yooralla

Insights into Practice

Palliative and End of Life Care for people with disability

Things you should know:

- Palliative care is an approach to care that focuses on quality of life when curative treatments are no longer effective.
- Everyone has the right to access palliative care irrespective of income, disease type or age.
- End of life care usually focuses on the last days to weeks of life.
- Good communication with the person, family, support staff, and health team can greatly improve choice and control even at the end of life.
- Recognising deterioration in a person with disability is challenging but more likely to be identified by people working daily with the client.
- In shared accommodation, consider the needs of all residents and staff, including bereavement.
- Earlier access to specialist and community palliative care services can assist in improving outcomes for people with disability.
- Training for all staff will improve confidence in supporting the person to stay in their home setting.

What is palliative care?

The World Health Organization (WHO) defines palliative care as an approach that prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.[1] Currently, across the globe, only about 14 per cent of the general population who would benefit from palliative care, receive it. People with disability are less likely to receive palliative care than people without disability.[2] Palliative care is explicitly recognised as a human right. It should be provided in accordance with the principles of universal health coverage through person-centred and integrated health services with particular attention to the specific needs and preferences of all individuals.[1]

Australian Institute of Health and Welfare (AIHW)[3] data indicates that factors such as lower socio-economic status, non-English speaking background, multiple health problems, living in a rural setting or being of Aboriginal and/or Torres Strait Islander background can contribute to poorer health. This can create additional barriers to positive health outcomes for people with disability. Diagnostic overshadowing – when a healthcare professional assumes a patient's symptoms are due to their disability rather than an illness – can delay the diagnosis of a life-limiting condition and access to palliative and end of life care for people with disability.[2]

Acknowledgements: This document was produced with assistance from the North and West Metropolitan Region Palliative Care Consortium in conjunction with associated Community Palliative Care providers.

Timely palliative care aligns well with the client-centred and psycho-social model of care currently provided to clients with disability. Palliative care should be considered as complementary care rather than a different way of caring.

> Palliative care seeks to prevent and relieve suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.

What is end of life care?

End of life care is usually provided in the last days to weeks of a person's life when they have higher care needs and more symptoms. Usually, routine medications may be withdrawn as these can sometimes worsen symptoms. The focus is on comfort, including pain relief, and care aims to promote a good death (as the client would perceive it).

The Victorian end of life and palliative care framework guides high-quality end of life care. The framework places the client and their family at the centre of this care, focusing on dignity, preferences, values, comfort and quality of life.[4] End of life care requires the collaboration of disability and palliative care services. To achieve palliative care goals, this collaboration should be led by disability services, with the person with disability maintaining choice and control wherever possible.[5]

> End of life care places the client and their family at the centre of care with a focus on dignity, preferences, values, comfort and a good death.

End of life care can be more difficult to identify in someone with multiple underlying conditions such as Down syndrome or dementia.[6,7] Changes may occur as part of these conditions, such as behavioural changes, disturbed sleep, eating and drinking less and less interest in previously enjoyed activities. However, the person's essence remains the same, and their wishes should be accommodated wherever possible. The person's needs and preferences, not the diagnosis, should determine their required services.[8]

Communication, choice and control

There is limited research into palliative care for people with disability, causing their needs to be overlooked and, in some ways, invisible.[9] Everyone should consider what they would like at the end of their life and discuss these preferences with the people they love and who care for them. These preferences can be included in Advance Care Plans (ACPs) to communicate their wishes to a broader group of support workers or hospital staff as their care needs change. Discussions about the goals of care should begin as early as possible and be reviewed regularly as the person's condition changes.[6,10]

> Early recognition and appropriate planning are essential for clients who require palliative care supports.

Early advance care planning is important for everyone, but especially when underlying health conditions or disabilities exist, such as dementia.[2,6,7] Cultural and ethnic needs should be considered with physical and care needs.[6] Respect for an individual's faith and cultural heritage should be incorporated into their care; this may be as simple as playing music with cultural meaning for the person or might include spiritual carers being part of the care team.

Collaboration between services is essential to provide coordinated care. Regular plan reviews are encouraged as the person receiving care may change their mind, and care may need to be provided in a hospital, inpatient palliative care unit, respite facility, or residential care facility as end of life approaches and care needs increase.[8] Good advance care planning allows care that meets the client's identified needs and wishes.[10]

> Early access to specialist and community palliative care services can assist in improving outcomes for people with disability.

Evidence exists that decisions related to end of life care, including treatment options, often do not include the person with disability in the process.[9,10] Others may make assumptions about the person's ability to cope with treatment options, potentially leading to compromised quality of life for the person with disability.[9] A systematic review[2] found challenges in identifying symptoms in people with significant communication difficulties and that these symptoms

are often expressed as changes in behaviour. The use of speech therapy expertise and communication devices is recommended in these cases.[2]

Depending on the person's capacity to make decisions, another person may need to be appointed as a decision-maker to assist with medical treatment decisions, such as a guardian or enduring medical power of attorney.[8] Planning is essential, and early appointment of a medical treatment decision-maker can help to ensure the person's wishes are respected when they can no longer make their own decisions. Multiple conversations are required to establish the person's care wishes over time and as their condition progresses.[11] Both formal and informal documentation of the person's wishes is encouraged.[10]

Support workers are often the first to recognise when a person is experiencing changes that may indicate they are approaching the end of their life.

Identifying End of Life for people with disability

Depending on the disability, clients may be able to identify a decline in their condition and advocate for themselves. Many people with disability have difficulties with communication, and some have no spoken language. The support workers working with clients daily may be more likely to notice gradual changes that indicate a decline in cognitive, behavioural, physical or mental health. These changes can indicate a worsening of underlying conditions. Communication tools exist for both verbal and non-verbal clients to help identify changes that may indicate a person is coming towards the end of their life.

There is evidence that minimal communication of dying and death occurs with clients with disability. Support workers and health professionals describe difficulties in having these conversations.[2,12] Improvements in medical treatments mean people with disability are living longer, but death may be preceded by increasing vulnerability and illness.[10]

Families may be reluctant to discuss palliative care with people with disability. They may be concerned that the person with disability does not have the intellectual or cognitive capacity to discuss this. Family members who have been long-term carers may feel a sense of failure alongside grief and loss,[13] which may limit the ability to make decisions about end of life care.

Education and training

Familiar support workers are more likely to notice small changes in abilities or health due to an underlying health condition such as cancer or dementia, indicating a change is needed in the client's overall management. Support workers may not understand that chronic conditions such as advanced dementia are appropriate for referral to palliative care.[7] Because dementia is common for people with intellectual disability and starts early in life (at an average age of 51), they may miss out on the care they need.[7]

Direct support workers must understand that palliative care and end of life care are ways to assist a client with symptom management.

Educating direct support workers to understand palliative care and assist with symptom management has been identified as a priority.[6,7] Health workers across primary, acute and sub-acute care require education to understand specific disabilities, communication and service needs.[2,5] There is a lack of training about how intellectual and physical disability can intersect with dementia. This training needs to focus on including people with disability in decision-making about their care.[6]

Health professionals have difficulty recognising the need for palliative care for people with disability, find it challenging to discuss end of life, and lack the skills to undertake advance care planning with this group of clients.[10]

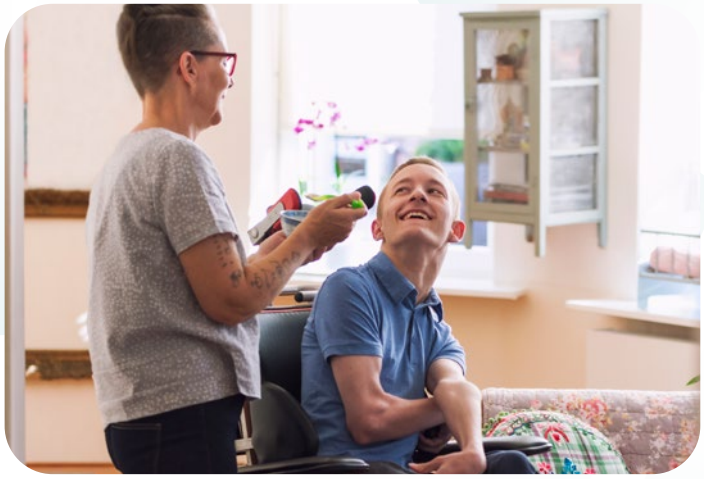
Bereavement needs

Most people, regardless of age and ability, would prefer to die at home – but to achieve this requires training in end of life and complex care needs.[7] A person's preferred place of death should be considered alongside the impact on others in that environment, including family and support workers. At the end of life, people wish to be surrounded by familiar faces, everyday routines, important relationships and treasured activities.[2]

Knowing a person is dying can create anticipatory grief for clients and support workers. Bereavement affects all group home members in various ways, potentially more so when a client dies at home.[6] Good palliative care should include bereavement care for all people affected by the death.[2]

In many cases, the death of a client in a disability support accommodation or supported independent living is considered a reportable death (even when expected) and requires investigation by the coroner. This can put additional strain on families, support workers and other residents living in the home. Families and clients should be informed of this requirement during palliative care discussions.

> Good palliative care should include bereavement care for everyone affected by the death.



Future directions

More research is needed on identifying when clients with disability need palliative care and how best to provide it. The views of clients, caregivers, families and health workers need to be included.[2,6,7,9,10] Policies, procedures, guidelines and tools are required to help support workers and healthcare workers provide client-centred, evidence-based, excellent palliative care to people with disability.[2,6,7,9]

While it is important to recognise that pain is not necessarily a part of end of life care, the following tools are available to assess the severity of symptoms:

- the DisDAT – Disability Distress Assessment Tool[14]
- the Abbey pain scale[15]
- PALLI – a tool for identifying people with intellectual disability needing palliative care. [16]

Increased use and testing of these and other tools will help to determine how they can be used with the most significant benefit and will guide future practice.

Palliative Care Victoria[17] has determined that the need for palliative care services across Victoria has increased steadily. Unmet need was underestimated in the figures available, and the report did not specifically discuss the disability sector. Therefore, early recognition and appropriate planning will be essential to ensure that clients with disability can access palliative or end of life care. Inequitable access to palliative care supports can be an additional source of discrimination against people with disability, but good planning can improve the use of available supports.

Resources:

- Advance care plans – Better Health Channel
- https://www.health.vic.gov.au/patient-care/advance-care-planning-1
- CareSearch palliative care knowledge network
- End of life and palliative care at home – Better Health Channel
- End of life and palliative care explained – Better Health Channel
- Guardianship and administration – Office of the Public Advocate
- guide-to-mtpd-act-2016-doc.docx (live.com) A guide to the Medical Treatment Planning and Decisions Act 2016 For health practitioners 2nd edition (2019)
- Healthy dying for people with disability – Li-Ve Tasmania (livetasmania.org)
- Home – Dying 2 Talk
- Palliative Care Advice Service
- Palliative Care Australia
- Palliative Care Victoria – Home (pallcarevic.asn.au)
- PEPA Learning Guide for Disabilit+y Support Workers _ WEB (pepaeducation.com)

References:

1. WHO. Palliative Care. WHO; 2020. https://www.who.int/news-room/fact-sheets/detail/palliative-care accessed 14 February 2023
2. Adam E, Sleeman KE, Brearley S, Hunt K, Tuffrey-Wijne I. The palliative care needs of adults with intellectual disabilities and their access to palliative care services: A systematic review. Palliat Med. 2020;34:1006-1018.
3. AIHW. People with disability in Australia 2022. Catalogue number DIS 72, Australian Government, AIHW; 2022.
4. Victoria Government. Victoria's end of life and palliative care framework – consumer summary. Victorian Government; 2022. (healthtranslations.vic.gov.au) accessed 14 February 2023.
5. Grindrod A, Rumbold B. Providing end-of-life care in disability community living services: An organizational capacity-building model using a public health approach. J Appl Res Intellect Disabil. 2017;30:1125-1137.
6. McCallion P, Hogan M, Santos FH, McCarron M, Service K, Stemp S, Keller S, Fortea J, Bishop K, Watchman K, Janicki MP; Working Group of the International Summit on Intellectual Disability and Dementia. Consensus statement of the International Summit on Intellectual Disability and Dementia related to end-of-life care in advanced dementia. J Appl Res Intellect Disabil. 2017;30:1160-1164.
7. McCarron M, McCallion P, Fahey-McCarthy E, Connaire K. The role and timing of palliative care in supporting persons with intellectual disability and advanced dementia. J Appl Res Intellect Disabil. 2011;24:189-198.
8. Better Health Channel. End of life and palliative care explained. betterhealth.vic.gov.au accessed 14 February 2023.
9. Tuffrey-Wijne I, Wicki M, Heslop P, McCarron M, Todd S, Oliver D, de Veer A, Ahlström G, Schäper S, Hynes G, O'Farrell J, Adler J, Riese F, Curfs L. Developing research priorities for palliative care of people with intellectual disabilities in Europe: a consultation process using nominal group technique. BMC Palliat Care. 2016;15:36.
10. Voss H, Vogel AGFM, Wagemans AMA, Francke AL, Metsemakers JFM, Courtens AM, de Veer AJE. Development, implementation, and evaluation of an advance care planning program for professionals in palliative care of people with intellectual disability. Intellect Dev Disabil. 2021;59:39-54.
11. Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney: ACSQHC, 2015.
12. Velepucha-Iniguez J, Bonilla Sierra P, Bruera E. Barriers to palliative care access in patients with intellectual disability: a scoping review. J Pain Symptom Manage. 2022;64:e347-e356.
13. Marlow S, Martin M. 'A voyage of grief and beauty': supporting a dying family member with an intellectual disability. Int J Palliat Nurs. 2008;14:342-9.
14. Regnard C, Reynolds J, Watson B, Matthews D, Gibson L, Clarke C. Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). J Intellect Disabil Res. 2007;51:277-92.
15. Abbey J, Piller N, De Bellis A, Esterman A, Parker D, Giles L, Lowcay B. The Abbey pain scale: a 1-minute numerical indicator for people with end-stage dementia. Int J Palliat Nurs. 2004;10:6-13.
16. Vrijmoeth C, Groot CM, Christians MGM, Assendelft WJJ, Festen DAM, van der Rijt CCD, van Schrojenstein Lantman-de Valk HMJ, Vissers KCP, Echteld MA. Feasibility and validity of a tool for identification of people with intellectual disabilities in need of palliative care (PALLI). Res Dev Disabil. 2018;72:67-78.
17. Palliative Care Victoria. The sustainability of palliative care in Victoria, KPMG; 2022.

For more information about Yooralla's Insights into Practice please contact:

yooralla.com.au | 1800 966 725 | yooralla@yooralla.com.au

Yooralla is a registered NDIS provider

yooralla.com.au/socials