



Australian Government Department of Health

Exploratory Analysis of Barriers to Palliative Care

Issues Report on People with Disabilities

September 2019

Acknowledgments

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Contents

Key messages.....	1	Figures and tables	
Barriers	1	Facilitators and underpinning enablers of quality palliative care.....	2
Promising approaches	1	Figure 1-1: Project activities.....	3
Recommendations.....	2	Figure 1-2: Suite of reports	4
1 Project background	3		
This report	4		
2 About this population group	5		
3 Findings.....	7		
Barriers to accessing palliative care	7		
Enablers and promising approaches	15		
Advance care planning	18		
4 Recommendations.....	21		
Addressing facilitators of appropriate palliative care for people with disabilities.....	22		
Addressing underpinning enablers.....	24		
Abbreviations.....	25		
Glossary	26		
References	28		

What is palliative care?

Palliative care is a person- and family-centred approach to care. Palliative care services are provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise quality of life.¹ It improves quality of life for individuals and families through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other physical, psychosocial or spiritual problems.³

Palliative care:

- Should be strongly responsive to the needs, preferences and values of people, their families and carers
- Should be available to all people with an active, progressive, advanced disease, regardless of diagnosis
- Affirms life while recognising that dying is an inevitable part of life.

This means that palliative care is provided during the time that the person is living with a life-limiting illness, but it is not directed at either bringing forward or delaying death.

Palliative care can be provided in a range of settings, including:

- At home
- At a hospital
- In a hospice
- In an aged care facility
- In an institutional setting (such as a correctional facility or accommodation for people living with a disability).

Palliative care involves a range of clinical and other supports delivered by different providers,

including volunteers, depending on the patient's needs. These may include:

- General practice and primary care
- Other specialist medical, nursing and allied health practitioners
- Community, disability, aged and social services
- Grief and bereavement services
- Specialist palliative care services (comprising multidisciplinary teams with specialised skills, competencies, experience and training in palliative care), for patients with complex needs.

This project adopts a broad view of palliative care, as outlined above, and is not limited to the provision of specialist palliative care services.

Therefore the term 'palliative care provider' is used in this document to refer to all health and social care providers involved in the delivery of palliative care.

Where relevant, the term 'specialist palliative care provider' is used to differentiate this group of professionals. More broadly, the term 'health and social care providers' is used to represent those within this category for whom palliative care is not considered core business.



Key messages

People with disabilities often experience significantly poorer health than those without, and many are likely to require palliative care during their lives. However, challenges exist to ensuring access to quality palliative care that meets the needs of people with disabilities.

Key barriers and promising approaches for improving access to and experience of palliative care for people with disabilities include:

Barriers

- Lack of awareness/understanding of palliative care
- Communication issues (care providers and people with disabilities)
- Service provider assumptions about competence of people with disabilities
- Diagnostic 'overshadowing'
- Physical barriers (access, mobility, transport)
- Distrust of health services
- Inadequate support for carers and families
- Lack of integration between health, disability and aged care sectors
- In community living settings, lack of organisational support for dying in place of choice

Promising approaches

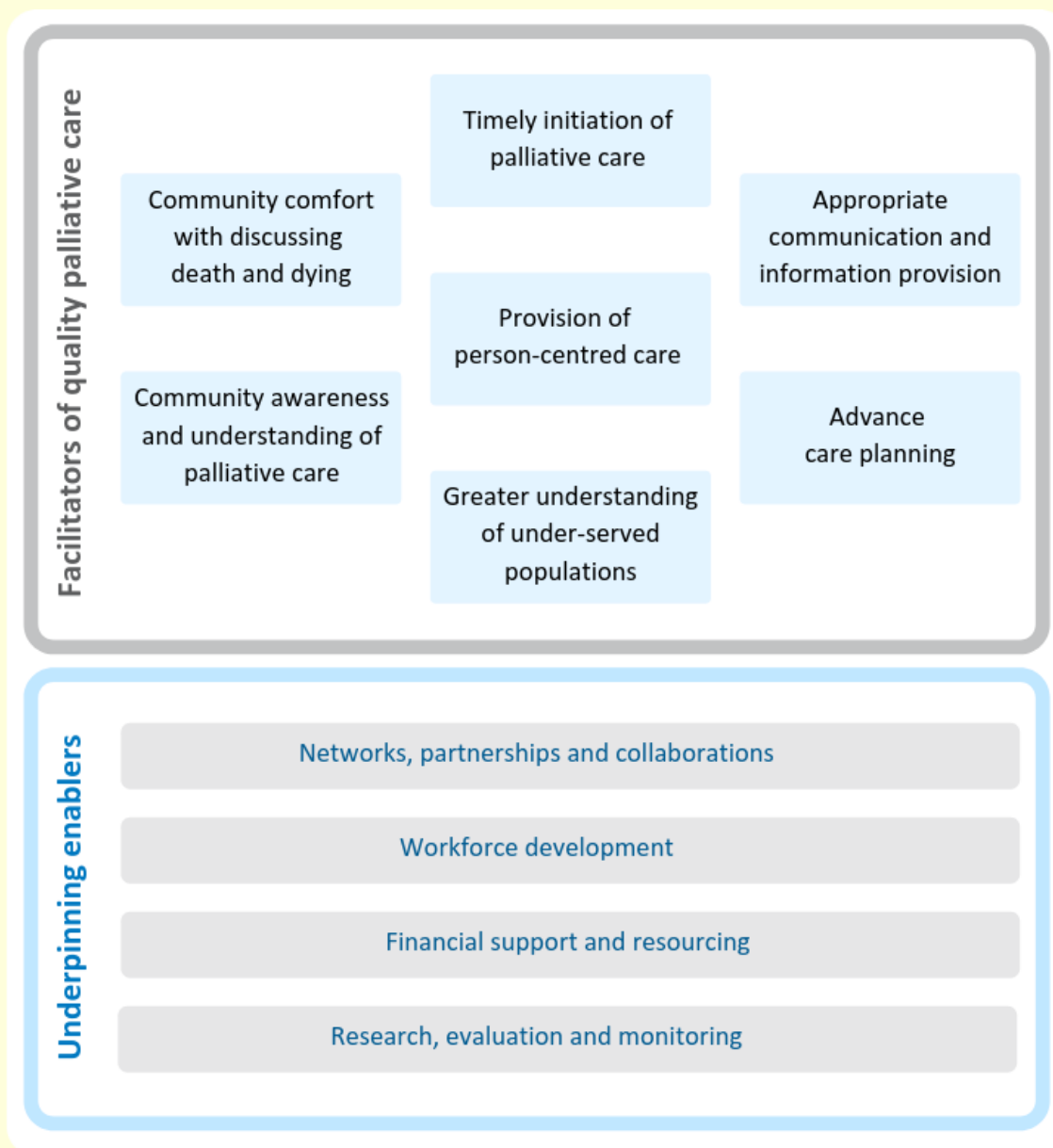
- Community awareness-raising
- Education and training for palliative care, disability service staff and people with disability
- Support for carers and families
- Advocacy support
- Collaboration and inter-agency communication to boost capacity for community-based palliative care
- Development of organisational policies and processes to support delivery of palliative care

Recommendations

Recommendations address seven domains that facilitate quality palliative care. These are underpinned by four key enablers, as illustrated below.

Specific recommendations are detailed in *section 4*.

Facilitators and underpinning enablers of quality palliative care



1 | Project background

Australian Healthcare Associates (AHA) was engaged by the Australian Government Department of Health (the Department) in February 2018, to conduct an exploratory analysis of barriers to accessing quality palliative care for people from under-served populations or people with complex needs (the project). The project ran from February 2018 to June 2019. The main activities that contributed to the project are summarised in *Figure 1-1*.

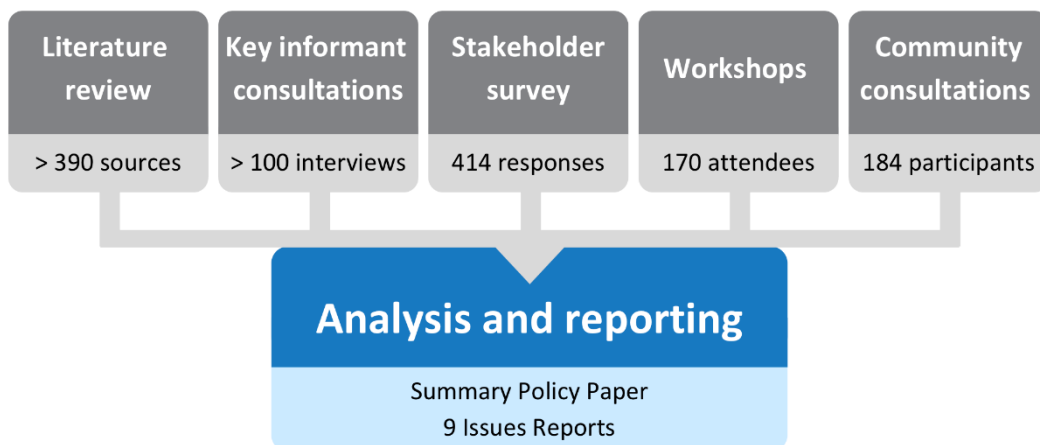
The project generated a high level of engagement from a broad range of stakeholders.

AHA acknowledges that the community members consulted for this project may not be representative of the broader community of people with disabilities.

In particular, it is likely that those who participated had a greater understanding of palliative care, and felt more comfortable discussing death and dying, than those who didn't participate and may be more 'difficult to reach'.

Please refer to the *Summary Policy Paper* for more information on project methodology and limitations.

Figure 1-1: Project activities



This report

This issues report describes key barriers and promising approaches for improving access to and experience of palliative care for people with disabilities in Australia. It also discusses the potential role of advance care planning and provides recommendations for the palliative care and other sectors to

improve access and quality of care for people with disabilities.

This issues report is part of a suite of documents developed through the project, as shown in *Figure 1-2*.

Figure 1-2: Suite of reports



2 | About this population group

Disability is an umbrella term that encompasses any or all of the following components (all of which also may be influenced by environmental and personal factors):

- Impairment—problems in body function or structure
- Activity limitation—difficulties in executing activities
- Participation restriction—problems an individual may experience in life situations.²

Disability is diverse and can be understood as a continuum from no impairment or limitation, to the complete loss or absence of functioning or ability to complete a task. Almost one in five Australians is living with a disability, and of these, one in three will have severe or profound limitation.³

Causes of disability include genetic disorders, physical and mental illnesses, accidents and ageing; or any combination thereof.

The prevalence of disability increases with age; over half of all Australians with disability are aged 65 years or older.⁴ In addition, due to a range of factors, people with disability often experience significantly poorer health than people without disability. It is therefore possible that people with disability may also have conditions that would benefit from palliative care. In some instances, the disease causing the disability may itself be a cause of death—e.g. dementia, which is the second leading cause of death of Australians, accounting for 13,729 deaths in 2017.⁵

Dementia is now recognised as a terminal condition for which palliative care is appropriate,⁶ and people with dementia account for 52% of all residents in residential aged care facilities.⁷

Context

In Australia, two sectors are responsible for delivering most disability supports:

- For people aged 65 years and older (55 years for Aboriginal and Torres Strait Islander peoples), disability support is largely provided through the aged care system. Depending on the extent and nature of the disability, support may be provided at home, or in a residential care facility.
- For people with disability who are under 65 years of age (at the time they enter the system), supports are provided primarily by disability sector (see below).

People with disabilities also use a range of mainstream health services for their healthcare (as separate from disability support) needs.

Australia's disability sector is undergoing significant reform following the introduction of the National Disability Insurance Scheme (NDIS) in 2016. The NDIS aims to ensure that adults (aged under 65 at the point of entry) and children living with a significant and permanent disability are able to obtain the support they need to fully participate in society, through a sustainable system that offers choice and control. However, not all Australians living with disabilities are eligible to participate in the NDIS.

Collaboration between sectors—in particular, health, disability and aged care — is critical to ensuring that people with disability receive the services they need. In principle, the health system is responsible for diagnosing and treating conditions and providing rehabilitation, while the NDIS is responsible for improving functional capacity. However, the division of responsibility between the health and disability sectors is not always clear-cut.⁸ It is recognised that both health and disability inputs may be needed at the same time, and there is a need for planning and coordination to ensure smooth transitions between services.⁹

It has been recognised that the NDIS faces challenges in ensuring that people with disabilities who have additional vulnerabilities or needs receive the supports they require. These include people in the criminal justice system, Aboriginal and Torres Strait Islander peoples, refugees and recent immigrants, and people from culturally and linguistically diverse (CALD) backgrounds. Coexisting conditions, including mental health disorders, may cause or contribute to disability.⁸ This is known as ‘multiple disadvantage’, highlighting the additional barriers faced by people with disability and other markers of vulnerability.

While there is significant diversity among people with disability, the literature concerning barriers to palliative care focuses primarily on neurodegenerative diseases (dementia, Alzheimer’s disease, Motor Neurone Disease) and intellectual disability (ID). However, the consultations undertaken for this project offered insight into a wider spectrum of disability.

3 | Findings

During the project it was noted that many of the issues identified as barriers, enablers and promising approaches to accessing palliative care by people with disabilities were actually *universal factors*, i.e. common to the general Australian population, rather than being specific to people with disabilities. These universal factors, along with a range of other factors that are common to all under-served populations, are described in the *Summary Policy Paper* from this project. The discussion below focuses on factors identified as *specific to people with disabilities*.

Many of the barriers raised through consultations and described below apply to health care and aged care more broadly and are not specific to palliative care.

It is also recognised that the population of people with disabilities is heterogeneous, and, while findings and recommendations in this issues report are generalised, they are unlikely to be relevant in all cases.

The barriers and enablers identified in this report have been categorised as ‘consumer-side’ and ‘service-side’. Consumer-side factors relate to characteristics of individuals, families and communities, while service-side factors relate to health professionals, services and organisations, and the healthcare system more broadly. These categories are not intended to lay fault for barriers or responsibility for enablers on one particular side of the palliative care relationship, but rather to provide a framework within which to consider an appropriate service system response.

Barriers to accessing palliative care

Consumer-side barriers

Individuals

Limited **understanding of death, dying and palliative care** is common among people with disabilities. Poor health literacy—and in some instances, reduced cognitive capacity—create additional challenges. As with the broader community, understandings of palliative care vary depending on each person’s familiarity and experience with the process. The notion that *‘palliative care is where you go to die’* was common among consumers interviewed for this project.

‘If you have only seen negative experiences, you may be frightened of palliative care’
—Person with disability

Distrust of the healthcare system was evident, with one stakeholder noting that there is a lot of angst within the disability community around end-of-life care:

‘There are perpetuating barriers of miscommunication in the disability sector, as well as fear that people will be “bumped off”—that their lives are of less value’ —Disability advocate

Communication issues, which can arise from cognitive, motor and/or sensory impairments, can raise a number of barriers to effective palliative care:

- Practitioners may not be able to form a clear understanding of a patient’s symptoms, making it difficult to reach an accurate diagnosis
- Some people with disability may lack the skills or confidence to effectively to speak up about symptoms
- Some people with disability that impacts on communication may use electronic devices to support communication, but this can be slow, *‘and the health system does not support things that are slow’ — Disability service provider.*

However, the most common communication concern reported in the literature and by stakeholders was that service providers—and families—**often underestimate the capacity of people with disability**. This can be detrimental to the experience of palliative care, foreclosing the possibility of person-centred care and even denying agency to people with disability.

‘People often don’t have the opportunity to be involved in conversations and decisions around end-of-life. There is a lack of openness and inclusion’ —disability service provider

Overshadowing—attributing the symptoms of a disease to the disability and thereby failing to diagnose or treat it¹⁰—can be a significant impediment to the **timely** introduction of palliative care.

Overshadowing is also a contributing factor in the **premature mortality** and high rates of **avoidable death** among people with ID.¹¹

Because disability may increase the **complexity of conditions**, high-quality palliative care for people with disability should often involve input from disability and mental health specialists in addition to specialist palliative care. However, evidence suggests that, in many instances, multidisciplinary care may not be provided.¹²

In addition, many people with disability who have progressive life-limiting conditions may benefit from palliative care involvement over a **much longer period** than current funding or service structure allows.

*‘There is a different concept of “palliation” in the disability sector’
—Disability service provider*

Physical barriers to health services (relating to access, mobility and parking) were also reported. Many participants were annoyed at the cost of hospital parking (exacerbated by long wait times for outpatient appointments).

Participants also expressed frustration with the bureaucratic challenges involved in accessing the NDIS and other government-funded supports.

Additional challenges to accessing palliative care were noted for those with disability who:

- Are **children**, due to a lack of specialised services, particularly outside of major centres
- Live in rural and remote areas
- Are socially isolated
- Are **reluctant to ask for help**, or do not have someone to advocate on their behalf. It was noted that there are many people living with disability who have never received disability supports, and whose needs are not well understood.

While not directly related to accessing palliative care, it was noted that introduction of the NDIS represents a major change in the relationship between service providers and consumers, with consumers **expected to exercise choice and control—without necessarily having the skills or knowledge** to be able to do so.

Family

Carers play a critical role in supporting people with disability to access palliative care. While having family members who are able to navigate the system and advocate are a key enabler to accessing services (including palliative care), they may **lack adequate support** and face significant challenges, as outlined below.

- Complex needs can place enormous physical and emotional strain on carers (often over a protracted time period), and carer burden is under-recognised

- Families may wish to care for their loved ones at home, but the level of support required may not be available. This was noted to be a particular problem for those looking after children at end-of-life, for whom specialised supports (including aids and equipment appropriate for age/size) were considered to be lacking
- Family members who are accustomed to ‘advocating fiercely’ for their loved ones may resist the introduction of palliative care as they assume it means the system has ‘given up’
- Conversely, family members who have not had a close relationship with the dying person may be drawn into a surrogate decision-making role without adequate preparation
- Families may be reluctant to talk about death and dying, which can negatively impact on the person undergoing palliative care
- Ineffective communication between health professionals and carers (e.g. in relation to medication changes) can cause confusion and uncertainty.

It was also recognised that carers may themselves be elderly, ill or have disability—which can make it even more difficult to cope.

Experiences of carers of people with dementia

Carers of people with dementia interviewed for this project noted a range of problems in navigating the health, disability and aged care system, and the need to constantly advocate for their loved ones:

‘My partner is dying. He is almost 65. Do we wait for a home care package, or do we wait for the NDIS?’

‘There’s no information. You have to go through My Aged Care and then wait.’

‘Who helps people navigate into palliative care, or aged care or the NDIS—is it the role of the GP?’

‘I wouldn’t know where to start trying to get help and information. As a carer you are traumatised by the knowledge that someone is coming to the end-of-life; you’re tired; you’re not in a normal healthy situation. You’re overwhelmed by everything.’

Service-side barriers

Health professionals

A key barrier preventing access to, and delivery of, quality palliative care for people with disability—particularly those with ID—relates to **suboptimal communication**. Many health professionals lack the skills or confidence to tell someone with ID that they are dying, or they may feel that it is somebody else’s responsibility (e.g. disability support staff). This lack of transparency can cause significant psychosocial distress to the individual.

‘How can you give palliative care as defined by the World Health Organization if the person doesn’t even know that they are dying?’
—Palliative medicine physician

Health professionals may **make assumptions about the quality of life of people with disability**—for example, they may assume that a person would not want to be resuscitated or may not wish to have active treatment. This was seen to reflect the assumptions and attitudes held by many in the broader community around the value of people with disability. It was noted, however, that it is also important to have conversations about futile medical interventions. There is a need to improve health professionals’ ability to have open, direct—yet sensitive—conversations with people with disability about their care preferences.

Another barrier was the **lack of recognition that a person may benefit from palliative care**, leading to late or non-referral to services. This relates to the concept of overshadowing (described earlier) and the fact that prognostication can be very

difficult, particularly for those with complex disability/comorbidity. In addition, there is a general lack of awareness that palliative care may be indicated for long-term degenerative conditions, such as dementia. This points to a broader issue around knowledge and understanding of palliative care among many health professionals outside of specialist palliative care services.

The project also identified that some palliative care providers **lack the confidence** to deliver palliative care in community living services (e.g. group homes or supported accommodation) because they are unfamiliar with the setting and processes.

Disability support workers

Much of the research into palliative care barriers for people with disabilities has focused on people with ID in community living services, which are the main supported accommodation option for people with ID who are unable to live independently and are no longer able to live at home with their parents. In this context, disability support staff are seen as critically important in influencing which services and supports people may have access to (even in the presence of supportive organisational culture).

*‘The [client’s] experience is often dictated by those supporting them’
—Disability service provider*

Similar to health professionals, many disability support workers are **‘terrified of having the conversation’** about death and dying with a person with disability, again due to a lack of skills and confidence, and concern about causing distress. This lack of willingness to engage in conversations around death, dying, grief and loss restricts opportunities for people with disability to

explore the topic. It was also noted that the meaning and intent of a health professional’s message may get changed as it is passed on from one person to another, and overlaid with the values of each person.

Many disability support workers are **not skilled or supported to provide palliative care**. The current certificate courses in the disability industry do not include compulsory learning on death and dying. Workers may not understand technical health language, have different work practices, or not consider that supporting palliative care is part of the disability service’s role.

‘The perception is that “We do the life part; and you [health services] do the death part”’ —Disability service provider

In addition, it was noted that since the introduction of the NDIS, the disability workforce is becoming increasingly casualised, and that **lack of continuity** may impact workers’ ability to provide the required practical and emotional support. Burnout and grief for disability support workers following the death of a client were noted as under-recognised issues.

Services or organisations

Service-level barriers centred on services providing residential care to people with disabilities—with most relating to providing support in **community living services**. Challenges to providing palliative care in this setting are outlined below.

Structural/policy concerns include:

- Uncertainty around the intersection/overlap between the health system and the NDIS, and what is funded by each system.
- Confusion about **legalities**, such as who can provide **consent** for treatment and advance care directives (ACDs).
- Inconsistent or incomplete **transfer of information** between disability support workers and health professionals (e.g. changes to weight, behaviour, etc). Specialist palliative care teams may find that they don't have a consistent 'key worker' to speak with when they attend community living services.
- Need for **additional support overnight**—both on-site nursing support and secondary consultations with palliative care staff.

Cultural or practice-related issues include:

- Due to a lack of open communication about death and dying, residents may be **confused and uncertain** about death. This lack of death literacy can make it very difficult to discuss end-of-life planning.
- Lack of trained staff on-site to administer certain classes of **medications** outside business hours.
- Disability service staff may feel isolated from medical services.
- Support workers are not typically trained in palliative care and may **not understand their role** in supporting clients with life-limiting illness.
- Referrals to specialist palliative care services may be made late (or not at all).
- Lack of **overall care coordination** role for residents in some instances.
- In some instances, **General practitioner (GP) support** in community living services may be inadequate.

- Staff, residents and families may not understand that all deaths in community living services are **reportable deaths** and the Coroner is required to investigate. This process can be lengthy, and includes having the police attend, secure the 'crime scene' and remove the body. This can cause distress for staff, residents and families, who may believe that coronial involvement indicates inadequate care.

Due to these challenges, there may be a tendency to:

'shunt people to hospital to avoid them dying in group homes, which is contrary to good clinical practice for people with disability' –Disability services academic.

As noted above, support for older people with disability is often provided through the aged care system. Issues related to the delivery of palliative care in aged care settings are noted in the *Summary Policy Paper*.

Healthcare/other systems

Stakeholders highlighted the need for much improved collaboration between the health system, the NDIS and the aged care system in providing quality, seamless palliative care for people with disability. The interactions between the service systems were described as 'siloes' and 'fragmented'. Issues include:

- The NDIS represents a cultural shift from an 'institutional or patronising' way of working to a consumer-directed approach. The system is not yet mature, and *'clients, carers, and service providers are on the back foot trying to understand the system'* –disability service provider.

- While the NDIS does provide some funding for Information, Linkages and Capacity building (ILC) in addition to direct care work, this is reportedly not enough to enable service providers to participate in collaborative or systems improvement activities.
- The NDIS is not sufficiently responsive to changing health needs—if a person secures an NDIS package when they are well and then their support needs change, the system does not respond quickly enough (often taking many months). Disability service providers reported cases of people with disabilities dying before their NDIS package could be reviewed. In addition:
 - Care plans were described as ‘rigid and task-based’
 - The paperwork involved in accessing equipment such as pressure mattresses is time-consuming
 - Disability services (and in some cases, community nursing services) take on the risk involved in providing additional support to clients who are waiting for approval for these increased supports—it is not guaranteed that the NDIS will approve the changes to the package and provide reimbursement for services already delivered. This is reportedly placing financial strain on services.

*‘There is no opportunity for prevention in the context of long administrative waits. There is a compounding psychosocial and physical burden on clients as a consequence of these waits’
—Health care provider*

Service providers reported uncertainty about whether NDIS funds can be used for nursing care and expressed fear of being prosecuted for fraud.

‘There are ongoing misunderstandings of who provides what’ —Disability service provider

Aside from issues relating to the NDIS, stakeholders noted a **lack of disability and palliative care services in rural and regional areas**.

Finally, a lack of **quality data** in relation to palliative care usage by people with disability was seen as a barrier to developing effective solutions.

Transitions to acute care for people with cognitive or intellectual impairment

Many people who are receiving palliative care will require acute hospital admissions during their disease trajectory. For people with cognitive or intellectual impairment, hospital can be a frightening and confusing setting. Many will need the help of a disability support worker who knows their needs, can help them communicate, and provide reassurance at a distressing time. This level of support does not relate to any specific medical intervention but rather allows for continuity of care, and—fundamentally—meets the need for familiar people in an unfamiliar environment.

However, the NDIS restricts funding for support workers while clients are inpatients in acute care services, on the basis that this is the responsibility of the healthcare service. Meanwhile, the healthcare services consider that providing support workers is the responsibility of the disability sector.

As a consequence, disability service providers are forced to bear the costs of providing this support, or else break with their principles and commitment to ensuring their clients' needs are met. This creates an unsustainable financial situation for providers and increases the risk of burnout for support workers.

'The NDIS has the view that death is a medical event, and does not consider the social dimensions of dying'
—Disability service provider

Enablers and promising approaches

Consumer-side enablers

Individual

The most prominent and consistent feedback arising from this project relates to a need for **clear, open and honest communication** about death and dying, and recognising the right of all people to be involved in decisions about their end-of-life care. Avoiding the topic of death and dying adds to feelings of confusion, isolation and fear. Suggestions for improving communication with people with intellectual or cognitive impairment (but which are also relevant more broadly) include:

- Use **clear, simple language** that avoids abstract concepts, euphemisms or indirect language (e.g. 'gone to sleep' or 'gone away').
- Explain the purpose of—and support people through—**rituals such as funerals**, which can be confronting and confusing.
- Provide plenty of time to **listen to and support** the person, and encourage them to ask questions.
- Ensure that death, dying, grief and loss are **accessible topics** that can be discussed openly and often.
- Use **communication aids** where needed.

'**Assisted capacity**' has been proposed as a method for ensuring that patients' wishes are effectively communicated in order to receive the palliative care they desire. Assisted capacity helps individuals who may be unable to make decisions about end-of-life care independently, to be able to participate in decision-making with the assistance and support of others, including

family, friends, health advocates and care providers.¹³

Other enablers include:

- **Disability advocates**, who can help people with disability to speak up about their concerns, wishes and needs, and assist them to navigate the system
- Availability of information about palliative care
- **Continuity of care** from people known to and trusted by the patient.

Family

As noted previously, the presence of an engaged, capable family that can advocate for their loved one is an important enabler of quality palliative care. However, the caring role can be stressful and challenging. Suggested **supports for family members** include:

- Providing adequate support to care for loved ones at home (including supporting co-residents in community living services)
- Providing respite care
- **Making room** for family in palliative care facilities, so they can stay with their loved ones
- Ensure thorough and regular communication and engagement
- **Support for family members following loss.** Grief may relate not just to the death of the loved one, but 'secondary loss' which may include loss of role as a caregiver, loss of identity and loss of self-confidence.

Service-side enablers

Health professionals

Enablers for health professionals (including GPs, nursing and allied health staff) include:

- Training and capacity-building in:
 - Identifying when people should be referred to palliative care
 - Understanding the needs of people with disability, including being aware of the possibility of trauma
 - Supporting people with disability to have conversations about end-of-life
 - Person-centred care: *‘Training for health workers on how to be more human. More humane.’* —person with disability
- Improved **availability of specialist palliative care** staff (including for consultations out-of-hours)
- Access to out-of-hours **community nursing** for administration of medications that are outside disability support workers’ scope of practice
- Designation of a health professional as the point of contact for care planning. This person’s role would include ensuring quality of care, continuity of people and environment, an individualised focus, and communication with all stakeholders.

Disability support workers

Workforce development is a key enabler for disability support workers, and should include:

- Building capability and confidence in talking about dying and death
- Increasing understanding of palliative care, including its aims, approach and who may be involved

- Identifying their role in providing palliative care, including recognising that many aspects of palliative care do not require specialist medical input
- For those working in community living settings, developing an understanding of the processes involved in supporting someone to die at home (e.g. that coronial involvement will be required). Familiarity with the experience of supporting people to die at home was noted to overcome many concerns.

Bereavement support for disability support workers is also important.

Services or organisations

It is recognised that there is a strong relationship between organisational structure (e.g. policies, protocols and practices) and culture. Consistent with a public health approach to palliative care, which considers ‘upstream’ and ‘downstream’ solutions (described in more detail in the *Summary Policy Paper*), efforts to improve the practices of individual workers must be cognisant of the broader system in which they operate.¹⁰

Supporting ageing and dying in place requires **organisational commitment** (by health, aged care and disability services) and a willingness to look for solutions. While individual staff sometimes act as unofficial ‘champions’ for supporting people to die in their place of choice, this may not lead to overall improvements to equity of access to palliative care unless the organisations within which they work articulate their support in policies and procedures.

As discussed above, **understanding** of coronial involvement following death in community living settings can reduce or remove this barrier—*‘if the service has*

processes and systems in place and understands what needs to happen. Issues arise when services are unprepared’ – Disability service provider.

Collaboration between services can enable quality palliative care. Networks and partnerships between disability services, palliative care services, other health services, peak organisations and advocacy groups are critical.

Programs and services that monitor the health needs of people with disability have been suggested as a useful way of identifying palliative care needs earlier.

Supports should be individualised, inclusive, flexible, and responsive, and be delivered by people who know the person well in order to achieve optimal treatment planning, pain management and quality of life and death experiences that are based on each person’s choices¹⁴

Talking end-of-life...with people with intellectual disability

The [Talking End-of-Life... with people with intellectual disabilityⁱ](https://www.caresearch.com.au/TEL/) toolkit was developed through a partnership between the University of Sydney, Western Sydney University, HammondCare, Flinders University and CareSearch, with funding from the Australian Government Department of Health.¹⁵ The toolkit aims to build the knowledge, skills and confidence of disability support workers to have conversations with people with ID. The goal is to help people with ID to learn about end of life and plan for it if they choose.

There are 12 modules designed around a suite of three topics:

1. How do I do this?: Five modules to help disability support workers understand their role, how to teach about end-of-life, and how to manage cultural beliefs or feelings
2. Teaching how to understand end-of-life: Three modules to teach others about dying, death, loss, grief and mourning
3. Teaching the planning options: Four modules about how to teach people about planning for end-of-life—covering areas such as organ and tissue donation, care when dying, funeral wishes and bequeathing.

ⁱ <https://www.caresearch.com.au/TEL/>

Advance care planning

The process of advance care planning involves conversations about future healthcare preferences between a competent person, healthcare providers and potential substitute decision-makers. The outcomes of the process can include the development of statutory or non-statutory advance care directives (ACDs), or other, less formal documentation of a person's preferences and substitute decision-maker.¹⁶

There is potential for people with disability to benefit greatly from having an ACD in place, given that health professionals may make assumptions that may not be in line with the person's preferences. Despite this, advance care planning among people with disability is low. Barriers to advance care planning include:

- Communication difficulties (as described in *Barriers* in section 4)
'I'm not good at communicating so I haven't spoken about my wishes'
—Person with disability
- Assumptions about competence may mean that health professionals, support workers and family do not attempt to engage people with disabilities in discussions about advance care planning or their preferences for their own management.

- A lack of understanding among health professionals, consumers and family members, and feeling intimidated by the amount of paperwork and the legal elements.
- The absence of a suitable substitute decision-maker.
- Lack of resources to support the process.
- Inadequate support to develop the plan (such as lack of a consistent GP or insufficient time in consultations).
- A view that *'my family will know what to do'* —Person with disability.

For people with disabilities interviewed for this project, knowledge of advance care planning varied, and appears to be influenced by educational status and cognitive ability. Among those who were aware of it, advance care planning was seen as offering comfort and reassurance to the individual and family members:

'Yes, I've made an advance care directive. I wanted a legal document as I didn't want to be resuscitated and end up as a vegetable for 13 years like my mother. My family and friends weren't very willing to discuss end-of-life though. People don't like the word "death"' —Person with disability

'It took a huge burden from my shoulders, because I knew what he wanted [having had previous discussions before he lost cognitive capacity]. He got pneumonia and I had the option of sending him to hospital, but I know that was against his advance care plan. You only get one chance to walk this journey with someone—you only have one chance to give them the best end-of-life experience that they can have' —Carer of a person with disability

Suggestions for improving advance care planning include:

- Advance care planning should be implemented early—such as at the point of diagnosis or at the point of entry into residential care. It was suggested that this should be a funding requirement for aged care facilities.
- People should be supported to plan for end-of-life while they still have capacity, and family members should be involved early on.
- Advance care planning can be promoted as 'helping your family by telling them your preferences'.

The need to address advance care planning from a systems perspective was also noted, given that ACDs may not always be followed.

Tasmanian Disability, End-of-Life and Bereavement Care Community of Practice

[Li-Ve Tasmania](https://livetasmania.org/)ⁱⁱ is a leader in the Tasmanian disability sector, with a long and successful history of supporting people with disabilities who have complex care and support needs across a broad age range. Over recent years, Li-Ve Tasmania has supported a number of people with life-limiting illness to remain in their own homes until death, with the support of the palliative care sector.

Recognising the need for collaboration between disability and other services, Li-Ve Tasmania established the Tasmanian Disability, End-of-Life and Bereavement Care Community of Practice (CoP). The purpose of the group is to:

- Provide a forum for collaborative working, learning and reflection around the issue of palliative care for people with disability in Tasmania
- Provide a vehicle for knowledge exchange and brokering research evidence for practice
- Foster innovation and cultivate best practice.

The CoP aims to represent the various service models in place to support people with disability in Tasmania (residential, social/recreational, employment, skill development, advocacy, etc). Membership is not limited to disability or health

professionals but also includes volunteers and people who are ‘experts by experience’.

The group was established in May 2018 and has 18 organisations represented in its membership. One of the benefits of the CoP is the opportunity to share practice-based wisdom across services and sectors within the local communities. This is resulting in an enhanced capacity within the Tasmanian health and disability community to share ideas, understand and embed quality enhancements to end-of-life and bereavement care for people with disability.

While there are high levels of motivation and goodwill among the group, Li-Ve Tasmania has reported that the rollout of the NDIS has constrained the capacity of many organisations to attend.

As an extension of this work, Li-Ve Tasmania (in partnership with University of Tasmania and La Trobe University) have developed an exciting new approach to improving experiences and outcomes for people with disability at end-of-life. This includes a comprehensive holistic model for organisations with tailor-designed support, resources and education for the disability workforce.

ⁱⁱ <https://livetasmania.org/>

4 | Recommendations

The *Summary Policy Paper* identifies facilitators of appropriate care in seven domains, underpinned by four key enablers (see p.2).

These domains and enablers are broadly consistent with the *National Palliative Care Strategy 2018* and other relevant policy documents. Recommendations arising from the project—including recommendations specific to people with disabilities—are framed in this context.

The recommendations reflect a public health approach to palliative care (see *Summary Policy Paper* for details), which involves multiple sectors—from individuals and families to specialist palliative care service providers and broadly-focused, ‘non-traditional’ partners and collaborators.

These recommendations are designed to bolster the capacity of all relevant sectors to promote access to appropriate, quality palliative care for people with disabilities who have life-limiting illness. In particular, the idea of **person-centred care shines through as the ultimate goal** of all palliative care service provision. Person-centred care is respectful of, and responsive to, the preferences, needs and values of individuals. As a concept, it incorporates respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of family and carers and access to care.¹⁷ See the *Summary Policy Paper* for more detail.

It is important to acknowledge that identifying and providing the elements necessary to deliver person-centred care for people from under-served populations,

including people with disabilities, is likely to be particularly challenging and resource-intensive.

Person-centred care shines through as the ultimate goal of all palliative care service provision.

It is also important to recognise that implementing the recommendations in this report may require service providers and other organisations to make significant changes to organisational policies and procedures, structures and systems.

It is therefore vital that the underpinning enablers identified through this project—particularly workforce development and financial support and resourcing—are firmly in place. Without this support, efforts to improve access to quality, appropriate palliative care for people with disabilities and other under-served population groups are unlikely to succeed.

Palliative care providers may also need assistance from those with a greater understanding of the needs of people with disabilities to co-design services and optimise person-centred care. Linkages between the palliative care sector and relevant community and support organisations—i.e. those with existing relationships and experience meeting the needs of this population group—are likely to be of particular importance (see *Summary Policy Paper* for further discussion).

Addressing facilitators of appropriate palliative care for people with disabilities

Increase community comfort with discussing death and dying

- Improve the comfort of all of society in discussing issues relevant to death and dying—including individuals, communities, health and social care providers.
- Assist health and social care providers to improve their skill and confidence in talking about these issues with people with disability. The [Talking end-of-Life... with people with intellectual disability](#) resources are particularly useful for conversations with people with ID.

Promote community awareness and understanding of palliative care

- Upskill health and social care providers and other relevant support people to identify when palliative care may be needed, engage in discussions with individuals and families and initiate or refer for care as appropriate.
- Consider introducing standard palliative care-related practices and/or referral processes for all at time of diagnosis with a life-limiting illness.

Facilitate timely initiation of palliative care

- Improve community understanding of palliative care through broad social marketing strategies as well as specific efforts focusing on people with disabilities (e.g. education sessions organised through existing support groups, engaging community leaders as champions).

Foster a greater understanding of people with disabilities

- Ensure all health and social care providers are aware of and responsive to the complexity of issues that may be faced by people with disabilities.

Improve communication and information provision

- Support effective provider–patient communication and the provision of appropriate information. Tailor resources to particular groups when required, and consider:
 - Information using appropriate language in different languages and formats, reflecting that people with disabilities may have a range of challenges including sensory loss, aphasia, cognitive loss or non-English language
 - Specific information about palliative care options and entitlements (including supports available through the NDIS or aged care system).
- Provide one-on-one support to individuals/families to navigate the relevant system(s).

Enhance provision of person-centred care

- Bolster communities' capacity to deliver palliative care that is flexible, individualised and delivered in setting(s) of choice where possible.
- Ensure appropriate setting design, including accessibility.
- Consider and respect the role of families (as defined by individuals) and communities in decision-making and person-centred care, and ensure carers are adequately supported.
- Embed cultural competency in relevant services (i.e. palliative care, primary care, aged care etc).
- Engage with people with disabilities to co-design services.
- Ensure organisational policies and culture are inclusive and support person-centred care.

Better support advance care planning

- Build on current approaches to enhance advance care planning among people with disability—particularly in specific settings such as primary care, aged care, and community living services as well as palliative care.
- Continue to explore opportunities for promoting consistency and mutual recognition of advance care planning documentation across Australian jurisdictions.

Addressing underpinning enablers

Networks, partnerships and collaborations

- Build the capacity of support organisations to undertake a linking role with palliative care services, e.g. to:
 - Assist individuals to navigate services—including health care, palliative care, disability, aged care and other services
 - Serve as a resource for palliative care services to understand the needs of people with disabilities
 - Assist with broader awareness-raising in relation to palliative care and advance care planning within the communities they serve.
- Build linkages and reciprocal collaborations between all relevant sectors to develop best-practice approaches to palliative care service delivery for people with disabilities. These may include palliative care, other health services, disability support services and community organisations, among others.

Workforce development

- Consider training and ongoing professional development initiatives that increase or improve health and social care providers':
 - Understanding of the diverse needs of people with disabilities
 - Understanding of and ability to provide or support person-centred palliative care
 - Knowledge of and skill with applying trauma-informed approaches
 - Comfort with and capacity to assist individuals with advance care planning.
- Adopt strategies to improve the diversity of the workforce, including employing people with disabilities and carers.

Financial support and resourcing

Noting that all recommendations in this document require appropriate levels of resourcing, more specific funding recommendations include:

- Ensure palliative care funding models are flexible to allow delivery of person-centred palliative care—recognising that meeting the needs of people with disabilities may be intensive in terms of both time and resources.
- Improve the alignment of the relevant funding systems (including NDIS, aged care, and primary and other healthcare) to support seamless transitions and to respond in a timely manner to changing needs.
- Fund community-based/population-specific approaches to palliative care, including establishment and maintenance of collaborative arrangements.

Research, evaluation and monitoring

- Consider appropriate research, evaluation and monitoring activities at all levels to improve understanding of the needs people with disabilities and evaluate efforts to improve access.

Abbreviations

Abbreviation	Definition
ACD	Advance care directive
AHA	Australian Healthcare Associates
CALD	Culturally and linguistically diverse
CoP	Community of Practice
GP	General practitioner
ID	Intellectual disability
ILC	Information, Linkages and Capacity building
NDIS	National Disability Insurance Scheme
the Department	Australian Government Department of Health

Glossary

Advance care directive (ACD):

An advance care directive is a type of written advance care plan recognised by common law or specific legislation. An ACD can only be completed and signed by a competent adult. It may record the person's values and preferences for future care, and/or include the appointment of a substitute decision-maker to make decisions about health care and personal life management. Forms and requirements vary between states and territories.¹⁸

Advance care planning:

The process of planning for future health and personal care needs. It provides a way for a person to make their values and preferences known in order to guide decision-making at a future time when they cannot make or communicate their decisions.¹⁹

Care leavers: Includes Forgotten Australians, Former Child Migrants and Stolen Generations.

Carers: People who provide personal care, support and assistance to people with a disability, medical condition, mental illness, or frailty due to age. Carers may include family members, friends, relatives, siblings or neighbours. The term 'carer' does not include people who provide care for payment (such as a care or support worker), as a volunteer for an organisation, or as part of the requirements of a course of education or training.²⁰

End-of-life care: Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and other staff. It includes the support of family and carers, and care of the

person's body after death. People are 'approaching the end-of-life' when they are likely to die within the next 12 months.²¹

Family: Includes people identified by the person as family and may include people who are biologically related and people who joined the family through marriage or other relationships, as well as family of choice and friends.¹

Life-limiting illness: Describes illnesses where it is expected that death will be a direct consequence of the specified illness. The term incorporates the concept that people are actively living with such illnesses, not simply dying.¹

Palliative care providers: Health and social care providers involved in the clinical management and coordination of care for people living with a life-limiting illness. Palliative care providers may include GPs, geriatricians, oncologists, physicians, paediatricians, renal specialists, cardiologists and other specialists. Other team members will include nurses, allied health professionals and pharmacists.¹

Person-centred care: Care that is 'respectful of, and responsive to, the preferences, needs and values of patients and consumers'.¹⁷

Specialist palliative care

services: Multidisciplinary teams with specialised skills, competencies, experience and training in palliative care. Care provided through these services is targeted at people with more complex needs, and is referred to as 'specialist palliative care'.¹

Substitute decision-maker: A

person appointed or identified by law to make decisions on behalf of a person whose decision-making capacity is impaired. A substitute decision-maker can be:

- Someone chosen (and appointed) by the person. Depending on the state or territory, they may be called an enduring guardian, a medical enduring power of attorney, an agent or a decision-maker.
- Someone assigned as a decision-maker for the person by law, in the absence of an appointed substitute decision-maker. The hierarchy for appointing a substitute decision-maker varies by jurisdiction. They may be a spouse or de facto spouse, carer, relative or friend.
- A substitute decision-maker appointed for the person (e.g. a guardian appointed by a guardianship tribunal).¹⁸

Trauma-informed care: 'An

organisational structure and treatment framework that involves understanding, recognising and responding to the effects of all types of trauma'.²²

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