

Tips for Careworkers: Advanced Dementia – Behavioural Changes



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

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

What I need to know: Common BPSD symptoms include:

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

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

Do

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

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

Do

Keep the person physically active if appropriate.

Do

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

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 Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets



Tips for Careworkers: 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, herbal medicine, and massage therapy.

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

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

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

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

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

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

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

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

Note Remember that most people are waiting to be asked before they disclose their use of CT. Lifestyle coordinators may be able to help with some approaches to CT.

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

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

Do You may wish to ask:
Have you tried anything else like herbal or natural remedies to help?
If so, then ask:

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

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

Name:

My reflections:

What complementary therapies do I use?

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

My notes:

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

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Tips for Careworkers: Psychosocial Assessment and Support



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

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

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

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

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

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

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

Do

Tips for talking:

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

Do

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

Do

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

Name:

My reflections:

What approaches to psychosocial care are used in my workplace?

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

My notes:

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

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



Tips for Careworkers: Quality of Life with Change and Deterioration

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

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

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

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

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

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

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

Do

Talk with the person and family

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

Do

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

Do

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

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

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

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Tips for Careworkers: Supporting Families



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

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

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

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

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

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

Note

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

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

Do

Tips for talking:

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

Do

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

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:
Case Conferences
Grief and Loss among Older People,
Families and Residents
Talking About Dying

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www.palliaged.com.au/PracticeTipSheets