

palliAGED

Practice Tips for Nurses in Aged Care



palliAGED

PALLIATIVE CARE AGED CARE EVIDENCE

1

**Introduction
& Care Provider
Issues**

2

**Decision-Making
& Communication**

3

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 nurses have been developed for nurses new to palliative care, and for those responsible for careworker training and education. A companion collection written for careworkers is also available. 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

palliAGED is managed by CareSearch with funding from the Australian Government Department of Health.

Using palliAGED Practice Tip Sheets

The palliAGED Practice Tip Sheets for nurses in aged care are suitable for nurses newly engaged with providing palliative care, and for those responsible for the training and education 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 available for careworkers. 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 nurses.

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 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.

In the palliAGED Practice Tip Sheets for nurses, this is then followed with tips as to what Actions to take and Tools that may be of use. This is not a recommendation for the tools listed, but serves to highlight the availability of useful tools that might be considered in providing care.

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. This might 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. palliAGED incorporates and updates the evidence-based information previously contained in the Guidelines for a Palliative Approach in Residential Aged Care (APRAC) and the Guidelines for a Palliative Approach for Aged Care in the Community Setting (COMPAC). 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.

Contents

Introduction & Care Provider Issues	7
Aged Care Access and Assessment	9
Palliative Care	11
Self-care	13
Decision-Making & Communication	15
Advance Care Planning	17
After-Death Choices	19
Case Conferences	21
Continuity of Care	23
Culturally Responsive Care - Communication	25
End-of-Life Care Pathways	27
First Australians - Communication	29
People with Intellectual Disability - Communication	31
Person-Centred Care	33
Quality of Life with Change and Deterioration	35
Supporting Families	37
Talking about Dying	39
Talking within the Aged Care Team	41
Care Issues	43
Advanced Dementia	45
Advanced Dementia - Behavioural Changes	47
Anxiety	49
Cachexia, Sarcopenia and Anorexia	51
Complementary Therapies	53
Constipation	55
Distress at End of Life	57
Dysphagia	59
Dyspnoea	61
Eye Care	63
Faecal Incontinence	65
Frailty	67
Grief and Loss among Older People, Families and Residents	69
Grief and Loss among Staff	71
Myths about Morphine	73
Nutrition and Hydration	75
Opioid Analgesics	77
Oral Care	79
Pain Management	81
People with Specific Needs	83
Psychosocial Assessment and Support	85
Recognising Deterioration	87
Respiratory Secretions	89
Signs of Imminent Death	91
Skin and Wound Care	93
Spiritual Care	95
Next Steps for Nurses	97

Introduction & Care Provider Issues

1

Tips for Nurses: 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 requires 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 make a recommendation for the type and level of care that will best meet the needs of older Australians with low to complex needs.

This includes access to the following government-funded services:

- home care support and packages
- residential aged care
- transition care
- respite care
- short-term restorative care.

Why it matters: Sometimes care decisions and expectations about who will provide what care 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 including assessment works means that you can better support clients and residents to navigate the system to receive the care they need. It can also help to manage expectations related to care.

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.

Following 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 should be referred to for 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.

Actions

If clients or families have any questions about access to aged care, refer them to your supervisor and/or the My Aged Care Contact Centre.

Speak with your supervisor to arrange a case conference if you notice increasing care needs.

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

Tools

Tools that may be useful include:

MyAgedCare website www.myagedcare.gov.au

palliAGED has information on access to aged care for older Australians www.palliAGED.com.au

Name:

My reflections:

How many aged care assessments of my clients or residents have I read?

In my organisation where are records of aged care assessments filed?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: 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 the elderly.

Why it matters: The prevalence of chronic life-limiting conditions and the number of older people requiring palliative care is increasing. Nurses in aged care have a key role in assessing individual needs and supporting the person, their carers, and families in line with their care goals.

What I need to know: The aim is to support people with life-limiting illness to live the best life they can to the end.

Dementia, cancer, and advanced heart, lung, kidney and liver disease, are all examples of life-limiting chronic conditions. People with these conditions can benefit from palliative care in addition to usual acute and primary care as needed. The time course from diagnosis to death varies.

Palliative care can provide the person with pain relief and manage symptoms and medicines associated with the condition(s), as well as providing spiritual, emotional, and social support. The timing of palliative care depends on the individual and the condition.

Palliative care is a person-centred approach to care often taken with older people requiring daily support to improve quality of life and minimise any pain and discomfort. Difficulty in managing symptoms may reflect unrecognised palliative care issues and needs. This could signal the need for palliative care specialist intervention.

People needing palliative care may have social and cultural needs. Common care issues include:

- pain
- anxiety
- dyspnoea
- dry mouth
- dysphagia
- fatigue
- constipation
- depression.

The metabolism of older people and people with a serious illness can change over time. Monitoring for adverse reactions to medications is required.

Actions

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

A complete biopsychosocial history should be documented and include the presence of any life-limiting or chronic illness.

Refer to the person's Advance Care Directive when planning palliative care. Consider psychosocial needs, review symptoms and emotional and psychological needs. Allied health professionals may assist in providing care.

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
- being less physically active e.g., getting slower and less mobile
- incontinence
- difficulties swallowing.

Notify the prescriber or other health professional if you notice any adverse reaction to pain or other medications. A review by a pharmacist may identify concerns with medications.

Tools

In line with the policies of your organisation the following tools may be useful:

SPIC T tool helps health and care professionals to identify people who are declining in health and might benefit from better supportive and palliative care.

Needs Assessment Tool: Progressive Disease - Cancer (NAT:PD-C)

Name:

My reflections:

How many of the people I care for would benefit from palliative care? What changes would prompt me to make a referral to a GP or palliative care specialist?

Careworkers spend a lot of time with the clients and residents. In my organisation how do they relay information to nursing/supervisory staff?

How do I support the team that I work with to provide palliative care?

My notes:

See related palliAGED Practice
Tip Sheets:

Advance Care Planning
End-of-Life Care Pathways
Pain Management

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Self-Care



What it is: Self-care is a range of knowledge, skills, and attitudes that health care professionals can use for themselves or to support others to maintain mental and physical wellbeing.

Why it matters: Grief over the death of clients is not unusual and may contribute to stress or burnout. Factors unique to palliative care include:

- accumulated losses
- emotionally-charged care
- sustained and exclusive focus on terminal illness and care
- acknowledging and living with grief
- loss within your own personal life.

Nurses, including those who care for only a few palliative care clients, may experience:

- difficulty shifting from curative mode to a palliative and supportive role, accepting death as an inevitable and appropriate outcome
- guilt, if perceiving that a diagnosis was missed or delayed
- stress, if unable to relieve difficult symptoms or intense distress in the patient or their family
- difficulty in handling their own mortality.

What I need to know: Self-care can include self-reflection and self-awareness, identification and prevention of burnout, appropriate professional boundaries, and grief and bereavement support.

Being part of a team that provides the opportunity for support, reflection and debriefing is beneficial. This may be particularly helpful in developing realistic expectations of the degree of support that can be provided to dying patients. A team may be your work colleagues or a network of people outside of work.

Actions

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.

Develop your self-awareness by reflecting on how you care for yourself. Consider:

- Physical: am I getting enough sleep, exercise, and healthy food?
- Psychological: am I doing enough to keep myself mentally stimulated?
- Social: do I get enough time for my relationships?
- Emotional: What am I doing to process my emotions?
- Spiritual: what questions do I ask myself about life and my experience?

Reflective practice includes a conscious look at emotions, experiences, actions, and responses, and using that information to understand our responses.

Look out for signs that demonstrate a person is not coping such as:

- physical and emotional exhaustion
- poor sleep
- headaches
- negativity and cynicism
- lack of enjoyment
- not working effectively
- absenteeism
- use of drugs or alcohol as ways of coping.

Tools

Tools that may be useful include:

Developing a self-care plan and strategies that promote your physical and emotional well-being.

Visit the ELDAC Self-care room.

Name:

My reflections:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Decision-Making & Communication

2

Tips for Nurses: Advance Care Planning



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 and territories 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 about health and personal care if later they are unable to. This person is called a substitute decision-maker (SDM). Some states and territories include this in an ACD.

An ACD is sometimes known as a living will because it is completed and signed by a competent adult and records their preferences for the future.

Why it matters: Advance care planning helps people receive the care that they would wish to receive. Nurses have a role in ensuring ACDs are referred to when planning care. It is particularly important for an older person who may:

- have advanced illness
- have multiple chronic illnesses
- be frail
- have cognitive impairment or live with dementia
- have unplanned admission(s) to hospital
- lose the capacity to make decisions or express their wishes.

What I need to know: It is not compulsory to have an ACD. ACDs only go into effect when a person is unable to make decisions for themselves. They do not replace the SDM.

A person may choose to forgo treatment. This is not giving up nor does it 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).

Actions

ACDs can be changed whenever the person wants and should be reviewed when circumstances change. 'We had a conversation where we decided on A, B and C, is that still current and what you want? If so, are you happy to record these changes so that they can be referred to if you cannot express your wishes?'

An assessment of capacity may be needed. This should occur at a time of day when the person is most likely to understand and when they are free of pain or other distressing symptoms. This assessment is usually made by the person's GP.

A person is considered competent or to have competency or have capacity if they can:

- understand the information
- retain information long enough to indicate their wishes, and
- express their wishes.

Remember to:

- store ACDs safely
- have ACDs accessible to staff who make decisions about care
- have ACDs accessible to visiting service providers including GPs
- make sure that a current ACD accompanies the older person moving to or from hospital or residential aged care.

Have clearly documented and accessible the contact details of the substitute decision-maker and person to contact in case of an emergency or death. These may not be the same person. Be clear about who you should contact.

Tools

Tools that may be useful include:

Visit Advance Care Planning Australia for state and territory forms and information on requirements.

Name:

My reflections:

How many of the older people I care for have an ACD? Where are they kept, and have I read them?

When should I implement an ACD?

What is the ACD legislation in my state/territory?

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: After-Death Choices



What it is: Planning and managing what happens after the death of an older person.

Why it matters: The person may have expressed their wishes in an Advance Care Directive (ACD). Some decisions may also need to be taken by members of the family. Planning can help with a healthy grieving process and nurses can refer to the person's ACD in support of this.

What I need to know: Before a body can be moved the death must be verified. Once the death has been verified, a funeral company can take the body into their care. Consider any cultural practices that may be important to the person and their family.

There may be requirements for reporting a death to the coroner. Relevant legal requirements are not the same across Australia. It is important to know what is required in your state/territory.

All relevant people need to be advised about the death and consulted as to actions following the death.

Income support may be available to spouses or carers through the Bereavement Allowance, Bereavement Payment or Pension Bonus Bereavement payment. See Department of Human Services.

Some people may decide to donate their body or brain to medical science or research. Written consent is needed from the person before their death. This may appear in the person's ACD. If not, the family may need to decide and provide written consent.

A body donation may be refused if:

- the person had a certain infectious illness
- it is not feasible or possible to transport the body within 24 hours
- the donation facility is full
- the person was very thin and weak.

It is important that the doctor is aware of a person's intention to be a donor. Contact the university, research or pathology service without delay regarding body or brain donation.

Actions

Include in the care plan details of actions that care staff will need to take at time of death including contact details for donor organisations (if relevant).

The RN needs to ensure that all relevant people (including GPs, home/community nurses and services) have been consulted and all special needs at the time of death have been attended to.

The body of the client or resident needs to be verified as dead by an authorised person, and a certificate signed to officially confirm the death.

You can use the Residential Aged Care End of Life Care Pathway (RAC EoLCP) for residents to guide care delivery.

Be aware of possible needs including religious and cultural practices following death, and time needed for the family to be with the deceased.

It is important that any medicines are disposed of safely, often returned to a pharmacy.

Family members may:

- need time to accept the death
- need time to travel to the site of death
- want to sit with the deceased person
- want to respect certain traditions
- need help to cancel any health appointments or arrangements.

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.

Name:

My reflections:

Does my organisation have a clear policy on procedures following the death of a client or resident?

Does my organisation have post-death rituals or memorial practices?

How can I recognise if a death of a client or resident has significantly affected a member(s) of my team?

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Case Conferences



What it is: A palliative care case conference is a meeting held between the older person (if able to attend), their family and their legal substitute decision-maker (SDM), and members of the care team including the doctor to assess care plans and clinical care needs.

Why it matters: They can be a useful way to:

- 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
- assess relevant options and choices in the case of an emergency
- check if there is an Advance Care Directive (ACD)
- check if the ACD needs to be updated.

What I need to know: Clear communication is an essential part of good aged and palliative care.

Palliative care provides physical, social, spiritual and psychological care. A multidisciplinary team including allied health can help to meet these varied care needs. A person's needs may frequently change. This means that decisions need to be made about treatments that include the wishes of the person and the needs of the family. It is helpful and important that the SDM and/or support person is aware of these decisions.

Family meetings or case conferences can be a comfortable way to:

- ask questions
- discuss issues
- make decisions.

Knowing who you can share client or resident information with is important.

Talking through issues in a case conference may stop them from becoming major issues. This way, emergencies or crises can be avoided.

Staff in residential aged care facilities often meet with families to discuss routine care of residents.

Actions

Holding a case conference can assist with communication between the person receiving care, substitute decision-maker(s), key family members, and the care team.

The aim of the case conference is to:

- discuss issues and identify unmet needs
- raise concerns about the person's condition
- review the person's ACD
- agree on clear goals for the person's future care
- support families.

Clearly record the organisation and content of the case conference.

Case conferences are held when the older person's health status is changing, they are also held when death is expected within days. Look out for and report any changes in a person's mood, ability to function, swallow, move, breathe etc.

Knowing who you can share client or resident information with is important.

Family meetings differ from case conferences. Family meetings focus on the person and their family's needs and preferences to establish goals of care.

Tools

Tools that may be useful include:

If organising a case conference, use of standardised forms can be useful to document activities and decisions. Check if your organisation has a preferred set of forms.

Name:

My reflections:

When I last met with a family to discuss changes in a client or resident, who gave me current information about the person?

What are the triggers for a case conference?

Does a member of my team have skills in conducting case conferences?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Continuity of Care



What it is: Continuity, coordination and transition of care are part of providing quality care to older adults at the end of life. Continuity refers to the exchange of knowledge between carers, the person and health professionals so that care is not interrupted or compromised.

Continuity of care has three main parts:

1. The care provider knows and follows the care of the older person.
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 based on 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
- regular meetings between team members and with the family helps to maintain a good level of communication.
- transition between acute care and home/ residential aged care (RAC) should include early discharge planning with advice for self-care, medications, and community support as appropriate.

Actions

Document the person's goals of care and regularly review these as a person's care needs change.

Prepare plans for managing exacerbations of their health condition. Also review the person's Advance Care Directive (ACD).

Clarify your role in the palliative care team and how you will stay 'in the loop' with care planning.

Make certain that all care providers understand the goals of care for the older person.

If you identify signs of imminent death communicate the person's end-of-life stage to the GP.

Ensure that all appropriate documents accompany a person when transferred between care settings.

Tools

Tools that may be useful include:

Continuity of care can be supported by use of an end-of-life care pathway such as Residential Aged Care End of Life Care Pathway (RAC EoLCP).

SPiCT tool helps health and care professionals to identify people who are declining in health and might benefit from better supportive and palliative care.

Name:

My reflections:

What processes are in place in my organisation that assist continuity of care?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

CareSearch is funded by the Australian Government Department of Health. Printed April 2022

Tips for Nurses: Culturally Responsive Care – Communication



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

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 effective communication is a key element.

Why it matters: Health care that respects a person's cultural and spiritual heritage can positively impact overall health and wellbeing. Nurses and care providers can directly influence how care is provided.

The Aged Care Quality Standards require that people are treated with dignity and respect, and that their identity, culture, and diversity are valued.

What I need to know: Approximately one in three older Australians were born outside Australia. One in five were born in a non-English speaking country.

Almost two in five people over 65 years of age who do not speak English at home are not proficient in spoken English.

Across cultures, what is normal to one person may not be normal to another person. 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:

- nurses to be aware of the influence of their own cultural beliefs on their practice
- sensitivity to the cultural practices and beliefs of others
- staff with training and skills in culturally safe practices
- organisational recognition and support for cultural diversity among residents and staff.

Actions

Build rapport and trust:

- always introduce yourself
- listen actively
- do not be judgemental
- show empathy
- show respect.

Ask the person about their specific needs as an individual.

Ask what the illness means to the person and to the family.

Remember that a person may prefer that another family member or community member is with them whenever possible and/or to speak on their behalf.

You can begin the conversation by asking 'Are there religious or cultural practices that affect the way you wish to be cared for?'

Be open and ask the older person:

- how they would like to be called
- what is appropriate physical contact
- what special days are important to them
- what food is culturally appropriate for them.

Be conscious of male/female physical contact; there are rules about what part of the body you can and cannot touch.

Where possible, in conversations involving issues of significant information use professional interpreting services (not family) with residents for whom English is their second or subsequent language.

Name:

My reflections:

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?

When an older person in my care speaks a language other than English how do I arrange for an interpreter?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: End-of-Life Care Pathways



What it is: A care pathway is a tool which outlines what is recognised as best practice for a certain disease or condition with an expected course. A care pathway guides and monitors a person's journey of best practice care between health professionals and across sectors. End-of-life care pathways can help prompt terminal care and encourage discussion with the person and their family.

Why it matters: Care pathways aim to:

- prompt and guide clinical decisions
- improve the timeliness of the start of care
- improve the consistency of care between different professionals
- reduce the risk of errors
- prevent unnecessary emergency treatments
- streamline care and therefore may reduce costs
- give confidence that the right care is being provided.

For long-term or chronic conditions, care pathways can guide healthcare professionals on when and/or how to:

- start treatment
- follow-up
- monitor change
- check for and monitor complications
- refer to other health professionals.

What I need to know: Care pathways differ from care plans. Care plans are based on the needs and preferences of an individual, and on the services available. Advance Care Directives should be included in planning.

Understanding the most common plans and pathways, and factors that influence these transitions can help medical practitioners and others to inform and advise older Australians who are:

- about to start using aged care services
- already using the aged care services.

Actions

End of life pathways guide terminal care. Recognising deterioration or signs of imminent death in the final days or weeks of life is critical.

Care pathways are based on available guidelines and evidence. They support clinical judgement but do not replace it.

When implementing a care pathway, remember to discuss it with the person and their family, and ensure that GPs and relevant staff are aware of this change. Discuss any changes or concerns and remember that **a person can come off a pathway**.

A care pathway represents the ideal way to manage people with a specific problem or long-term condition.

A care plan is based on the individual, and on the services available.

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

Good communication within the care team and between the team and the person and their family is essential so that the person and the family understand the benefit of the care pathway.

Tools

Tools that may be useful include:

The Residential Aged Care End of Life Care Pathway (RAC EoLCP) – this tool guides the provision of good quality terminal care in residential aged care. It includes guidance on comprehensive planning, delivery, evaluation and documentation of terminal care.

Name:

My reflections:

How do care pathways and care plans differ?

When was the last time I used a care pathway for an older person, and how did this improve care?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: First Australians – Communication



What it is: Appropriate care for Aboriginal and Torres Strait Islander peoples is person-centred and meets their needs, expectations, rights, and those of their family. Cultural safety further provides people with power to influence care and support positive patient-centred outcomes. Communication is central to providing safe and appropriate care.

Why it matters: Aboriginal and Torres Strait Islander people have high risk of life-limiting conditions including cardiovascular, kidney and respiratory disease, and dementia. Communication with nurses supports the person and their family to influence care decisions.

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

If an Aboriginal or Torres Strait Islander patient is close to death, it is important that they do not die alone. Family presence is culturally important.

Building good relationships is important. Listen more than you speak. Introduce yourself and begin by simply 'having a yarn'.

Post-death practices or requirements will differ across communities. If these are not met, there can be significant cultural consequences and distress caused to the family and the community. If an Aboriginal or Torres Strait Islander person dies away from country, it is important to have the details of the correct family member who plans to escort the deceased back to country.

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

Actions

Ask the person if they want to hear information about what is happening now; or whether they prefer you to talk to family members instead.

Ask who has the right and obligation 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?'

'How can I provide the best care for you?'

'Are there other people that should be included in talks about your health care?'

Tips for talking together:

- don't talk too fast
- explain any terms you use
- don't mimic people's ways of speaking
- don't be too direct as this may be seen as confrontational and/or rude
- some people culturally avoid eye contact, even if they're not looking at you they may still be listening
- deal in practical, real issues, not uncertainties
- talk about what is happening now rather than the future or past
- avoid questions requiring a 'yes' or 'no' answer
- be a listener more than a speaker
- take time to build relationships.

Tools

Tools that may be useful include:

Assess cognitive function, KICA-cog, a culturally sensitive assessment tool developed for older Aboriginal people living in rural and remote areas.

Name:

My reflections:

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

What should I 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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: People with Disability - Communication



What it is: Here we refer to people with an intellectual or developmental disability or limited communication ability.

Why it matters: An increasing number of older people with an intellectual disability have co-morbid conditions or advanced illnesses requiring palliative care.

Language and communication skills vary between people with an intellectual disability hence care needs to be taken to understand each other as much as possible.

What I need to know: In some cases, people with an intellectual disability may be admitted to residential aged care because of:

- ageing carers or death of a family carer
- supported care, independent living or
- community services no longer meet care needs
- lack of appropriate local services or accommodation.

Older people with an intellectual disability:

- have high rates of illnesses like epilepsy, diabetes, and heart disease
- may have difficulty with communication, both in understanding and speaking
- are likely to experience premature ageing
- experience high rates of depression and dementia
- are likely to have difficulties with hearing, vision, mobility, and stamina
- may find that standard aged care or usual activity programs do not meet their needs
- may have difficulty accessing specific disability services in an aged care facility.

People with Down's syndrome are at risk of developing Alzheimer's disease at a younger age, hypothyroidism, loss of vision, loss of hearing, arthritis, instability of the neck joint leading to pain and spinal cord damage and in women, early menopause.

Actions

Always give the person your full and complete attention and make sure you introduce yourself and let the person know why you are there. Do not talk over the person as though they are not there.

Look at the person and not the disability.

Establish communication needs and preferences for the person. Ensure a communication assessment has been completed. A speech pathologist may be able to assist.

Give clear and simple information. Use language that fits with the person's communication level.

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

Tools

Tools that may be useful include:

Disability Distress Assessment Tool (DisDat)

Talking End of Life with people with disability (TEL) – includes education modules and information on person-centred thinking tools to establish a better understanding of the person's needs, likes, relationships and mood signals
www.caresearch.com.au/TEL.

Name:

My reflections:

What could I do to better understand a person with intellectual disability?

Have I ever used childish language to speak with older people with intellectual disability?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Person-Centred Care



What it is: Person-centred care reflects the related concepts of dignity, worth and human rights. It sees care providers listening and responding to the needs and preferences of those in their care. In this way, person-centred care supports quality of life and enables people to live a meaningful life based on what they value.

Why it matters: Person-centred care is a key element of many national guidance documents including Standard 1 of the Aged Care Quality Standards, and the Aged Care Diversity Framework. Quality care is more than good symptom control and emotional support. It includes assisting the older person to live well and maintain self-determination, relationships, and social connections as their dependence on others increases.

What I need to know: Palliative care focuses on quality of life and includes dignity, respect, compassion and valuing the whole person.

Person-centred care:

- acknowledges uniqueness and individuality in care coordination and planning, and through shared decision-making and communication
- shows empathy and respect
- is professional care that respects autonomy, dignity, privacy, relationships, and the rights of the person
- identifies strengths and positive aspects, rather than weaknesses and problems
- has a holistic focus that acknowledges the person's lived world and what they and others important to them value about their life.

Helping people retain dignity as they die includes:

- symptom control
- psychological and spiritual support
- care of the family.

Language and terminology are very important.

Actions

Always greet the person and introduce yourself. Let them know why you are there. Ask their permission to interact with them, provide care or undertake any procedure.

Always give the person your full and complete attention.

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'.

To promote a sense of dignity, value people as the person they are, rather than just the illness they have.

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?'

Implementing a person-centred approach to care is more likely to succeed when management demonstrates a person-centred approach to staff.

Name:

My reflections:

What can 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 or preserved dignity?
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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Quality of Life with Change and Deterioration



What it is: Quality of Life (QoL) is a person's perception of their life in the context of their health, culture, and values and 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 loved ones
- having as much independence as possible
- not feeling like a burden
- feeling emotionally well and supported.

Why it matters: QoL is central to palliative care. Across the course of life-limiting illness, support to live well while adapting to functional decline is about QoL.

Standards 1 and 4 of the Aged Care Quality Standards also emphasise QoL.

What I need to know: To assess QoL, you need to know what issues are of most concern to the person at the time. Where possible, the older person should rate their own experiences. Family and health professionals may not always rate these the same.

Older people can experience deterioration in QoL as their disease progresses. Often this reflects changes in their ability to complete daily activities or to socialise and form relationships with others. Changes in QoL may be slow with diseases like dementia that progress slowly (over a long period).

Others may not register a change in QoL. Their goals and expectations may adapt to what is currently possible.

Actions

Regularly ask what is currently important to the older person and their family.

Use ongoing assessment with a validated tool for QoL.

Engage with the older person to set individual goals and support them with activities that are meaningful to them.

Provide families with information about changes.

Help the older person to stay connected with family and friends.

If language is a barrier try to match them with staff who speak their language.

Assist them to maintain their spiritual perspectives and spiritual connections.

Encourage them to remain active with tasks that they can manage. Adapt personal interests and activities as functional abilities change.

If tasks become more difficult, help rather than doing it for them.

Tools

Tools that may be useful include:

ICEpop CAPability Index for Older people (ICECAP-O) measures five dimensions (attachment, security, role, enjoyment, and control)

Quality of Life - Aged Care Consumers (QOL-ACC) instrument, visit www.qol-acc.org/

Name:

My reflections:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: 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. It acknowledges the older person's life and connection with family as being an important part of who they are. It recognises the physical and emotional support and assistance that family members provide.

What I need to know: Carers often look to health professionals to help them understand the disease, symptom management, and End-of-Life planning. Frequent, short conversations with small amounts of information may be helpful.

Family members can also experience many emotional issues that they need your help with including:

- guilt and/or relief if they can no longer manage care at home and an older person needs to move into residential aged care
- sadness and distress at the person's deteriorating condition
- anticipatory grief in response to impending death
- grief due to death of a loved one, an end to their role as carer, and changes to their daily routine
- distress from a sense that:
 - the person's dignity and identity are not being maintained
 - they are not seen as a partner in providing care
 - carers are 'cold' and 'clinical'
 - not enough care is being provided.

It can help if you welcome family as partners in providing care and acknowledge their understanding of the older person.

Actions

Reassure family that you care:

- Be available to talk and actively listen to the older person and their family
- Establish a trusting relationship with the older person and treat them with respect.
- Support the older person's dignity by attending to essential and spiritual care needs. This includes attention to physical appearance and involving them in making daily choices.

Identify the substitute decision-maker and the key contact. Establish regular communication with them and notify them of changes in health or to care.

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.

In family discussions, check what they have understood. Refer to previous discussions and confirm continuing appropriateness. Invite family to actively participate in family meetings and case conferences. Ask for their perspective about what they are seeing before offering your own.

Acknowledge:

- grief that starts before death
- cultural needs of the person and family.

Tools

Tools that may be useful include:

Carer Support Needs Assessment Tool (CSNAT)

Carers' Alert Thermometer (CAT)

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

Visit CarerHelp for resources for carers.

Name: _____

My reflections:

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:
Grief and Loss among Older People,
Families and Residents
Psychosocial Assessment
and Support
Talking About Death and Dying

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Talking about Dying



What it is: Talking about death and dying can be challenging for everyone involved. It can be difficult to tell someone that care will be about comfort, not cure.

Why it matters: These conversations can help the person and their family to make decisions about future care and improve the care that the person receives. Many people may know or suspect that they are dying. Acknowledging that a person is dying allows them to express their fears and concerns. Nurses can provide support and information and explain any changes in care.

What I need to know: Cultural considerations may influence how and if talking about dying is appropriate. Acknowledging the role of family and talking with the family can improve the care of the person, their family and carers.

Effective communication:

- allows staff to identify individualised needs and to provide individualised care
- may reduce agitated behaviour in older people with impaired cognition
- requires specific skills that can be developed with training.

When talking about a person, aged care workers need to remember:

- the person's right to privacy and autonomy
- the organisation's policies and relevant legislation
- the Charter of Aged Care Rights.

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

Many relatives find comfort in talking about their loved one as they were in the past and appreciate someone listening to their story. It helps them to feel that staff understand the person he or she was and to treat them as an individual.

Actions

When talking about dying remember to:

- check if the person wants to talk about this
- make appropriate eye contact
- keep your face in view if appropriate
- be aware of sensory impairments, check that the person has their glasses and/or hearing aid if needed
- speak slowly or as loudly as needed
- use an appropriate tone of voice and gestures
- check a person's understanding of what is being discussed.

Refer to the person's Advance Care Directive (ACD) to identify the substitute decision-maker and a family member with whom you can discuss death and dying.

Record and report a person's likes and dislikes, behaviours, and responses to care. That way, their preferences can be respected when they cannot communicate.

Actively listen to the person and their family and allow feelings to show. Acknowledging their feelings and yours can be beneficial to care.

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

Tools

Tools that may be useful include:

SPIKES – a tool for breaking bad news.

Name:

My reflections:

How comfortable am I with talking about death and dying and, if needed, what might be done to improve my confidence and that of my staff?

Does my organisation have support such as pastoral care or counsellors that I can call on to help with difficult discussions about death and dying?

Do I know where to find the Charter of Aged Care Rights?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Talking within the Aged Care Team



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 between careworkers and other staff helps the quality of palliative care provided to clients or residents. It means everyone 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. The nurse has a leadership role within the team.

What I need to know: Often the Registered Nurse (RN) 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).

Written records are a common way for teams to communicate.

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.

Actions

Case conferences are one way to share information among the care team members.

If organising a case conference document notes on the discussions and any decisions made.

Provide staff with tools to facilitate and document case conferences. This might include an invitation and questionnaire for families, and planning checklists and communication sheets for staff.

Support all staff involved in the care of a person to talk with the team and to share the information they have about the person.

Seeking advice from or observing more experienced colleagues communicate is one way to improve communication skills.

Name:

My reflections:

Improved team communication may lead to more effective care, better outcomes for the older person and greater staff satisfaction. How is information about a person being cared for communicated within care teams in my organisation?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Care Issues



Tips for Nurses: Advanced Dementia



What it is: Dementia is a group of progressive neurological illnesses with a long, slow pattern of decline over many years. Alzheimer's disease is the most common form of dementia, but there are others and it is not limited to older people. Definitions of advanced dementia vary. Dementia Australia defines it as the third stage where the person is severely disabled and needs total care. Dementia is a life-limiting illness.

Why it matters: Need for palliative care depends on the stage of illness and co-existing conditions. It is indicated in advanced stages. Care provided and planned by nurses is important to support a person's often complex needs. People with dementia often have other diseases including cardiovascular and pulmonary disease. Pain is common. These can add to the frailty and decline of a person and may indicate need for palliative care.

What I need to know: Palliative care with dementia supports a focus on care and quality of life to enhance comfort and functioning of the person. It can be difficult to know when a person with dementia is approaching the end of their life.

Many people with dementia receive palliative support in the community. Often by the time a person enters an aged care facility they have advanced dementia. Even if a person with dementia is unable to speak, they may still sense the presence of loved ones, and experience fear and loss. A person with advanced dementia may experience loss of:

- memory
- rationality and judgement
- communication
- social skills
- inhibition
- physical functioning.

This can be frightening for the person and their family.

As dementia advances people may lack capacity to:

- attend to daily tasks and hygiene
- make decisions
- speak
- respond
- swallow
- move purposefully.

Actions

Be patient and remain calm. When talking allow plenty of time for a response.

Remember changes in behaviour and personality are common, including aggression, apathy, agitation and anxiety. But these often reflect a need such as pain relief or fear, but not the person's personality.

Use language and a time frame in a context that the person understands.

Suggest what they can do, instead of focusing on what they can't do.

Conducting case conferences with the person and their family can help to manage and plan care. A person can nominate a substitute decision-maker to make decisions on their behalf when they are unable to make decisions themselves.

Check for signs of deterioration such as changes in:

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

Note who is the person's appointed substitute decision-maker and the extent of their decision-making power.

Tools

Tools that may be useful include:

Abbey Pain Scale – useful if a client is unable to communicate their pain

Pain Assessment in Advanced Dementia Scale (PAINAD)

Visit the ELDAC Dementia toolkit.

Name:

My reflections:

How many of the people I care for have dementia and how do careworkers/personal attendants report any changes in their behaviour to nursing/supervisory staff?

What do I do for people with dementia to help with communication or to assess for pain?

Are there people who show varied response depending on which staff attend them?
What might this mean?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Advanced Dementia – Behavioural Changes



What it is: People with advanced dementia may develop emotional, perceptual, and behavioural disturbances out of step with their character. If these are considered part of the dementia process, then they are commonly known as behavioural and psychological symptoms of dementia (BPSD).

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. BPSD commonly appears as aggression, agitation, anxiety, depression, or apathy.

What I need to know: Common BPSD symptoms include:

- being easily upset or worried
- repeating questions
- arguing or complaining
- physical aggression
- rummaging or hoarding
- inappropriate screaming or sexual behaviour
- rejection of care (bathing, dressing, grooming)
- wandering or shadowing (following a carer).

Ongoing staff training to understand and communicate with people with dementia helps. BPSD management should begin with non-pharmacological strategies (that is without medications). A focus on individualised or person-centred care based on the person's preferences is recommended. For example, music therapy where the person makes choices and engages with the activity. Ask the person or their family what things they do or do not like.

Use of restraint should be minimised. Due to the increased risk of serious adverse events (e.g. falls, fractures, death), for people with mild-to-moderate BPSD antipsychotic medications should be avoided. Antipsychotic medications can be used if the person has severe BPSD, is at immediate risk of harming themselves or others, or is in extreme distress. Non-pharmacological approaches should be continued if antipsychotics are used.

A focus on underlying factors rather than the behaviour itself is a more effective way to manage BPSD.

Actions

Put in place a Behaviour Support Plan for residents who exhibit behaviours of concern as part of their care and services plan.

Create supportive relationships to promote trust:

- Take 10 minutes a day/shift to talk one-to-one
- Help them choose activities that will keep them stimulated. Offer only a few options.

Watch for signs that they agree (smiling, laughing, talking) or disagree (agitation, resistance, restlessness).

Ask prescribers to review medications for side effects.

If symptoms of BPSD are apparent look for and work with the person to address underlying factors:

- unmet needs such as pain, hunger, toileting
- social environment stressors such as conflicts or poor communication among families or staff, lack of supportive relationships or meaningful activity, communication difficulties – call a family meeting, take time to ask the person who they want to sit with or what they would like to wear or do
- physical environment stressors such as noise or light levels, wish for privacy – ask before turning lights on or off, help them find a quiet place, knock before entering
- things that have changed for them e.g., staff, routine, physical ability – gently talk with them about this
- patterns in the behaviours e.g., time of day, a certain activity – allocate more time for support.

Keep the person physically active if appropriate.

Tools

Tools that may be useful include:

DTA Responsive Behaviours Quick Reference Cards

Behaviour Support Plan resources from www.dementia.com.au

Dementia Behaviour Management Advisory Service (**DBMAS**) on 1800 699 799

Visit the ELDAC Dementia Toolkit.

Name:

My reflections:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Anxiety



What it is: Anxiety is when feelings of nervousness, stress and worry don't go away.

Why it matters: Anxiety is common at the end of life and it can also reflect the uncertainties of serious illness. Anxiety can affect quality of life and wellbeing. When anxiety and depression are experienced together the symptoms and outcomes are more severe.

What I need to know: Recognising anxiety can be difficult because it is often associated with depression and/or dementia. Assessment is important to identify the underlying cause. There can be medical and/or psychological causes.

Anxiety may be due to several factors including:

- pain
- poor symptom control
- medications
- changes in living arrangements
- relationship problems
- verbal, sexual, physical or emotional abuse
- management of care
- loss of dignity
- reactivation of Post-Traumatic Stress Disorder (PTSD) including in survivors of institutional abuse, genocide, torture, and war
- fear of impending dying
- concern for loved ones.

Anxiety may present as:

- generalised anxiety
- panic disorders
- social phobias
- agoraphobia (fear of open places).

Physiological signs of anxiety include breathlessness (dyspnoea) and palpitations.

Families and carers also experience anxiety. Carers of people with dementia often experience anxiety and depression. This affects carer wellbeing and their capacity to provide care.

Actions

Fostering a person's sense of self, hope, dignity, and spiritual well-being may help.

Sensitively asking 'Is there anything else troubling you?' or 'Is there anything you would like to talk about?' can help a person talk about things that worry them.

Psychotherapies are recommended for anxiety and depression, and use may significantly reduce symptoms.

Relaxation, touch and massage therapies may be helpful for reducing anxiety.

In people with serious illness or approaching the end of life, look for signs of anxiety:

- restlessness
- muscle tension
- irritability.

Assessment with a validated tool should include recording of outcomes in care notes. If appropriate, referral to a doctor, specialist, or allied health should be considered.

Tools

Tools that may be useful include:

Cornell Scale for Depression in Dementia

– a 19-question interview tool for older people.

Geriatric Anxiety Inventory (GAI) – a 20-item self-report screening tool developed for the assessment of older people. Available under license from www.gai.net.au

Name:

My reflections:

What assessment tools have I used to assess anxiety in an older person?

Providing care to a person with anxiety is challenging. What approaches have I used previously?

In my organisation, how do careworkers report to nursing/supervisory staff perceived changes in mental health of older people in their care?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Cachexia, Sarcopenia and Anorexia



What it is: Cachexia is a complex condition related to an underlying illness. It results in weight loss with a loss of muscle with or without loss of fat mass. It cannot be fully reversed by regular nutritional support.

Anorexia is the loss of appetite or reduced nutritional intake.

Sarcopenia is the loss of muscle mass and function associated with ageing.

Why it matters: Anorexia and cachexia are common in people receiving palliative care, and sarcopenia is common in older people.

What I need to know: Both sarcopenia and cachexia result in muscle wasting and weight loss. Loss of muscle mass and strength is common in people aged 65 and over, and is associated with increased dependence, frailty and mortality.

Cachexia can indicate a poor prognosis and transition to terminal phase in people with advanced disease. This includes dementia. Between 10-40% of people with chronic conditions (heart failure, chronic obstructive pulmonary disease (COPD), cancer, HIV, renal and liver failure) suffer from cachexia.

People with cachexia will often have anorexia or reduced nutritional intake, generalised inflammation, decreased muscle bulk (sarcopenia) and strength, and fatigue.

Anorexia is common among older adults, and in chronic diseases such as chronic kidney disease (CKD), heart failure and chronic obstructive pulmonary disease (COPD). It usually results in malnourishment and weight loss.

Actions

For cachexia, a clear explanation that weight loss is likely due to the disease may help the person and the family to be not so worried about appetite and eating.

For cachexia, the focus may be about adequate fluid intake and eating for pleasure, that is small portions of food and fluids throughout the day that the person enjoys and are easy to eat.

Nursing staff should respond if a person:

- has a change in eating or drinking habits
- stops eating or drinking
- is noticeably less active or is unable to do things
- has difficulty swallowing
- has diarrhoea or constipation
- has nausea or vomiting
- has clothing that becomes ill-fitting.

For poor appetite without cachexia, foods and fluids that maximise dietary intake but are easy to eat and drink, for example, foods that are soft and can be fortified. Speaking with a dietitian may help.

Remember that meals are important for maintaining relationships – the person can continue to be part of daily family routines and events with or without eating.

With changes in weight and in their condition, a client or resident may be concerned about their appearance. Responding respectfully and helpfully can help the person keep their self-esteem and dignity.

Name:

My reflections:

When an older person is losing weight in association with a chronic disease, what allied health professionals could I speak with about encouraging them to eat or building or maintaining physical condition?

Do I or other members of my team check if other team members need assistance to care for clients or residents who have high care needs or increasing care needs?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Complementary Therapies



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, acupuncture, 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.

Nurses can support a person's preferences and help them to avoid CT that may interfere with medications or cause harm. It is important to know what is being used.

What I need to know: Palliative care patients may use CT to relieve physical symptoms, help control treatment side effects and/or improve their psychological well-being. Evidence to support CT use is emerging for some approaches but unclear for others.

Nutritional supplements are a form of CT covered by guidelines and can be associated with drug interactions or adverse events. The range of mind-body CT practices used by people with life-limiting illness includes massage, music therapy, art therapy, aromatherapy, acupuncture, acupuncture, hypnotherapy, meditation, reflexology, and reiki. 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' and therefore reduce their worries about their disease and future.

Actions

CT is a very personal choice. Have open and non-judgemental discussions.

Record information about the CT that people in your care are using.

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

You may wish to ask:

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

If so:

Have you noticed any benefit?

Have you noticed any side effects?

Suggest they keep a diary of how they feel while using the CT.

Ask if they would like help to understand any information about the CT.

Lifestyle coordinators have an important role in making people comfortable and may be able to help with some approaches to CT.

Tools

Tools that may be useful include:

Visit palliAGED website: www.palliaged.com.au

Visit CareSearch website: www.caresearch.com.au

Read NHMRC Talking about complementary medicine – resource for Clinicians.

Name:

What complementary therapies do I use for myself?

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Constipation



What it is: Constipation is the limited or difficult passing of hard, dry stools (faeces). The time it takes for food to pass through the gut will depend on the individual.

Why it matters: Constipation is common in people with palliative care needs. Nurses have a role in assessment and care because constipation reduces quality of life and can cause:

- pain
- delirium
- changes in behaviour
- urinary retention
- faecal impaction and/or faecal incontinence
- bowel damage.

What I need to know: Constipation is a common concern in older adults. It is one of the most common symptoms in people receiving palliative care at an advanced stage of disease. Some specific factors relating to end of life that can influence constipation are:

- medications especially opioid analgesics and anticholinergic medications
- limited mobility
- not recognising the need to defecate
- lack of assistance to access a toilet
- neurological illnesses especially dementia, stroke, depression, Multiple Sclerosis and Parkinson's Disease
- general disability
- low caloric intake due to reduced appetite.

A bowel management program developed to address constipation concerns should reflect the person's preferences and be consistent with the current goals of care for the person.

Aperients as treatment for constipation:

- fibre-based medication requires adequate fluid intake
- polyethylene glycol preparations can be more effective and better tolerated than lactulose.

Actions

To know what the usual bowel habits for the individual are ask the person or their family.

A bowel management program can include:

- daily monitoring of bowel function (Bristol Stool Chart)
- medication review
- increased fluid and/or fibre intake
- increased exercise if relevant.

For palliative care:

- consider if the person is close to death
- consider their ability to safely swallow
- increasing fluids and fibre content of diet may not be realistic
- consider non-pharmacological approaches to relieve constipation
- use of suppository enemas may be appropriate.

Choice of aperient should be based on patient preference and circumstance. Consider what other medications the person is taking and for oral aperients the person's capacity to swallow.

Tools

Tools that may be useful include:

Screening Tool of Older Persons Prescriptions in Frail adults with limited life expectancy (STOPPFrail) – identifies medications which can cause or exacerbate constipation.

Bristol Stool Chart – a visual aid based on seven stool types.

Name:

My reflections:

How could I investigate whether the older person's medications are causing the constipation?

Careworkers are well placed to notice when a person's toileting patterns change.
How does this information reach nursing/supervisory staff in my organisation?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Distress at the End of Life



What it is: Distress at the end of life, also known as existential distress, death distress, or death anxiety, refers to the emotional suffering of dying which includes thoughts about:

- death
- the meaning of life
- loneliness
- loss of dignity
- loss of control
- achieving life's goals.

Why it matters: People with life-limiting illnesses often suffer distress at 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. Nurses and careworkers are well placed to observe signs of distress that might indicate a person's need for assistance.

What I need to know: In people needing palliative care, distress at the end of life may lead to a wish for hastened death.

Existential therapies including meaning-centred interventions, supportive-expressive groups, cognitive therapy, life review, dignity therapy, and hope interventions may help with quality of life and wellbeing in the short-term.

A few psychotherapies can treat distress at the end of life in the elderly, including reminiscence therapy. Acknowledging and supporting a person's spirituality has been shown to reduce the distress that many people experience when they are ill or dying.

Pet therapy or animal-assisted therapy may help.

Pharmacotherapy has not been well studied.

Actions

Psychotherapies are recommended for distress but pharmacotherapy is not.

Relaxation, touch and massage therapies may be helpful for reducing anxiety.

Look for signs of distress:

- restlessness
- breathlessness
- muscle tension
- irritability.

Sensitively asking 'Is there anything else troubling you?' or 'Is there anything you would like to talk about?' can help a person talk about things that worry them.

Tools

Tools that may be useful include:

Cornell Scale for Depression in Dementia

– a 19-question interview tool for older people.

Geriatric Anxiety Inventory (GAI)

– a 20-item self-report screening tool developed for older people (available under license from www.gai.net.au)

Name:

My reflections:

When making an assessment it is also important to know what can be done for the person experiencing distress at the end of life. What approaches to this are used in my workplace?

How can I support a client or resident expressing distress at the end of life?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Dysphagia



What it is: Dysphagia is defined as difficulty swallowing food or liquid, including medications in liquid or tablet form.

Why it matters: Dysphagia is common in people with a serious life-limiting illness including cancer, dementia, Motor Neurone Diseases (MND), and Parkinson's Disease.

Dysphagia can lead to:

- poor nutrition
- dehydration
- aspiration
- asphyxiation
- pneumonia.

Nurses can plan care in response to the person's needs and capacity, to maximise comfort and reassure their family.

What I need to know: Any changes to the normal function of the mouth, pharynx, larynx and oesophagus can cause dysphagia. This includes physiological changes associated with ageing or the side effect of medication. It is common in the terminal phase.

Dysphagia may be due to an obstruction or a mechanical problem of the mouth, throat or oesophagus.

People with dysphagia may also experience difficulty with speech, a facial droop, and difficulty controlling head or neck movements.

Side-effects of radiation and chemotherapy for cancer include development of xerostomia (dry mouth) or mucositis (inflammation of mucous membranes). These can lead to dysphagia.

A multidisciplinary approach including a dentist can help manage the treatable causes of dysphagia such as dry mouth, dental problems and medications affecting swallowing. A speech pathologist can assess a person's ability to swallow and give recommendations for care.

If appropriate, other routes may be considered including artificial nutrition via percutaneous endoscopic gastrostomy tube. If indicated, refer to the person's Advance Care Directive and discuss with family the risks and options of alternative management choices.

Actions

Look for:

- choking when eating or drinking or a feeling of food sticking in the throat
- drooling of saliva or food escaping from the mouth
- coughing during or after eating or drinking
- very slow eating and drinking times
- refusing food and fluids
- retaining food and fluids in the mouth
- weight loss.

Explain to family the consequences of giving and not giving food or liquid. In the terminal phase, carers and family can be encouraged to give sips of water or, if appropriate, to moisten the person's mouth with a swab.

Oral care and patient positioning remain very important to maximise swallowing. This also reassures family that the person is being cared for.

Food and fluids must be the correct consistency, ask a speech pathologist for help with care planning.

Remember people with dysphagia may not be able to take medication by mouth. Discuss other routes such as subcutaneous with the prescriber.

Tools

Tools that may be useful include:

Malnutrition Universal Screening Tool (MUST)

Mini-Nutritional Assessment Short-Form (MNA®-SF)

Name:

My reflections:

When was the last time a careworker informed me that someone was having difficulty with dysphagia and what was my response?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Dyspnoea



What it is: Dyspnoea is breathing difficulties or the sensation of breathlessness or 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. Assessment and management planning by nurses is essential.

What I need to know: Effective assessment and management of dyspnoea is seen as an important quality measure in palliative care.

Dyspnoea is a subjective experience and may or may not relate to oxygen saturation levels. The use of oxygen will depend on the person's acceptance and comfort. People with dyspnoea tire quickly and people who are easily fatigued often complain of dyspnoea.

Dyspnoea may be associated with heart failure, lung disease or cancer. It can also occur when there is no apparent diagnosis of cardiac or respiratory illness.

Dyspnoea reduces quality of life and it affects emotional, spiritual and physical wellbeing. Dyspnoea is made worse by fear and panic.

Shortness of breath is a complex symptom. Its treatment often requires a combination of general measures, non-pharmacological measures, and drugs. Opioids may help but people need to be monitored for any adverse effects.

Recommendations for managing dyspnoea at the end of life include:

- care based on a comprehensive assessment of the person and symptom distress
- discussion with person, family and health care team to agree goals of care
- manage related issues such as: fatigue, depression, anxiety, emotional issues
- physiotherapists can show the person, carers, health care staff, and the family useful exercises, positions and breathing control techniques
- opioids
- non-pharmacological approaches.

Actions

General care of dyspnoea includes:

- allowing time between care and other activities
- encouraging energy intake, consider appropriateness of food or drink provided
- the presence of someone who can calm and reassure the person can help.

Ways to manage dyspnoea at the end of life include:

- optimising air circulation around the person e.g., fan or open window
- breathing-control techniques e.g., purse lip breathing, mimicking blowing out a candle
- relaxation exercises e.g., use of handheld fan and holding nurse's hand
- upright positions:
 - supported sitting
 - leaning on a supportive table
 - lying in a reclining chair or electric bed with backrest and knee break.

Organise all equipment and staff before you begin care procedures. This reduces time taken for care and is less tiring for the person.

Tools

Tools that may be useful.

Dyspnoea at the end of life needs to be assessed. Tools used will depend on the situation but may include:

Asking residents who can self-report, if they are experiencing breathing difficulties and how that is affecting them is the best guide.

Visual Analogue Scale (VAS) for people who can self-report.

The Modified Borg Scale (mBORG) for people who may have difficulty with numerical rating.

Name:

My reflections:

How often do I observe older people with dyspnoea, and what interventions have I used to provide relief?

What could I do if dyspnoea can't be controlled?

My notes:

See related palliAGED Practice
Tip Sheets:
Anxiety
Opioid Analgesics

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Eye Care



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 and excessive eye secretions are both common and can cause discomfort.

Reduced visual acuity (the eye's ability to resolve fine detail) is also 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 eye health may be compromised in older people including:

- impaired vision due to:
 - cataracts
 - diabetic retinopathy
 - age-related macular degeneration
 - glaucoma
 - uncorrected refractive error
- improper contact lens hygiene
- prolonged wearing of contact lenses
- accumulation of secretions on eyelids.

In older people with palliative care needs eye health can also be impacted by:

- their condition or adverse effects of certain medications
- advanced illness of the eye and treatments such as radiation therapy to the head.

Cachexia-related weight loss is associated with significant loss of muscle with or without fat loss. Around the eye this can lead to altered eye positioning and in the terminal phase eyes may become dry if the eyelids do not fully close even when the person is sleeping.

It should also be noted that as a person approaches death, the pupils of their eyes become fixed and dilated. The eyes may become sunken or bulging and glazed, and eye secretions may accumulate around the eye.

Actions

For eye health, consult with a GP or optometrist to determine the most appropriate treatment.

Hand hygiene is important when attending to eye care.

For eye secretions

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

For dry eyes, use of ophthalmic lubricants, artificial tears or saline can help.

Remove contact lenses for seriously ill people and reinsert only when they become more active in their care and require the lenses to see properly.

Provide regular access to eye examination services. An optometrist or ophthalmologist can perform an eye test.

Ask whether the older person wears glasses or other eye wear and offer vision aids where needed.

Name:

My reflections:

What can I do when an older person has signs of eye secretions?

How often do older people in my care have their eyes assessed?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Faecal Incontinence



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 people. Prevalence increases with multimorbidity and at the end of life. Faecal incontinence can affect a person's health, dignity, and independence. It is also a hygiene concern. Nurse-led assessment and care planning can help.

Respecting an older person's dignity is important when assisting them with bowel management.

What I need to know: Faecal incontinence may be related to:

- illness
- treatment
- other factors including infection.

Faecal incontinence can indicate frailty and increased mortality risk, and reduces quality of life.

Faecal impaction (constipation-related hard immovable stools) is a common and treatable cause of faecal incontinence in older people.

Medications such as opioids and anticholinergics may slow gut transit time contributing to the increased risk of faecal impaction and subsequent faecal incontinence.

Faecal incontinence is a risk factor for pressure injury in frail older adults. Excessive moisture affects skin integrity.

Cognitive and neurological diseases including dementia, Parkinson's disease, and stroke can contribute to faecal incontinence.

Actions

A bowel management program can include:

- daily monitoring of bowel function (Bristol Stool Chart)
- medication review
- increased fluid and/or fibre intake
- increased exercise if appropriate.

For palliative care

- consider if the person is close to death
- consider their ability to safely swallow
- increasing fluids and fibre content of diet may not be realistic
- consider the use of continence aids as required.

Integrated continence care with assisted toileting and assistance with continence needs as required may be the most effective way to manage faecal incontinence.

The combination of an exercise program (if possible), and integrated continence care with prompted toileting and changing as required, may be the most effective management.

Tools

Tools that may be useful include:

Bristol Stool Chart – a visual aid based on seven stool types.

Visit RACGP Aged Care Clinical guide (Silver Book), Part A. Faecal incontinence, at www.racgp.org.au

Name:

My reflections:

If an older person is experiencing concerns with bowel movement which allied health professional groups could I discuss this with?

Careworkers are well placed to notice when a person's toileting patterns change, how does this information reach nursing/supervisory staff in my organisation?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Frailty



What it is: Frailty describes a condition which includes unintentional weight loss, self-reported exhaustion, slow gait, weakness and low physical activity.

Why it matters: The risk of frailty increases as people age and is most common in people aged over 80 years, and in people with multiple illnesses and disability. This includes people with a life-limiting illness.

Frailty affects a person's function, resilience, and ability to recover from an episode of ill health. It often indicates that they are approaching death and palliative care may be appropriate. Nurses can plan care with the person and their family.

What I need to know: It is important to identify when a person with a life-limiting illness is frail or is at risk of becoming frail, as their outcomes are poorer with minor illnesses such as infections.

The last year of life is generally characterised by a steady decline in overall function and increasing frailty, rather than a sudden decline in any one aspect of health. This can mean that carers and health professionals may not recognise that death is approaching and that palliative care needs should be assessed.

For people with a life-limiting illness the trajectory will depend on their underlying condition(s).

Screening and assessment for frailty should look at a person's:

- physical performance
- nutritional status
- cognition
- mental health
- support that they may receive from family, the community, their social connections
- financial situation.

Use a validated tool to assess frailty, this will help to identify any needed changes and provide evidence for the impact of any changes made.

Frailty and dementia together predict a more rapid decline and shorter life expectancy.

Actions

Look for signs of frailty:

- non-specific signs of extreme fatigue, slow walking speed, unexplained weight loss, frequent infections
- falls, frequent falls, fear of falling, restricted activity
- delirium, acute changes to their cognition
- luctuating disability 'experiencing good and bad days' with, for example, a loss of interest in food, or difficulty getting dressed.

Know that frailty may be associated with:

- falls
- fractures
- osteoporosis
- disability
- shortened life expectancy
- multiple co-morbid illnesses.

Remember frail older people may be taking many medications (polypharmacy). Recommend a prescriber or pharmacist review medications regularly and make sure that dosages are individualised.

Tools

Tools that may be useful include:

Australian modified Karnofsky Performance Scale (AKPS) to measure a person's ability to perform their activities of daily living.

Screening Tool of Older Persons Prescriptions in Frail adults with limited life expectancy (STOPPFrail)

SPICt tool helps health and care professionals to identify people who might benefit from better supportive and palliative care.

Name:

My reflections:

How many of the people I care for might be considered as frail?

What possible events or conditions are they at risk of because of their frailty?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

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



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

Bereavement is the period of grieving experienced by family and friends in response to the death of someone close to them. A family includes people (and pets) identified by the person as family.

Why it matters: Feelings of grief and loss can affect a person's physical health, or mental wellbeing. Older people may be able to deal with grief, but if not, it may cause depression or complicated or prolonged grief. Observation and assessment by nurses are important and ensures people receive help when needed.

What I need to know: Grief and bereavement are natural responses to loss. Older people with palliative care needs or approaching the end of life may experience these due to changes in living arrangements, capacity or opportunity for usual daily activities, or the death of relatives or friends.

The range of losses that might be experienced by older people includes loss of:

- the ability to do things that they used to enjoy
- their independence
- control or 'having their say' in their care or activities
- things that are familiar to them especially when they move from their home into residential aged care
- a spouse, partner, close relative or friend, or pet.

Everyone grieves in their own way; there is no right or wrong way or time to grieve.

Having social support networks including family, visitor volunteers, or pastoral care may help.

Complicated or prolonged grief is extreme, disabling, and/or long-lasting grief. It is less common and should be reported.

Actions

The person may not need answers or advice; listening to them may give the greatest comfort. Use phrases such as 'I'm awfully sorry for your loss' and then take time to listen to their response.

Signs of grief to look for in older people include:

- crying or difficulty in expressing sadness
- anger
- anxiety or worry
- a change in eating habits
- losing interest in family, friends, or hobbies
- difficulty in sleeping, concentrating, or making decisions.

Let the older person know that grieving is a natural response to loss and respect cultural differences in grieving.

Spend time with the person in a gentle and unhurried way. Offer them and their family the opportunity to talk.

Talking with a GP, counsellor, or pastoral care worker may help.

Current evidence does not support systematic screening of all people recently bereaved but should be considered for those with persistent signs and symptoms of complicated or prolonged grief.

Tools

Many bereavement measurement tools are available, but no single tool is considered better than others.

Name:

My reflections:

Thinking back to the last time someone in my care died, what was done to support the older people around them?

What internal and external sources does my organisation use to support grief and loss?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Grief and Loss among Staff



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

Bereavement is the period of grieving experienced by family and friends in response to the death of someone close to them.

Why it matters: Staff working in aged care look after many people who die. As a result, they may experience repeated grief.

Caring for others may provide job satisfaction. But grief over the death of people in your care is not unusual and may contribute to burnout and overwhelming stress. This should be acknowledged.

Sometimes it can lead to complicated or prolonged grief where grief is intense, debilitating and/or persistent. This should be reported. Meetings to debrief staff following a death may be appropriate. Organisations can help through supportive policies and allowing time to grieve.

What I need to know: Grief is a common response to bereavement and loss. People with palliative care needs are often dependent on their carers, and you may feel a strong sense of loss when they die. How people express grief varies, no one can tell another how they should grieve.

Talking to a GP, counsellor, or pastoral care worker may help aged care workers to acknowledge their grief and to grieve in a healthy way.

There are bereavement services to help you with grief and loss. Strategies including acknowledging the work of the team, memorials, and allowing staff to sign condolence cards to families can help.

Reducing burnout among aged care staff can improve morale and leads to better care.

Education in grief, loss, and bereavement for aged care workers can help them:

- manage their own grief and burnout
- with emotional and professional growth.

Actions

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.

Education in cultural and spiritual differences in responding to death can also help staff to understand and cope with deaths and a range of family responses.

Talking to your supervisor and colleagues about what you are experiencing can help. If you need more support request their help to find this. Talking with a counsellor or pastoral care worker may help.

Taking care of your own physical and mental health can help you to cope with grief and bereavement and avoid burnout.

Healthy grieving may be beneficial to aged care staff. This may include:

- memorial rituals for clients or residents who have died
- the opportunity for staff to sign condolence cards to families
- annual memorial services
- following the protocols of your organisation.

Developing self-awareness is an important step in self-care. It assists you to identify your strengths and weaknesses as well as to understand why you react the way you do in certain situations. Being self-aware can assist you to manage your emotions rather than being overwhelmed by them.

Tools

Visit the ELDAC Self-care room.

Name:

My reflections:

How could/do I support staff to cope with grief in the workplace?

Do I have an opportunity to be supported/mentored about grief?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Myths about Morphine



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

Morphine is an opioid analgesic that offers safe and effective relief of moderate to severe pain. There are other opioids. Myths are widely believed but untrue beliefs.

Why it matters: Morphine is often the preferred opioid analgesic in palliative care unless contraindicated. However, there are many myths about morphine that may affect its acceptance for treatment of pain.

Nursing staff often administer medications and can provide older people and their families with information to reassure them.

What I need to know: Wrong information may affect:

- willingness to accept morphine for pain
- the family's understanding of why morphine is being prescribed
- a nurse's readiness to administer morphine.

Begin the conversation by asking 'What do you understand about morphine?' or 'Do you have any queries about morphine?'

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.

Fact 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.

Name:

My reflections:

Have I ever had to address family member concerns about the use of morphine or other opioids for an older person?

What information might be helpful for family members?

My notes:

See related palliAGED Practice
Tip Sheets:
Opioid Analgesics
Pain Management

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Nutrition and Hydration



What it is: Nutrition is about the intake of food and how this maintains health of the body. Hydration is the intake of fluids to maintain health.

Why it matters: Food and fluids are necessary to support life and promote healing. In the early stages of palliative care, nutritional intervention can help to boost tissue repair and general wellbeing and prevent infection. When people are dying, they may have less interest in or need for food, and they may have difficulties with swallowing or fatigue. Needs assessment by a nurse is important.

Eating and drinking are also important parts of daily life and social interactions. Family attitudes and values are important in the decisions about eating and drinking.

What I need to know: It is important to consider where the person is on their palliative care journey.

In early palliative care stages and depending on a person's illness, unexplained weight loss may be due to reasons that can be reversed:

- pain
- poor oral health
- nausea
- confusion or not recognising food
- swallowing difficulties (dysphagia)
- need for physical assistance to eat.

Effective management of nutrition and hydration can improve the quality of life for patients by reducing the effects of weight loss, and improving wound healing and fatigue. People may also have established nutritional plans based on percutaneous endoscopic gastrostomy (PEG).

Nutrition and hydration at later stages of palliative care will reflect changed capacity and needs. Malnutrition involving cachexia is more common in people with advanced cancer, dementia, and other chronic diseases.

Decisions around artificial feeding in the terminal phase can be challenging. Refer to the person's ACD. Information about the person's capacity to benefit versus any risk can help. Family meetings to discuss this and care needs may also help.

Actions

Towards the end of life, the goal is to maximise food enjoyment and reduce food-related discomfort. Family members may be distressed if the person cannot or will not eat. They may need to be reassured but can also provide comfort through mouth care or assisting with drinks.

Oral care remains important at all stages, use appropriate and regular assessment.

An assessment of needs includes review of:

- pain
- oral health
- behaviours and cognition
- mobility and dexterity
- environmental factors – including dining arrangements, noise and distractions at meal times
- individual food preferences.

Nutritional counselling from a dietitian or speech pathologist can help.

Offering meals or snacks often and when the person is most alert and receptive can be beneficial.

Tools

Tools that may be useful include:

Oral Health Assessment Tool (OHAT) is a validated screening tool suitable for older people including people with dementia.

Mini-Nutritional Assessment Short-Form (MNA®-SF)

Name:

My reflections:

When was the last time I cared for someone having difficulty with swallowing, and what was done for this person?

Thinking of a situation where a family's opinion about a person's feeding and hydration conflicted with best practice based on their capacity to take in nourishment – what did I do that helped to resolve the conflict and what didn't work?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Opioid Analgesics



What it is: Analgesics are medications used to relieve the symptom of pain. Opioids are analgesics. They are often used for pain and dyspnoea in terminal illness.

Morphine is an opioid analgesic that offers safe and effective relief of moderate to severe pain. There are others. Opioid induced constipation requiring use of laxatives is a common side effect.

Why it matters: Opioids can be administered to reduce or minimise pain via various routes including: oral, transdermal, injection, and subcutaneous infusion. The route chosen will depend on the individual. Nurses have an important role because they often administer medications. Nurse Practitioners may also prescribe medications.

What I need to know: Response to opioids including the dose required or tolerated depends on the individual. Older people and their family may need to be reassured as there are many myths about opioids. Nursing staff can provide older people and their families with information to reassure them.

Wrong information may affect:

- willingness to accept morphine for pain
- understanding of why morphine is needed
- a nurse's readiness to administer morphine.

Appropriateness of opioids needs to be taken into consideration in the case of:

- liver or kidney disease
- an allergy to opioids
- pain that is difficult to control.

'Opioid switching' is the practice of switching to another opioid if pain persists or the person experiences adverse effects. This requires frequent review and assessment for pain and adverse effects.

Breakthrough pain should be treated with a relevant immediate-release opioid. Individual opioids may interact with other medications and this should always be assessed.

Be aware that 'spiritual pain' is different to physical pain.

Actions

Registered Nurses (RNs) can:

- provide information to the person and their family regarding medications
- discuss with the person and their family the way that the medications need to be taken
- provide feedback to the prescriber
- complete an assessment before pain medication is changed and refer to the Advance Care Directive (ACD) to make sure actions align with their goals of care.

Monitor the person frequently for the:

- effectiveness of the pain relief, ask about any pain and discomfort affecting their ability to function
- presence of adverse effects e.g., falls, nausea, vomiting, constipation, sedation, respiratory depression, dry mouth, cognitive impairment, delirium, hallucinations, or seizures.

Family carers providing palliative care at home can be involved in medication management.

This includes:

- monitoring and assessing symptoms and side effects
- administering medication
- making various decisions on medication administration.

Tools

Tools that may be useful include:

Asking if a person has pain is considered the most reliable indicator of pain.

Abbey Pain Scale – useful if a client is unable to communicate their pain

Pain Assessment in Advanced Dementia Scale (PAINAD)

Bristol Stool Chart – a visual aid based on seven stool types.

Name:

My reflections:

Before changes are made to pain medication for an older person receiving palliative care, what document should be referred to?

What adverse effects of opioid pain management might careworkers observe and report to nursing/supervisory staff? In my organisation how is this communicated?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: 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 and/or at the end of life report a high prevalence of oral conditions including hyposalivation, mucositis, ulceration, erythema. Oral symptoms xerostomia (dry mouth) and mucositis (inflammation of the mucosa) are adverse effects of chemo- and radiation-therapy for cancer. A needs assessment is important to ensure a person's comfort and to alert nursing staff to any underlying concerns.

Nurses have a role in assessing and maintaining good oral health in the people in their care.

Poor oral and dental health causes discomfort and can be associated with:

- bad breath
- bleeding gums, tooth decay and tooth loss
- altered appearance and poor self-esteem
- swallowing and nutritional problems, and weight loss
- speech difficulties and problems with social interactions
- pain and discomfort
- change in behaviour
- increased risk of respiratory infection
- other infections.

What I need to know: Most people at the end of life need help with oral care. Many don't or can't communicate that they are in pain or discomfort. Knowing the signs of oral and dental pain can improve care.

Some older people are particularly at risk of poor oral health, including those:

- with severe dementia
- unable to express their needs
- who are dependent on staff for assistance with activities of daily living.

Actions

People at the end of life often need help with oral care. Explain what you are doing and try to involve them if possible.

In residential aged care, registered nurses are responsible for assessing, planning, and evaluating oral care provided by careworkers.

Signs of oral and dental pain may include:

- not eating
- decreased interest in food
- pulling at face or mouth
- chewing at lip, tongue or hands
- aggression
- changes in activity levels.

To provide good oral care remember to:

- always explain in clear language what you are doing
- maintain regular routines in a quiet environment
- use a brightly coloured toothbrush so it can be easily seen by the person
- use a soft toothbrush which can be bent or mouth swabs
- ask the person to copy your actions of brushing or gently help them to brush their teeth, or use objects to keep their hands busy while you brush their teeth
- ask a colleague or a dental hygienist to help
- avoid products containing lemon juice, glycerine, or alcohol as they may cause dryness or pain.

Tools

Tools that may be useful include:

Oral Health Assessment Tool (OHAT) is a validated screening tool suitable for older people including people with dementia.

Name:

My reflections:

What advice can I give careworkers when a person doesn't want to have their teeth cleaned?

How many of the people I care for need an oral assessment or assistance with oral cleaning?

Does my workplace encourage staff to regularly check clients' or residents' oral health?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Pain Management



What it is: Pain is an unpleasant sensory and emotional experience. This includes physical and spiritual pain.

Why it matters: People with advanced disease often experience many types of pain requiring multiple treatment approaches. Registered nurses are responsible for pain assessment.

What I need to know: Pain is whatever a person says it is. The feeling and expression of pain will be affected by the person's experience, attitudes, and beliefs. Pain is common in chronic progressive illness, but needs may change as the illness progresses.

Palliative care helps to manage pain and improve quality of life. The principles of pain management remain the same, but palliative care decisions and pain management may be influenced by the person's preferences and values. Refer to their Advance Care Directive (ACD). Alterations to liver and kidney function in older people may affect clearance of medication. Choice of medication may be influenced by a person's preference and capacity e.g., swallowing of oral medications.

Causes of pain include:

- neurological illnesses
- musculoskeletal pain, contractures
- wounds
- vascular disease.

Poorly managed pain can cause:

- a decrease in physical function and appetite
- social isolation
- sleep and rest disturbance
- depression
- family distress
- poor cognitive function
- challenging behaviours and delirium
- increased vocalisation and/or resistance.

Pain identification and assessment in older people:

- requires observation and communication skills
- use of appropriate validated assessment tools
- includes reports from the person, their family and carers to assess pain and response to treatment
- recognises cultural and personal beliefs about pain and includes them in the care plan
- may require consultation with specialists.

Actions

Assessments are repeated regularly to evaluate effectiveness and safety of any treatment. Assessment:

- identifies illnesses and conditions that contribute to pain
- identifies activities that exacerbate pain, or activities that are avoided because they cause pain.

Assessment should be undertaken while the older person is moving or being assisted to move. The right assessment tool should be used to monitor the person for any change.

Careful positioning of immobile clients or residents can minimise muscle pain and cramps.

A combination of pharmacological and non-pharmacological measures, emotional support and psychological interventions may be utilised.

Clinical assessment using a multidisciplinary approach can assist with care planning to manage pain.

Tools

Tools that may be useful.

Choice of assessment tool depends on the person's capacity to respond but includes:

- **Asking if a person has pain** is considered the most reliable indicator of pain
- **Modified Resident's Verbal Brief Pain Inventory (RVBPI)** – for people able to communicate
- **Abbey Pain Scale** – useful if a client is unable to communicate their pain
- **Pain Assessment in Advanced Dementia Scale (PAINAD)**.

Name:

My reflections:

How many of the people I care for are regularly assessed for pain using an appropriate scale?

Are they re-assessed, and is their care evaluated following changes in their condition?

How many of the people I care for would benefit from use of the Abbey Pain Scale to assess pain?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: People with Specific Needs



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. The Australian Government's Aged Care Diversity Framework provides the mechanism for aged care service providers to ensure that the services provided meet the diverse needs of older people. It complements the Single Quality Framework.

What I need to know: 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.

Recognised specific groups in aged care include people who:

- are Aboriginal and/or Torres Strait Islander
- 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.

Actions

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 the person's GP or other specialist including allied health.

Provide information in an appropriate format and form (online/hardcopy/verbal) and in a language the older person and their family understands.

Be aware of your organisation's policy on privacy and confidentiality.

Tools

Tools that may be useful include:

Visit Talking End of Life with people with intellectual disability (TEL)

www.caresearch.com.au/TEL/

palliAGED Community Centre has a Diversity section with relevant resources in more than 50 languages.

The Aged Care Diversity Framework

provides guidance on how the common barriers which prevent people accessing the aged care services they need can be remedied. See

www.health.gov.au/health-topics/aged-care

Name:

My reflections:

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?

What does my organisation's policy on privacy and confidentiality mean for me?

My notes:

See related palliAGED Practice
Tip Sheets:
Case Conferences
Culturally Responsive Care
– Communication
Psychosocial Assessment
and Support

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Psychosocial Assessment and Support



What it is: Psychosocial support includes psychological and social aspects of a person's life. It acknowledges their 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: Frailty, loss of independence, financial stress, changed living arrangements, or social isolation can cause an older person stress. A life-limiting illness can make it even harder to adapt and cope. Together this can lead to anxiety, depression, grief, distress, fear of becoming a burden, loneliness, and a sense of helplessness or 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: There are validated tools available to assess and monitor psychosocial needs.

Ongoing meaningful conversations (with empathy and active listening) can assist you to identify any needs or concerns. They also provide the base to engage support that can help.

Psychosocial needs are best addressed by a multidisciplinary team.

Physical symptoms indicating possible psychosocial needs include:

- breathlessness,
- insomnia,
- pain,
- sadness,
- crying,
- or changes to appetite, weight, or sleep.

Actions

Compassionate communication is important especially if the older person is feeling lonely or isolated. You can:

- take time to talk with the older person and their family, and actively listen
- ask them how they feel and what they think they need
- use open questions to elicit how the person is feeling 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
- consider the government funded Community Visitors Scheme which arranges for volunteers to visit with older people.

Look out for physical symptoms and assess and monitor these carefully.

Use the same tool to assess and monitor for change.

Consider massage, art therapy, music therapy, spiritual support, counselling, psychoeducational interventions, telemonitoring, environmental changes and psychotherapy.

Provide information about support groups for carers and families.

Tools

Tools that may be useful include:

Geriatric Anxiety Inventory (GAI)

Geriatric Depression Scale (GDS)

Two-Question Screen

Carer Support Needs Assessment Tool (CSNAT)

Carers' Alert Thermometer (CAT)

Name:

My reflections:

What approaches to psychosocial assessment 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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Recognising Deterioration



What it is: Deterioration refers to signs of a person's decline or reduced state of health. They may become bedbound, spend more time sleeping or resting, have reduced intake of food, difficulty with swallowing or fluctuating consciousness.

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

- the review of care needs and goals of care with the person (if able), the family and GP
- starting a palliative care plan or pathway
- ensuring care is given in line with their wishes
- managing symptoms appropriately
- withdrawing treatments, activities, medication that are no longer appropriate or beneficial
- providing counselling and support, to the person, the family and staff
- avoiding inappropriate hospital transfers.

Nurses have a major role in each of these activities.

What I need to know: Recognising deterioration can mean different things to different people including the:

- person's health is declining
- person has months of life left
- person is actively dying.

It is common to think of the terminal phase of care as being short (e.g., cancer) but for conditions like dementia and organ failure, it can extend over months or years. Signs of decline should be recorded so that care plans can be implemented or changed to meet needs.

Many people experience deteriorating health over a long period. People who are declining may have episodes of decline followed by partial improvement and even times when death is expected but does not take place.

Loss of swallowing ability is an inevitable part of deterioration.

Actions

Possible indicators of deterioration include when the person:

- has lost a noticeable amount of weight over the previous few months or stays underweight
- has general health that is poor
- following illness, does not return to previous level of health
- displays decreased activity and a reluctance to engage
- needs help from others for care due to increasing physical and/or mental health concerns
- has troublesome symptoms most of the time despite appropriate management of their health concerns
- has unplanned (emergency) transfer(s) to hospital.

Tools

Tools that may be useful include:

Three triggers that a person may be deteriorating and nearing the end of life:

- If the answer is 'yes' to the question 'Would you be surprised if this patient were to die in the next few months or weeks?'
- possible general indicators of deterioration are increasing care needs, choice for no further active care, increasing physical or mental health concerns
- special condition-related clinical indicators.

SPICIT or the simplified **SPICIT4ALL** tool can help to recognise signs that a person's overall health may be declining.

Australian modified Karnofsky Performance Scale (AKPS) to measure a person's ability to perform their activities of daily living.

Name:

My reflections:

How often do I assess people in my care for signs of deterioration?

How do careworkers in my team report to nursing/supervisory staff any changes in health of the clients or residents?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Respiratory Secretions



What it is: The inability to clear secretions from the upper respiratory tract results in the presence of pooled respiratory secretions. Air flow through the secretions when breathing can result in noisy respiration (rattling).

Why it matters: Noisy breathing is one of the most common terminal phase symptoms in people who are dying. 'Death rattle' is a strong predictor of death.

Problems related to respiratory secretions can be caused by infection or aspiration, or by pooling of normal oropharyngeal secretions in a patient who is weak or unable to swallow or cough effectively or who has a reduced state of consciousness. Pulmonary oedema also causes increased respiratory secretions.

What I need to know: There is currently no evidence to show that medications for treating respiratory secretions at the end of life are effective.

There is no evidence that noisy breathing distresses the person experiencing this. However, noisy breathing can be distressing to carers and family and therefore it may be necessary to initiate treatment based on individual needs.

Counselling of relatives and caregivers is important. Not all people find the symptom distressing but for those that do this needs to be considered.

Antimuscarinic agents such as hyoscine or glycopyrrolate can be used to reduce the salivary secretions. These agents inhibit salivary secretions more than bronchial secretions. Currently no particular medication is recommended.

Actions

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

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

Suctioning of the oropharynx is sometimes recommended, but its effectiveness has not been established and it may cause distress.

If medications are prescribed, monitor for side effects including:

- delirium / agitation
- sedation
- dry mouth
- urinary retention
- palpitations.

Counsel family and carers to ensure they understand what is happening.

Continue to provide frequent mouth care.

Name:

My reflections:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Signs of Imminent Death



What it is: Imminent death means that the older person's decline in health is irreversible and they are likely to die in the coming hours, days or weeks.

Why it matters: Recognising when death is imminent is difficult but 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 'typical illness trajectory' may not hold and giving family a prognosis may not be appropriate. However, the signs of imminent death include:

- profound weakness - totally bed-bound and requiring extensive nursing care
- drowsy, poorly responsive or unconscious with limited response to verbal or physical stimuli
- difficulty with swallowing or inability to swallow
- diminished intake of food and fluids, reduced or no urine output
- changes in breathing pattern including noisy secretions (death rattle) and Cheyne-Stokes (several breaths followed by a long pause)
- skin that is cool to touch or waxy in appearance.

These signs are included in the Residential Aged Care End of Life Care Pathway (RAC EoLCP).

Managing symptoms in the last days of a patient's life is generally a continuation of what is already being done with attention to symptoms that worsen or new symptoms which develop. This includes pain, dyspnoea, delirium, agitation, respiratory secretions, and functional decline.

Communication may be difficult. Assessment and monitoring can be based on signs such as agitation, restlessness, facial expression, body posture and changes in breathing.

Actions

Contact the GP, multidisciplinary team members, the older person's substitute decision-maker and family of choice when death is imminent.

Review the person's wishes and goals of care; this may include reference to an advance care plan (ACP) and/or an advance care directive (ACD) and discussion(s) with a substitute decision-maker, and consideration of discontinuation of treatment.

Provide family and carers with information and guidance on the likely course of the person's illness and what they can do to provide comfort.

Communication needs to be honest, direct, and compassionate, and allow for the concerns and opinions of the family to be heard and appreciated.

Respect and support the older person's sense of dignity in relation to symptom care including bowel and bladder function.

Offer emotional and spiritual 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.

Tools

Tools that may be useful include:

Residential Aged Care End of Life Care Pathway (RAC EoLCP)

palliAGEDnurse app: Recognising dying

Name:

My reflections:

What changes might I notice in an older person's breathing as they approach death?

Who should I inform if imminent death is suspected?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Skin and Wound Care



What it is: As the body deteriorates with severe illness or multiple illnesses, the risk of developing wounds increases. People receiving palliative care have less capacity for skin healing.

Why it matters: The skin is an organ. It deteriorates with advanced disease and therefore wounds are common at the end of life. In advanced cancer, fungating wounds occur when malignant tumour cells infiltrate and break through the skin. Pressure ulcers occur in people with limited mobility and are common in palliative care. Organ failure may limit oxygen supply to the skin leading to breakdown and wounds.

What I need to know: Early signs of skin breakdown include:

- dusky erythema
- mottled discolouration
- local temperature change.

Care teams for wound care may include GPs, nurses, allied health, wound care specialists, and family. Typical end-of-life wounds include:

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

Wounds affect quality of life due to:

- pain
- unpleasant odour
- putrid discharge
- the time required to take care of wounds.

Pressure injuries are a quality indicator in the National Aged Care Quality Indicator Program.

Wounds may not heal despite best practices in wound management. This may be due to:

- advanced disease and/or organ failure
- frailty or compromised mobility
- weakened immune response to infection
- vascular insufficiency
- diabetic neuropathy
- cachexia.

The aim of wound care may be to prevent a wound from getting worse.

Actions

Always be meticulous with your hand hygiene.

Protect the person from injury by:

- careful positioning to avoid friction and shearing forces, bumps and scratches
- avoiding vigorous skin rubbing
- appropriate continence management program
- cleaning skin with pH neutral skin cleanser and thoroughly drying
- protecting skin with water based skin emollients
- using pressure relieving devices.

Good wound care includes:

- thorough assessment identifying the type of wound and predisposing factors
- identification of the underlying cause(s) and if it can be modified
- determining the impact of the wound on the person
- determining if the wound has the potential to heal
- discussing with the person, their family and care team the best approach to wound management
- developing strategies to manage concerns identified
- referral to wound care specialist for complex wounds or when symptoms are not well controlled.

Manage pain with regular analgesia and pain relief prior to wound care.

Choose wound cleansers and dressings that reduce the pain and require less frequent changing, and wound cleansers that are warm rather than room temperature.

Tools

Tools that may be useful include:

Braden Scale to assess risk for pressure sore.

Pain assessment e.g., **Abbey Pain Scale**.

Name:

My reflections:

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

What factors might prevent a wound from healing?

My notes:

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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Tips for Nurses: Spiritual Care



What it is: Spirituality may be defined as a person's connections to other people, to the natural world, or to what gives them meaning and purpose. Spirituality is very personal.

Why it matters: For many people, spirituality is important throughout life. Spiritual care may be especially important for older people at the end of life. Spiritual pain has a negative effect on well-being and may be expressed in a physical response (e.g., increased pain) or an emotional response (e.g., anxiety, depression or anger).

What I need to know: Providing spiritual support is an important aspect of palliative care.

A person's spirituality does not always include religious belief.

But, spirituality may be linked to religious belief and practices or recognition of a higher power.

Spiritual care includes:

- sensitive and respectful interactions
- patient communication
- activities like story-telling, reminiscing, mindfulness and meditation, prayer, therapeutic life review or dignity therapy.

Showing respect and support for a person's spirituality can reduce the distress of being ill or dying.

All people working in aged care can provide spiritual support. Some aged care staff may have skills to screen for spiritual needs, to plan spiritual care or to refer to spiritual care practitioners or faith representatives. Chaplains and faith representatives can provide religious spiritual care.

Actions

Use touch and eye contact that is appropriate, and a welcoming and unhurried approach to conversation.

Listen so that the person feels heard and valued.

Be sensitive to and respectful of the spiritual and religious needs of people in your care and their families. Allow for privacy and uninterrupted time for spiritual practice.

Offer opportunities for a connection with external spiritual practices.

Provide opportunities for discussion with chaplaincy staff, spiritual care practitioners or faith representatives. Facilitate opportunity for re-connection.

Offer activities and roles that give people purpose.

Tools

Tools that may be useful include:

Connecto is a tool adapted by Meaningful Ageing Australia to identify spiritual strengths and capacities, and spiritual weaknesses and vulnerabilities (not restricted to religion, requires payment).

Palliative Outcome Scale (POS)

Name:

My reflections:

In my place of work how is spirituality supported?

How could 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

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

Next Steps for Nurses



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 for nurses

An advanced learner

- Visit palliAGED Practice & Evidence Centres
- Read CareSearch Clinical Evidence summaries
- Make use of the ELDAC toolkits
- Sign up for online training such as:
 - Advance
 - caring@home
 - End-of-Life Essentials.

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 Evidence Centre and invite staff to contribute to policy development
- Promote the ELDAC toolkits
- Use the CareSearch guide to establish a journal club to build knowledge
- Discuss options for further education with staff
- Arrange for Reverse PEPA placements.

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets

CareSearch is funded by the Australian Government Department of Health. Printed April 2022



palliAGED
PALLIATIVE CARE AGED CARE EVIDENCE



palliAGED

supporting those who care

Learn more at www.palliaged.com.au

@ For enquiries or feedback please email: palliaged@flinders.edu.au

🐦 Keep up to date and follow us on twitter [@palliAGED](https://twitter.com/palliAGED)