

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: 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, acupressure, 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, acupressure, 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

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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: 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