoms and outcomes are more severe.

What I need to know: Anxiety can create physical symptoms, and changed behaviours and thoughts. These responses affect a person's health and quality of life.

Look out for and report to nursing/ supervisory staff, if a person:

- becomes unable to relax
- · becomes bad tempered
- has trouble sleeping or concentrating
- feels very tired or very awake
- is short of breath.

Do Gently ask the person 'Is there anything else troubling you?' or 'Is there anything you would like to talk about?' It can help a person to talk about things that worry them.

Treat the person with respect. Help them to maintain their sense of dignity, purpose, and spiritual well-being.

What is anxiety?

What signs of anxiety should I report to the nurse or supervisor?

My notes:

See related palliAGED Practice
Tip Sheets:
Distress at the End of Life
Pain Management
Psychosocial Assessment
and Support



Flinders University



Tips for Careworkers: Cachexia, Sarcopenia and Anorexia



What it is: Weight loss is common with advanced disease. The processes behind this are cachexia, sarcopenia and anorexia.

Cachexia is common in people with chronic conditions such as cancer, heart or kidney failure. The person loses weight and muscle and, sometimes but not always, fat.

Anorexia is when a person no longer wants to eat.

Sarcopenia is the loss of muscle mass and function as people get older.

Why it matters: Weight loss is a part of the natural processes at the end of life. Your observations are important.

Fatigue and frailty may accompany the weight loss and so additional comfort measures may be needed. You may need to adjust approaches to care including:

- the time it takes
- careful repositioning
- use of cushions, a pressure-relieving mattress
- · 2-person assists
- the use of a hoist or wheelchair.

With changes in weight and in their condition, clients or residents may be concerned about their appearance. If you can respond respectfully and helpfully, you can help the person keep their self-esteem and dignity.

What I need to know: Anorexia and cachexia are common in people receiving palliative care, and sarcopenia is common in older people.

Some staff can find it distressing to care for people with cachexia and sarcopenia. Seek help if you feel uncomfortable or need support.

- **Do** Report to nursing staff if a person:
 - · changes their eating or drinking habit
 - stops eating or drinking
 - is less active or unable to do things
 - finds it hard to swallow
 - has diarrhoea or constipation
 - · feels sick or vomits
 - has clothing that becomes ill-fitting and oversized, needing to be replaced.
- Ask if the person would like snacks or small amounts of food throughout the day, respecting their choice to refuse.
- Look out for skin care, pressure injuries and heightened sensitivity to cold.
- Ask the person how you can assist them in a way that supports their remaining strength and respects their loss of ability.

What changes related to eating and activity should I report to nursing/supervisory staff?

In the daily care of an older person with significant weight loss, what should I pay attention to?

My notes:

See related palliAGED Practice
Tip Sheets:
Frailty
Nutrition and Hydration
Recognising Deterioration









What it is: Complementary therapies (CT) are often used alongside conventional medical treatments but have not been developed using the same evidence approaches. CT cover a variety of practices and physical therapies including aromatherapy, herbal medicine, and massage therapy.

Why it matters: CT are often used in Australia. Therefore, patients who transition to palliative care may already be using CTs or may wish to start to use CTs.

Some forms of CT can interfere with medications or cause harm. It is important to know what is being used.

What I need to know: CT may be used by palliative care patients to relieve physical symptoms, help control treatment side effects, and/or improve their wellbeing.

CT nutritional supplements can interact with medicines or cause adverse events. It is important to know what is being taken.

The range of CT practices used by people with life-limiting illness includes:

- acupressure
- acupuncture
- aromatherapy
- art therapy
- massage
- meditation
- music therapy

The person's relationship with the complementary therapist can be important.

CT benefits may be uncertain or short-lived but can provide the opportunity for the person to 'escape' or 'live in the moment'. This might reduce their worries about their disease and future.

Note

Remember that most people are waiting to be asked before they disclose their use of CT.

Lifestyle coordinators may be able to help with some approaches to CT.

Do

• Talk openly with the person and do not judge them. CT is a very personal choice.

Do

Record information about the CT that people in your care are using and let your supervisor know.

Do

You may wish to ask:

Have you tried anything else like herbal or natural remedies to help?

If so, then ask:

- Have you noticed any benefit?
- Have you noticed any side effects?

Do

Ask if they would like help to understand any information about the CT and let your supervisor know.

What complementary therapies do I use?

What questions can I ask to find out what therapies a person I care for is using or wanting to use?

My notes:

See related palliAGED Practice Tip Sheets: Pain Management Person-Centred Care Talking About Dying









What it is: Constipation occurs when there is limited or difficult passing of hard, dry stools (faeces).

Why it matters: Constipation is common in older adults. However, it is more common in older people with palliative care needs and as a person comes to the end of their life.

Constipation can lead to a person not eating, feeling sick, having pain, or becoming weaker and more unwell. Pain may be severe. Careworkers are likely to notice these changes and can also actively support the older person to manage concerns with constipation.

What I need to know: The Bristol Stool Chart can be used to decide if a person's stool is normal or not.

Food with increased fluid and fibre may be useful.

Consider the person's dignity when helping with toileting.

To know what is usual, ask the person or their family how often they usually pass a stool.

Make sure that it is easy and safe for a person to use the toilet – this can mean good lighting, safe bed height, toilet height, and clothing that is easy to wear and remove.

Observe toileting patterns of a person and support them to go to the toilet.

Report to nursing/supervisory staff any change in toileting pattern, discomfort, straining, or leakages. Document this accurately in care notes.

When attending to a person's concerns with constipation what should I consider?

What can I do to make it easier for the older person to use the toilet?

My notes:

See related palliAGED Practice
Tip Sheets:
Faecal Incontinence
Nutrition and Hydration
Opioid Analgesics









What it is: Distress at the end of life is when a person finds it hard to come to terms with dying.

It includes thoughts about:

- death
- the meaning of life
- Ioneliness
- · loss of dignity
- · achieving life's goals.

Distress at the end of life may also be called existential distress, death distress, or death anxiety.

Why it matters: People with life-limiting illnesses often suffer from distress at the end of life.

Older people with limited ability to connect with others can also have existential loneliness with strong feelings of emptiness, sadness, and longing. This can lead to anxiety and depression.

What I need to know: In people needing palliative care, distress at the end of life may lead to a wish for hastened death. Therapies such as life review or dignity therapy may help with quality of life and wellbeing in the short-term.

Take note and report to nursing/ supervisory staff if the person shows signs of distress such as trouble breathing or appearing upset or annoyed.

Take time with the person, giving them your full attention and allowing them to talk to you, with you.

Ask questions like 'How are you feeling?' or 'Is there anything else troubling you?' or 'Is there anything you would like to talk about?'

How do I cope with a client or resident expressing distress at the end of life?

My notes:

See related palliAGED Practice Tip Sheets: Psychosocial Assessment and Support Anxiety Spiritual Care





Tips for Careworkers: **Dysphagia**



What it is: Dysphagia is difficulty swallowing. The person finds it difficult to swallow food or liquid, including medications in liquid or tablet form.

Why it matters: Dysphagia is common in older people and people in palliative care. Careworkers have an important role in supporting oral care and positioning of the person. Dysphagia can lead to:

- · poor nutrition
- dehydration
- aspiration (breathing a foreign object or liquid into an airway)
- asphyxiation (lack of oxygen)
- · pneumonia.

What I need to know: Any changes to the normal function of the mouth, pharynx or larynx or oesophagus can cause dysphagia.

Dysphagia may be due to:

- · changes associated with ageing
- the side effect of medication
- treatment including radiation and chemotherapy for cancer.

Dysphagia is common in advanced or terminal illness. Dysphagia is also associated with neurological conditions particularly:

- dementia
- Parkinson's Disease (PD)
- Motor Neurone Disease (MND)
- stroke.

Note

People providing meal time assistance should have received training in assisting people with swallowing problems and managing choking episodes.

Do

Look out for and report to nursing/ supervisory staff if a person:

- chokes when eating, drinking or taking medication
- has the feeling of food sticking in the throat
- dribbles or has food escaping from the mouth
- coughs during or after eating, drinking or taking medication
- eats or drinks very slowly
- refuses food and fluids
- doesn't swallow food, fluids or medication but keeps it in the mouth.

Do

When someone is dying, their family can be upset that they are not eating or drinking. You can:

- · reassure the family
- let them offer the person sips of water or if appropriate moisten the mouth with a wet swab.

Dysphagia is difficulty with what?

What are some of the signs I should look out for and report to nursing/supervisory staff?

My notes:

See related palliAGED Practice
Tip Sheets:
Advance Dementia
Nutrition and Hydration
Oral Care









What it is: Dyspnoea is when a person has trouble breathing or has shortness of breath.

Why it matters: Breathing difficulties are a common and distressing symptom in many advanced life-limiting diseases, and can cause significant disability, anxiety, and social isolation. Careworkers can help the older person by reporting signs of dyspnoea and keeping them calm and comfortable.

What I need to know: Breathing concerns:

- · reduce quality of life
- affect emotional, spiritual and physical wellbeing
- are made worse by fear and panic.

Treatment often requires a combination of measures. This includes medication and other forms of care.

People with dyspnoea get tired quickly and people who tire easily often complain of dyspnoea.

Dyspnoea in palliative care and at the end of life needs to be assessed by nursing staff.

General care of dyspnoea:

- leave time between care and activities
- calm and reassure the person by being with them
- alert nursing/supervisory staff if breathing remains difficult.

Non-pharmacological ways to relieve dyspnoea at end-of-life:

- optimise air flow around the person
 e.g., table or handheld fan, open window
 if appropriate
- breathing-control techniques
 e.g., pretend to blow out a candle
- relaxation exercises
- position the person in:
 - supported upright sitting
 - leaning on a supportive table
 - lying in a reclining chair or electric bed with a backrest and a knee break.

Do Get all equipment and staff ready prior to commencing care procedures. This will shorten the time taken for care and reduce the impact on the person.

What is the clinical term for difficulty with breathing?

What can I do to help a person having difficulty with breathing at the end of life?

My notes:

See related palliAGED Practice Tip Sheets: Anxiety Opioid Analgesics









What it is: Eye care is attention to the health and comfort of a person's eyes.

Why it matters: Towards the end of life, dry eyes are common and can cause discomfort. Eye secretions (fluid from the eye) can also cause discomfort when they collect around the eye.

More generally, poor eyesight is common in older people. It affects the risk of falls, and impacts emotional health, independence, and participation in usual activities.

What I need to know: There are many reasons that older people may have poor eye health.

These include:

- impaired vision due to:
 - cataracts (clouding of the eye)
 - age-related macular degeneration
- improper contact lens hygiene
- prolonged wearing of contact lenses

Start the conversation by asking the older person if they usually wear glasses or if they need help to see.

In advanced illness or as the person approaches death there may be changes in their eye health and appearance. This can include dryness, bulging of the eye, not being able to close eyes, or build-up of secretions on eyelids.

When attending to eye care make sure that your hands are clean.

Let nursing/supervisory staff know if the older person's eyes seem to be different to usual. This includes any:

- · build-up of eye secretions
- signs of irritation or redness
- discomfort or if unable to close eyes.

Do If removing eye secretions:

- use a sterile cotton ball moistened with sterile water or normal saline over the lid margins
- wipe from the inner corner of the eye to the outer edge
- use a new cotton ball and repeat until secretions are clear
- use a separate pad for each eye.

Let nursing/supervisory staff know if the older person is experiencing new problems with reading, daily activities, or mobility.

What role do I have in eye care of the people in my care?

What changes in an older person's activity might I notice if they are having problems with eyesight?

My notes:

See related palliAGED Practice
Tip Sheets:
Oral Care
Recognising Deterioration
Signs of Imminent Death









What it is: Faecal incontinence is the inability to control bowel movements which leads to unexpected leakage of liquid and/or solid stool.

Why it matters: Faecal incontinence is common in older adults. However, it is more common in people with palliative care needs and as a person comes to the end of their life.

Faecal incontinence can affect a person's health, dignity, and independence. It is also a hygiene concern.

Faecal incontinence is a risk factor for pressure injury in frail older adults. The leaking fluids affect the health of skin.

Careworkers are likely to notice if a person experiences faecal incontinence. Together with nursing/supervisory staff they can help manage any concerns and look for signs of new or ongoing needs.

What I need to know: The Bristol Stool Chart can be used to decide if a person's stool is healthy or not.

Food with increased fluid and fibre may be useful.

Consider the person's dignity when helping with toileting and assisting with their continence needs.

The person may be unhappy and ashamed about faecal incontinence – be calm and patient with them.

Do Make sure that it is easy and safe for a person to use the toilet – this can mean good lighting, safe bed height, safe toilet height, and clothing that is easy to wear and remove.

Observe toileting patterns of a person and support them to go to the toilet.

Report to nursing/supervisory staff any change in toileting pattern, discomfort, straining or leakages, and document this in care notes.

When attending to a person's concerns with toileting and faecal incontinence, what should I consider?

What can I do to make it easier for the older person to use the toilet?

My notes:

See related palliAGED Practice
Tip Sheets:
Constipation
Opioid Analgesics
Nutrition and Hydration









What it is: Signs of frailty include unplanned weight loss, slow walking speed, weakness and low physical activity with the person feeling exhausted or tired.

Why it matters: Older people are not always frail or dependent. After the age of 80 years it is more common. Frailty affects a person's health, and ability to recover from poor health. Frailty and dementia together predict a more rapid decline and shorter life expectancy.

Knowing when older people with life-limiting illness are frail, helps us to know they are approaching death. Careworkers spend a lot of time with the older person and by reporting signs of frailty they can make certain that the right care is received.

What I need to know: Older people who are frail often have poor health, many conditions, falls and disability, as well as longer stays in hospital, and are more likely to die.

When a person is frail or at risk of becoming frail, illnesses such as infections are harder to recover from.

Older people and people with a life-limiting illness should be monitored for frailty so that care plans can be made to support their needs.

Do Look out for non-specific signs of frailty:

- extreme fatigue
- slow walking speed
- unexplained weight loss
- many infections.

Do Look out for specific signs of frailty:

- frequent falls
- fear of falling
- restricted activity
- delirium (acute change to their mental state)
- fluctuating disability (having good days and bad days) with, for example,
 - loss of interest in food
 - difficulty getting dressed.

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What are some of the signs of frailty? How do I report these?

How many people in my care could be considered fail?

At what age does frailty become more common?

My notes:

See related palliAGED Practice
Tip Sheets:
Cachexia, Sarcopenia,
and Anorexia
Palliative Care
Recognising Deterioration

For references and the latest version of all Tip Sheets visit palliaged.com.au/Practice-Centre/For-Careworkers





Tips for Careworkers: Grief and Loss among Older People, Families and Residents



What it is: Grief is a response to loss. It can affect all parts of a person's life.

Bereavement is the time of grief experienced by people following the death of someone close to them.

Why it matters: Grief and loss are common among people who receive care and their families. For people with palliative care needs or approaching the end of life, there may be more than one trigger for grief. Older people may be able to deal with grief, but signs of intense or ongoing grief should be reported.

Feelings of grief and loss can have a great affect on a person's physical health and mental wellbeing. Careworkers are likely to notice signs of grief in the people they care for. Cultural differences in grief should be respected.

What I need to know: Older people and their families may experience grief and loss due to the death of relatives or the death of friends or fellow residents. Family includes people (and pets) identified by the person as family.

Older people can also experience grief because of loss of independence (need for help from others), or not being able to do things that they once enjoyed. Signs of grief in older people include:

- crying or finding it hard to talk of their sadness
- anger, anxiety or worry
- a change in eating habits
- losing interest in family, friends, or hobbies
- finding it hard to sleep, concentrate, or make decisions.

There is no right or wrong way to grieve.

Offer the person and their family a chance to talk. For some people talking with a GP, counsellor, or pastoral care worker may help.

Note

The person may not need answers or advice; listening to them may give the greatest comfort.

Do

Let the older person know that grieving is a natural response to loss.

Do

Spend time with the person in a gentle and unhurried way. Use phrases such as 'I'm awfully sorry for your loss' and then take time to listen to their response.

What are some of the reasons for which an older person may grieve?

What is one thing I can do to help an older person with grief?

My notes:

See related palliAGED Practice
Tip Sheets:
Grief and Loss among Staff
Spiritual Care
Talking about Dying









What it is: Grief is a response to a loss. Bereavement is the time of grief experienced by people following the death of someone close to them.

Why it matters: Caring for others can be rewarding. But grief over the death of people you care for is not unusual. It may contribute to burnout and overwhelming stress.

Staff working in aged care look after many people who die. As a result, they may experience repeated grief. Sometimes it can lead to complicated or prolonged grief where grief is very intense and/or long lasting. Report to nursing/supervisory staff any feelings of grief that are very strong, last for more than six months or make it difficult for you to do your work appropriately.

What I need to know: Grief is a response to bereavement and loss. How people grieve varies. No-one can tell another how they should grieve.

There are bereavement services to help you deal with grief and loss.

Talking to your supervisor and colleagues about what you are experiencing can help. If you need more support, request their help to find it.

Note

Ways of dealing with grief include:

- taking care of your own physical health
- acknowledging your grief
- talking with colleagues
- talking with pastoral care providers
- talking with bereavement counsellors
- · talking with a GP.

Note

Careworkers in aged care can develop close bonds with older people and families. You may experience grief.

Do

Instead of 'protecting yourself' from future loss by keeping a distance from clients, learn ways to cope with grief and develop self-care. You can grieve and still care well.

Do

Visit the ELDAC self-care room for self-care ideas.

Who can I talk with if I experience grief?

How could I start a conversation with other staff experiencing grief?

My notes:

See related palliAGED Practice
Tip Sheets:
Grief and Loss among Older People,
Families and Residents
Self-care
Talking about Dying









What it is: Opioids are analgesics. They are medications often used to treat pain from terminal illnesses.

Morphine is an opioid. It is often used in palliative care to manage moderate to severe pain. There are other opioids. Myths are widely believed but untrue beliefs.

Why it matters: Morphine provides effective pain relief. The dose can be adjusted to reduce pain. Older people and their family may have heard myths about morphine and be concerned. Careworkers have direct contact with the person and their family and can ask nursing/ supervisory staff to answer any questions they may have.

What I need to know: Facts and common myths about morphine use.

Myth Once on morphine the end is near.

Fact Morphine properly used does not cause death, the underlying illness does.

Myth Enduring pain will enhance one's character.

Pain decreases quality of life and causes suffering.

Myth Morphine is addictive.

Fact When given at the right dose to relieve pain, morphine is not addictive.

Myth Injections are better than oral.

Fact Oral preparations are as effective as injections; long-acting forms mean better pain control and less frequent administration.

Myth Side effects (nausea, vomiting, constipation, sleepiness, etc.) are due to allergies.

Fact Allergies to morphine are rare, side effects can be managed and should be reported to the prescriber.

Myth Tolerance to morphine will develop and higher doses will be needed.

Fact Tolerance develops slowly. Disease progression may cause increasing pain and increased need for analgesia.

Myth Morphine is a treatment for cancer.

Fact

No, morphine is not a treatment for cancer, it is an analgesic medication used to relieve the symptoms of pain.

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Why might a person need increasing doses of morphine?

Who should answer any questions that older people and their families might have about morphine or other opioids?

My notes:

See related palliAGED Practice Tip Sheets: Opioid Analgesics Pain Management









What it is: Nutrition is about the intake of food and how this helps health of the body. Good nutrition helps people stay healthy. Nutrition depends on the quality of food and how often we eat.

Hydration is about the intake of fluids to help with growth and health.

Why it matters: In the early stages of palliative care, nutritional intervention can help people boost tissue repair and general wellbeing and prevent infection. However, as people come to the end of their life, they may have less interest in food, and they may have difficulties with swallowing or tiredness. This can be due to many reasons. Careworkers can help by reporting any difficulties and assisting the person to eat and drink if possible.

Eating and drinking are important parts of a person's life and social interactions. The attitudes and values of the person and their family are important in the decisions about eating and drinking.

What I need to know: Good food and drink can improve a person's quality of life by reducing the effects of weight loss, improving wound healing and tiredness. In the early stages of palliative care the person may need help with eating and drinking.

Towards the end of life, a person may be less interested in food and drink. Changes in their body's function and activity may mean less nutrition is needed. The goal is to enjoy food and reduce food-related discomfort. Family and carers may be distressed if a person does not eat. They can be reassured and provide comfort through mouth care or assisting with drinks. Mouth care remains important.

Ask the person what foods and drinks they like, or if they cannot answer ask their family and look at their dietary plan. Report or record this information.

Offer meals or snacks when the person is most alert and receptive.

Report to nursing/supervisory staff if you think that the:

- person
 - is in pain
 - has poor oral health
 - is confused
 - has difficulty swallowing
- carer
 - is stressed about weight loss.

Do Help the person to eat or drink if they:

- have trouble being able to eat or drink
- are confused
- do not recognise food.

Why are nutrition and hydration important?

What can I do to encourage someone to eat? What do I need to be careful of?

My notes:

See related palliAGED Practice
Tip Sheets:
Cachexia, Sarcopenia
and Anorexia
Dysphagia
Oral Care









What it is: Analgesics are medications used to relieve the symptom of pain. Opioids are analgesics. They are often used to treat pain from terminal illnesses.

Morphine is an opioid. It is often used in palliative care to manage moderate to severe pain. There are other opioids.

Why it matters: Opioids provide effective pain relief. The dose can be adjusted to reduce pain. Like all medications there can be side effects. Careworkers are likely to notice if there are side effects or pain persists.

What I need to know: Opioids can be given by:

- mouth (orally)
- a transdermal patch (skin patch)
- injection
- subcutaneous infusion (syringe driver).

Morphine, properly used, does not cause death; the person's illness does. Like all medications there can be side effects. Constipation is common.

Tolerance (lack of response) develops slowly, but rapid disease progression may cause increasing pain and increased need for pain medication.

Older people and their families may be concerned about opioid use. Ask nursing/ supervisory staff to answer any questions.

Note

Be aware that a person may be given opioids or other analgesics.

Do

Watch whether the person still has pain after being given analgesia. Careful repositioning and gentle massage may also help with pain relief.

Do

When a person is taking morphine, it is important to note certain possible changes. Report to nursing/supervisory staff if the person shows signs of adverse effects such as:

- nausea or vomiting
- constipation
- sedation
- respiratory depression (slower breathing)
- dry mouth
- cognitive impairment
- delirium (confusion)
- hallucinations
- seizures.

Why are opioids used in palliative care?

What side effects of morphine should I look for and report to nursing/supervisory staff?

My notes:

See related palliAGED Practice Tip Sheets: Myths about Morphine Pain Management





Tips for Careworkers: Oral Care



What it is: Oral health covers the ability to eat, speak and socialise without discomfort or active disease in the teeth, mouth or gums.

Why it matters: People in need of palliative care or at the end of life often have poor oral health. Treatment for cancer can cause poor oral health. Good oral health is important to quality of life and wellbeing. It affects the person's ability to eat, speak and interact with others. Oral care provided by careworkers helps.

What I need to know: Poor oral and dental health can be associated with:

- dry mouth (xerostomia)
- bad breath
- bleeding gums, tooth decay and tooth loss
- being withdrawn and behaviour changes
- pain and discomfort
- swallowing and nutritional problems, and weight loss
- speech difficulties and problems with social interactions
- increased risk of respiratory infection or other infections.

Whether the older person has natural teeth or dentures, it is important to keep a good routine for cleaning the teeth, mouth and lips. The person may not say if they have pain or discomfort. Look for signs including pulling at face, chewing at lip or tongue or not eating.

Do Remember when cleaning the mouth to:

- give explanations and allow time for the person to respond
- maintain regular routines in a quiet environment
- use a soft toothbrush which can be bent or a mouth swab
- always rinse the mouth with water
- ask the person to copy your actions of brushing or help the person brush their teeth
- use props to distract the person's hands while you gently brush their teeth
- ask a colleague or a dental hygienist to help.

Do For denture care (false teeth):

Do

- label dentures and soak in cold water
- use a denture brush for cleaning dentures morning and night
- encourage the person to remove dentures overnight if this is what they usually do
- encourage the person to remove dentures after each meal and rinse mouth with water.

Report to the nursing/supervisory staff any changes in a person's mouth, teeth or lips or any pain or discomfort with oral care.

Ask about the Oral Health Assessment Tool (OHAT).

What are three signs of poor oral health?

What can I do to make cleaning of the mouth easier for a person?

My notes:

See related palliAGED Practice Tip Sheets: Advanced Dementia Nutrition and Hydration Dysphagia









What it is: Pain can be physical or emotional. Older people often have pain. This includes physical and spiritual pain.

Why it matters: Pain is a very common symptom in chronic progressive illness. People in need of palliative care often have more than one type of pain. Careworkers spend a lot of time with the older person and may notice signs of pain or changes in the level of pain experienced.

What I need to know: The expression of pain is different for everyone. It will be affected by the person's experience, attitudes, and beliefs. Palliative care helps to manage pain and improve quality of life. The aim is to manage pain in line with the person's wishes.

Pain that is not properly treated can cause:

- a person to eat and move less
- a person to avoid other people
- poor sleep
- depression
- · family distress.

Unrelieved pain may affect cognitive function. It may contribute to an increase in challenging behaviours and delirium.

Nursing staff are responsible for assessing a person's pain. Careworkers can play a part by reporting discomfort noted during care.

Do Careworkers can look out for signs:

- report if a person has had any difficulties with walking, moving, normal activities
- report if a person says they are in pain
- monitor the person's response to prescribed pain treatments
- notify a nurse/supervisor if comfort measures have been tried but are not effective
- report any discomfort.

Do You can help relieve pain:

- by repositioning the person
- by reassuring the person, by word and by action, that they are safe
- with therapies e.g., gentle massage or application of warmth.

Careful positioning of people who are immobile can minimise muscle pain and cramps.

What are some of the signs that a person is in pain?

What comfort measures could I try to reduce the pain felt by an older person?

Who would I speak to if an older person is crying out in pain during care?

My notes:

See related palliAGED Practice
Tip Sheets:
Myths about Morphine
Opioid Analagesics
Palliative Care









What it is: Some people may have specific care needs related to their cultural or linguistic (language) background, sexuality, religious or faith beliefs, life circumstance or location. People may identify with one or more of these attributes.

Why it matters: Culture is not just about language, ethnicity or nationality. It is also about identity and relationships, and shared (sometimes painful) experiences.

Events early in life may significantly affect health and wellbeing in later life. Understanding the person's circumstances is an important part of person-centred care.

What I need to know: There are many recognised specific groups in aged care which include people who:

- identify as Aboriginal and/or Torres
 Strait Islander
- are from culturally and linguistically diverse (CALD) backgrounds
- · live in rural or remote areas
- · are financially or socially disadvantaged
- are veterans of the Australian Defence
 Force or an allied defence force and their spouse, widow or widower
- are homeless, or at risk of becoming homeless
- are care leavers (people who spent time in care as a child, Forgotten Australians, Former Child Migrants and Stolen Generations)

- as parents, were separated from their children by forced adoption or removal
- identify as lesbian, gay, bisexual, trans/ transgender or intersex (LGBTI)
- have a disability
- are refugees or asylum seekers
- are prisoners.

It is important to be aware of people's privacy and know who you may share information with.

Note

Everyone is a unique person with their own life and life story. Some issues are complex, you may or may not be able to help them. If you have concerns talk with nursing/supervisory staff.

Do

If you are uncertain about a person's culture, beliefs or specific needs, ask questions in a respectful way, for example 'Good morning Mrs xxx, could I ask you about something?'

Do

Ask 'Are there religious or cultural practices that affect the way you wish to be cared for?' or 'Is there anything I need to know about you and your preferences in order to care for you?'

When meeting someone I will be caring for how do I respectfully understand their specific needs?

Sometimes in caring for people we learn things about them which do not affect their care. How can I respect their care yet address things that I have learnt that are of concern?

My notes:

See related palliAGED Practice Tip Sheets: Anxiety Continuity of Care Psychosocial Assessment and Support



Flinders University



Tips for Careworkers: Psychosocial Assessment and Support



What it is: Psychosocial support includes mental well-being and social aspects of a person's life. It responds to emotions, thoughts, attitudes, motivation, and behavioural needs as well as their social circumstances. This includes their sense of identity, relationships, or living arrangements.

Why it matters: Older people can have stress related to frailty, loss of independence, money, changed living arrangements, or social isolation. A life-limiting illness can make it even harder to adapt and cope. Together this can lead to anxiety, depression, grief, distress, and loss of identity and meaning.

Identifying and addressing a person's psychosocial needs is important. Recognising and understanding the family's role and need for support is also important.

What I need to know: Ongoing meaningful conversations can help to identify any needs or concerns.

Psychosocial needs are best addressed by a multidisciplinary team. This can include careworkers, counsellors, GPs, medical specialists, nurses, pharmacists, psychologists, occupational therapists, and social workers.

Friendly communication is important especially if the older person is feeling lonely or isolated.

Information about support groups for carers might also be helpful for families.

Tips for talking:

- Take time to talk with and understand the older person and their family
- Take time to reflect on what they have said
- Ask them how they feel and what they think they need
- Use open questions that require more than a 'yes' or 'no' answer, e.g. 'What would help?' is better than 'Do you need help?'
- Encourage them to participate in activities and connect with others in the facility or their community.

Look out for physical symptoms such as breathlessness, not sleeping well, pain, sadness, crying, or weight loss. Let your supervisor know if you notice any of these.

Talk with your supervisor about massage, art therapy, music therapy, spiritual support, or counselling for the older person.

What approaches to psychosocial care are used in my workplace?

How can I support a client or resident's psychosocial needs?

My notes:

See related palliAGED Practice
Tip Sheets:
Person-Centred Care
Talking About Dying
Supporting Families



Flinders University



Tips for Careworkers: Recognising Deterioration



What it is: Deterioration is when a person's state of health declines (worsens). They may:

- become bedbound (stay in bed)
- · spend more time sleeping or resting
- have reduced intake of food (eat less)
- · have difficulty with swallowing, or
- have fluctuating consciousness.

Why it matters: Recognising that a person is deteriorating is important so that:

- this can be discussed with the person and their family
- care is reviewed with the person (if able), the family and GP
- a palliative care plan or pathway can be started or changed
- care is given in line with the person's wishes
- symptoms are managed appropriately
- support to the person, the family and staff can be provided.

Careworkers often care for people on a daily basis and may notice signs of deterioration.

What I need to know: Many people suffer from chronic (long-term) conditions that are not always recognised as life-limiting (e.g., dementia).

The terminal or end phase of care for conditions like dementia and organ failure can extend over months or years. Signs of deterioration should be reported to nursing/supervisory staff.

Look out for and report to the nursing/ supervisory staff if:

- a person has changes in level of usual activity or engagement including a reluctance to get out of bed
- a person needs help from others for care due to increasing physical or mental health concerns
- a person loses weight or stays underweight
- a person has poor general health that is getting worse or not improving
- symptoms persist despite appropriate management
- there are emergency transfers to hospital
- the carer increasingly needs help and support.

Ask nursing/supervisory staff about SPICT4ALL, a tool to identify when a person's health is declining.

Ask nursing/supervisory staff to show you the forms used to help determine deterioration.

What tool can be used to tell if someone's health is deteriorating?

What changes should I report to nursing/supervisory staff?

My notes:

See related palliAGED Practice Tip Sheets: Case Conferences End-of-Life Care Pathways Frailty





Tips for Careworkers: Respiratory Secretions



What it is: When people have an infection of their airways or if they have difficulty swallowing then there can be a build-up of fluid in the respiratory tract. When they breathe and air passes through the fluid this can result in noisy breathing.

Why it matters: Noisy breathing is one of the most common terminal phase symptoms in people who are dying. Being unable to swallow or cough is common in people who are weak.

What I need to know: Noisy breathing due to respiratory secretions is often called 'rattle' or 'death rattle'.

The noisy breathing does not usually worry the older person. However, the family and carers may be concerned. Note

Noisy breathing due to respiratory secretions might be referred to as 'death rattle' or 'rattling'.

If the older person has noisy breathing, try repositioning them from side-to-side in a semi-upright position.

Do If family or carers are distressed by the person's noisy breathing let the nurse/ supervisor know so that they can explain what is happening.

Do

If the older person is given medication for noisy breathing let nursing /supervisory staff know if you notice side effects including:

- delirium / agitation
- sedation (sleepiness)
- dry mouth
- urinary retention (not passing urine).

Continue to provide mouth care often.

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Does 'death rattle' worry the older person?

Does my organisation provide any material for family and friends to help them better understand what 'death rattle' is?

My notes:

See related palliAGED Practice Tip Sheets: Oral Care Signs of Imminent Death





Tips for Careworkers: Signs of Imminent Death



What it is: Imminent death means that the older person is likely to die in the coming hours, days or weeks.

Why it matters: Recognising when death is near is important because it allows the older person to spend time with their friends and family of choice if that is their wish. It also alerts their health care team to the need for terminal care.

What I need to know: The signs of imminent death include:

- weakness totally bed-bound and requiring extensive nursing care
- sleepy and not responding to sound or touch
- difficulty with swallowing or inability to swallow
- · reduced eating and drinking
- reduced or no urine output
- changes in breathing pattern including noisy breathing or very long pauses between breaths
- skin that is cool to touch.

Communication from the older person may not be possible. Look for signs such as agitation, restlessness, facial expression, body posture and changes in breathing.

Care should continue with cultural and spiritual needs respected.

- Let your nursing/supervisory staff know if you notice any of the signs of imminent death.
- Continue to care for the person and make sure that family know that death is likely so that they can say goodbye.
- Listen to any concerns and opinions of the family and let nursing/supervisory staff know of these.
- Offer emotional support appropriate to the older person's needs and preferences.
- Continue to talk calmly with the person and let them know what you are doing hearing is believed to be the last sense to be lost.

What signs should I look for that might mean a person is likely to die soon?

Who should I speak with if I think a person in my care is approaching death?

My notes:

See related palliAGED Practice
Tip Sheets:
Distress at the End of Life
Recognising Deterioration
Spiritual Care





Tips for Careworkers: Skin and **Wound Care**



What it is: Wounds are damage or breaks of the skin and are common at the end of life. Wounds include:

- pressure ulcers
- · ischemic wounds
- skin tears
- skin changes.

Why it matters: The skin is an organ. The skin deteriorates with advanced disease. As the body weakens with age, severe illness, or multiple illnesses, wounds can become more common. Wounds affect a person's quality of life due to:

- pain
- unpleasant smell
- putrid or bad smelling discharge
- disturbed sleep
- the time it takes to look after a wound.

A person with a wound or skin changes may feel embarrassed. They may not want to be around other people.

Wounds can be worsened by:

- poor handling technique
- rushing the person during care
- poor hygiene
- inadequate wound care.

What I need to know: Despite good wound care, wounds may not heal. However, wound care should be continued to prevent more damage.

Note

Remember that the person will be more comfortable if they have regular pain medication and if they are given analgesics before starting wound care.

Do

Report to nursing staff:

- pain during wound care or when moving
- skin changes redness, dryness, itchiness
- skin tears or ulcers
- smell
- · oozing or bleeding
- any worsening of a known wound.

Do

Follow hand hygiene steps so that your hands are always clean.

Protect the person from injury by:

- careful positioning to avoid friction and shearing forces, bumps and scratches
- avoiding vigorous skin rubbing
- appropriate continence care
- cleaning skin with gentle skin cleanser and thoroughly drying
- protecting skin with water based skin moisturiser
- using pressure relieving devices.

What changes in the skin should I report to nursing/supervisory staff?

Skin deteriorates with advanced diseases. What approaches to care can be taken to avoid skin damage and wounds at the end of life?

My notes:

See related palliAGED Practice
Tip Sheets:
Cachexia, Sarcopenia
and Anorexia
Frailty
Pain Management









What it is: Spirituality can be a person's connection to other people, to nature, or to what gives them meaning and purpose.

Spirituality depends on the person. It is not always about religion.

Why it matters: For many people, spirituality is important throughout life and at the end of life. Spiritual pain may lead to a physical response (e.g., increased pain) or an emotional response (e.g., anxiety, depression, or anger).

What I need to know: Spiritual support is an important aspect of palliative care. Showing respect and support for a person's spirituality can reduce the distress of being ill or dying.

People may appreciate opportunity for discussion with chaplaincy staff, spiritual care practitioners, or faith representatives.

Do When you interact with the person use:

- appropriate touch
- eye contact if appropriate
- a welcoming unhurried approach to conversation and listening so that the person feels heard and valued.

Be sensitive and respectful of the spiritual, cultural and religious needs of people in your care and their families.

Offer opportunities for a connection with spiritual practices outside of those in the place of care.

What can I do to support someone's spirituality?

How can my own beliefs affect how I care for other people?

My notes:

See related palliAGED Practice
Tip Sheets:
Distress at the End of Life
Grief and Loss among Older People,
Families and Residents
Talking about Dying





Next Steps for Careworkers



What can I do next as:



A beginner

- Start a personal learning folder
- Complete the palliAGED Introduction Modules and add the completion certificates to my learning folder.

An intermediate learner

- Visit the palliAGED Practice Centre for more tips and discuss these with my supervisor
- Complete the ELDAC personal learning assessment
- Do some online training
 e.g., PCC4U and The Advance
 Project (Dementia) for careworkers.

An advanced learner

- Map my specific knowledge needs with the palliAGED course selection tool
- Build specific knowledge with resources in the palliAGED Practice & Evidence Centres.

What can my organisation do for:

Beginners

- Order palliAGED Practice Tip Sheet booklets for all staff members as part of induction
- Ask to install palliAGED Introduction Modules onto the local LMS
- Print out palliAGED Tip Sheets for the staff room
- Discuss how the palliAGED Practice
 Tip Sheet topics overlap with the aged care standards.

Intermediate learners

- Promote online education including the National Palliative Care program courses listed in the palliAGED Practice Centre
- Use selected Tip sheets and modules to start discussions about local care issues
- · Arrange for an onsite PEPA workshop.

Advanced learners

- Promote the palliAGED Practice Centre
- Discuss options for further education with staff
- Arrange for Reverse PEPA placements.









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