



# ROYAL COMMISSION INTO VIOLENCE, ABUSE, NEGLECT AND EXPLOITATION OF PEOPLE WITH DISABILITY

*Submission from Palliative Care Australia*

DECEMBER 2022



**PalliativeCare**  
AUSTRALIA



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# **Palliative Care Australia Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability**

## **Accessible Summary**

This document is about people with disability getting palliative care. Palliative care is care for people who have an illness that they will die from. We want to find ways to make palliative care better for people with different types of disability. We want palliative care to be person-centred and high quality. Person-centred care is care that puts the person first. It is care that is based on:

- what people need
- how people want to be cared for.

High-quality care means very good care. It means getting very good palliative care.

We want to make sure people get good palliative care when they need it. This could be ways of making sure good palliative care is given to people who:

- Are living in different place including big cities and small towns
- Have different illnesses
- Are from different cultures
- Speak different languages.

We want to make sure people get good palliative care where they need it and that they can die where they choose to die. This may be in residential aged care, in a home in the community, health care facility like a hospital or a group home. Group homes are where people with disability live together and get support.

Ideas to understand where people want to be cared for are:

- Health workers should ask what the person with disability wants
- Health workers should ask families what they want.

Ideas to help people get good palliative care include:

- Make people feel comfortable
- Make people feel safe.

Everyone will die someday. It is a part of life. It can be hard to talk about death and dying. We want to find ways to help health workers to communicate to people with intellectual disabilities about death and dying. To communicate is how you understand and share your feelings or information. How to let people know about different types of palliative care that they can use. Ideas to help are:

- Give health workers more training about how to talk to people with disability
- Helping people with disability to express their feelings and wants
- Talk to a person with their family
- Making a plan for what will happen at the end of a person's life.

We want to help families and supporters of people with disabilities. Supporters can be friends or disability workers.

Ideas to help are to give families and supporters:

- Information about palliative care services
- Information about how to support a person who needs palliative care
- Support after a person they care for has died.

Integrated care is when different health, aged care and disability services work together to give very good palliative care. Ideas to help services work together are:

- For important information to be shared between people who give care
- Give training to health workers and disability workers about disability, in particular intellectual disability.<sup>1</sup>

## Summary

In this submission PCA advocates that all Australians, including people with a disability, have a human right to quality palliative care, when and where they need it. It is essential that people with a disability are supported to receive the best care they can and that their preferences are respected.

The submission outlines the various cultural and social barriers as well as the systems-level barriers that can prevent people with disabilities from accessing palliative care. Research highlights how people with disability want to engage in open discussions about death and dying and be empowered to voice their preferences. However care providers, including disability support workers, aged care workers, healthcare professionals and specialist palliative care staff do not consistently talk with people with intellectual disability about their dying and death. Understanding around consent for treatment and decision-making for people with disability can be improved by ensuring that clinicians have the required skills, or access to someone with the skills, to communicate appropriately.

PCA identifies gaps in research and data and makes recommendations regarding improvements to workforce, training and education, and systems and processes to support the palliative care needs of Australians with disabilities.

## About Palliative Care Australia

**Palliative Care Australia (PCA)** is the national peak body for palliative care. PCA represents those who work towards high quality palliative care for all Australians who need it.

### PCA Purpose

PCA leads a united voice to strengthen our collective impact towards excellence in palliative care.

### Vision

We see a world where quality palliative care is available for all, when and where it is needed.

## Acknowledgements

PCA includes membership of all eight State and Territory palliative care peak organisations and affiliate membership with the following professional bodies:

- The Australian and New Zealand Society of Palliative Medicine (ANZSPM)
- Palliative Care Nurses Australia (PCNA)
- Palliative Care Social Work Australia (PCSWA)

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<sup>1</sup> This is an accessible summary that provides a short and clear summary of key themes and recommendations.

- Paediatric Palliative Care Australia and New Zealand (PaPCANZ).

In this submission, PCA references input from these bodies together with input from health professionals and experts working in palliative care from the National Expert Advisory Panel (NEAP) as well as the National Register of Palliative Care Consumers and Carers. These stakeholders have navigated, observed and fiercely advocated for equal access to palliative care, at end of life, for people with disability.

Please note that the case studies shared in this submission are drawn from PCA's Member Organisation network. Names and some details have been changed; however the case studies are representative of real life experiences.

Palliative Care Australia appreciates the opportunity to contribute to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. PCA welcomes the opportunity to speak to the experiences of people with disability diagnosed with a life-limiting illness who need access to palliative care.

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## Definition of Palliative Care

PCA uses the definition of palliative care outlined in the *National Palliative Care Strategy 2018* (signed by the Australian Government and all State and Territory governments). It is based on a definition first outlined by the World Health Organization:

**Palliative care** is an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

The [\*National Palliative Care Strategy 2018\*](#) provides that palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness

- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and
- includes those investigations needed to better understand and manage distressing clinical complications.<sup>2</sup>

## Introduction

PCA welcomes the opportunity to make a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (the Commission). PCA notes the Royal Commission's Terms of Reference includes a human rights focus and inquiry into all forms of neglect of people with disability, in all settings and contexts.

Operating within a human rights framework of disability puts a focus on rights articulated in law, including those stated in the United Nations Convention on the Rights of Persons with Disabilities (CRPD), which Australia ratified in 2006.<sup>3</sup> The right to health is provided for in the CRPD and Article 25 recognises the right to the highest attainable standard of health, without discrimination on the basis of disability. Palliative care is established as a fundamental human right,<sup>4</sup> and depriving people with disability of access to palliative care is medical neglect.

While palliative care is needed and accessed by people of all ages, there is an emerging need for older people with disability dying from health conditions requiring palliative care and experiencing a prolonged period of declining health and palliative care. People with intellectual disabilities are living longer than perhaps any other time in history<sup>5</sup> as are people with enduring physical disabilities.<sup>6</sup> That being said, this submission focusses on people with disability of all ages – noting that quality and safety in aged care was the subject of a different Royal Commission.

People with disability should be able to receive palliative care in the setting of their choice, including their home, in specialist disability accommodation, residential aged care, a hospice or a hospital. Where practical they should have the choice to be in a familiar setting with family<sup>7</sup> and friends, as well as residents and/or staff that they know. They should also be engaged in end of life discussions and decisions. However, for many people with disability there are barriers to accessing palliative care.

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<sup>2</sup> Definition of Palliative Care in [The National Palliative Care Strategy 2018 | Australian Government Department of Health](#) Based on World Health Organization, 2017.

<sup>3</sup> United Nations. (2006). Convention on the Rights of Persons with Disabilities. Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

<sup>4</sup> Brennan F. (2007) [Palliative care as an International Human Right](#). Journal of Pain Symptom Management. 33: 494-499

<sup>5</sup> Foo B, Wiese M, Curryer B, Stancliffe RJ, Wilson NJ, Clayton JM. [Specialist palliative care staff's varying experiences of talking with people with intellectual disability about their dying and death: A thematic analysis of in-depth interviews](#). Palliative Medicine. 2021;35(4):738-749. doi:10.1177/0269216321998207

<sup>6</sup> Belperio I, Devery K, Morgan DD, Rawlings D, Raghavendra P, Walker R. [Health and disability care providers' experiences and perspectives on end-of-life care needs of individuals with long-standing physical disability: A qualitative interview study](#). Palliative Medicine. 2022;0(0). doi:10.1177/02692163221128702

<sup>7</sup> The term 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 chosen family and friends (including pets). Carers may include family members and other members of their community (such as close friends and neighbours) who the person agrees to being involved in their care.

In 2018, the Australian Government Department of Health commissioned an exploratory analysis of barriers to accessing quality palliative care for people with disabilities. The final [Issues Report](#) provides an overview of the main barriers to access, which are outlined below:

- Lack of integration and co-ordination between health, disability and aged care sectors
- Lack of awareness/understanding of palliative care
- Communication issues (care providers and people with disabilities)
- Service provider assumptions about competence of people with disabilities
- Inadequate support for carers, families and loved ones
- Diagnostic 'overshadowing' and diagnosis of palliative care needs
- Physical barriers (access, mobility, transport)
- In community living settings, lack of organisational support for dying in place of choice.<sup>8</sup>

The multiple barriers that people with disability experience at end of life is concerning. People with disability are often not able to receive the same level of care in their homes as others navigating their palliative journey. Research indicates that early access to palliative care enhances quality of life for patients and families.<sup>9</sup> People with disability deserve holistic and quality palliative care with good control of physical symptoms as well as psychosocial and spiritual support and excellent communication regarding goals of care and end of life planning.

Equity of access to palliative care is a complex issue and PCA acknowledges the multiple factors that influence outcomes for people with a disability. These include comorbidity with mental health and other illnesses. People living with mental illness are more likely to develop comorbid physical illness and tend to die earlier than the general population.<sup>10</sup> Access and experiences of palliative care must also be considered from an intersectional perspective with factors such as gender, sexuality, culture, faith, indigeneity and age for people with disability. A robust approach to intersectionality is needed to reflect that there is no one homogenous group of people with disability in Australia. Victoria in particular has made progress in this space with additional funding for end-of-life care programs to address care needs in its diverse communities. Use of bilingual and bicultural professional health workers in community health programs and access to interpreters has increased trust and confidence in many areas, particularly in Victoria, during COVID-19.

People in rural and remote areas have access to fewer specialist palliative care services and this is especially true for people with disability, who may require additional supports when accessing palliative care and for paediatric patients. There are significant issues of isolation across both rural and

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<sup>8</sup> Australian Government Department of Health (September 2019). *Exploratory Analysis of Barriers to Palliative Care: Issues Report on People with Disabilities*. Retrieved from: <https://www.health.gov.au/resources/publications/exploratory-analysis-of-barriers-to-palliative-care-issues-report-on-people-with-disabilities>

<sup>9</sup> Hui, D., & Bruera, E. (2016). [Integrating palliative care into the trajectory of cancer care](#). *Nature reviews Clinical oncology*, 13(3), 159-171.

<sup>10</sup> Australian Institute of Health and Welfare (AIHW), (2022) [Mental health services in Australia: Physical health of people with mental illness - Australian Institute of Health and Welfare \(aihw.gov.au\)](#), AIHW, Australian Government, accessed 12 December 2022.

metropolitan locations that result in an inability to consistently access mainstream health services and gain the necessary resources to assist with care provision.<sup>11</sup>

## 1. The National Palliative Care Standards

The PCA [National Palliative Care Standards](#)<sup>12</sup> and [National Palliative Care Standards for All Health Professionals and Aged Care Services](#)<sup>13</sup> (collectively, the *PCA Standards*) have been developed with the aim of supporting better experiences and outcomes for people receiving palliative care.

The PCA Standards are generally normative standards but also incorporate aspirational components to support providers and services seeking to enhance capability and achieve best practice. PCA encourages consideration of the PCA Standards in all aspects of healthcare and disability support.

## 2. Integration and Co-ordination between the Disability, Health and Aged Care Sectors

The delivery of better palliative care for people with disabilities goes across three spheres: disability services, aged care, and healthcare. However, there is a lack of coordination across these systems. People with a disability and carers struggle to navigate each system and often need to advocate strongly for needs to be met. It is the responsibility of the health system to ensure all people get access to palliative care when and where it is needed and to ensure a seamless transition to palliative care services. Nevertheless, poor communication and sharing of information between treating and support services results in fragmented care. Well-prepared and collaborative disability and health service workforces are needed, together with flexible and adequate end-of-life funding to ensure compassionate and person-centred care.<sup>14</sup>

### National Disability Insurance Scheme

One of the largest system barriers for people accessing palliative care stem from the current structure and operation of the NDIS. These factors are outlined below.

- The NDIS has an emphasis on exercising choice and control but does not always ensure that people with disability have the necessary skills or knowledge to be able to do so.
- Limited funding for Information, Linkages and Capacity building (ILC), meaning that service providers are not supported to participate in collaborative or systems improvement activities.
- The NDIS is not sufficiently responsive to rapidly changing health needs and people with

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<sup>11</sup> Wark, S, Hussain, R, Müller, A, Ryan, P, Parmenter, T. [Challenges in providing end-of-life care for people with intellectual disability: Health services access](#). Journal of Applied Research in Intellectual Disabilities. 2017; 30: 1151– 1159. <https://doi.org/10.1111/jar.12408>

<sup>12</sup> <https://palliativecare.org.au/publication/standards>.

<sup>13</sup> <https://palliativecare.org.au/publication/national-palliative-care-standards-for-all-health-professionals-and-aged-care-services>.

<sup>14</sup> McNamara, B., Same, A., & Rosenwax, L. (2020). [Creating person-centred support for people with intellectual disabilities at the end of life: An Australian qualitative study of unmet needs and strategies](#). Journal of intellectual disabilities : JOID, 24(4), 543–558. <https://doi.org/10.1177/1744629518823887>



disabilities whose health is rapidly declining may die before their NDIS package is reviewed or changes in support can be arranged. This is not just a health system challenge; the NDIS also needs to adopt systems that allow for timely responses in such circumstances.

- Disability and community nursing services take on the financial risk of providing additional supports to clients with no guarantee that the NDIS will approve package changes or provide reimbursement.
- The process for accessing equipment is bureaucratic and time-consuming.
- Lack of clarity on claimable items on NDIS. Some service providers can be unsure of what they can claim and are afraid of being prosecuted for fraud.
- There is no funding to support people with disability transitioning between the disability system and acute care hospital admissions. For example, the NDIS does not fund a support worker to accompany the person to hospital and/or support them during their stay. This is a significant issue with hospitals at times being used as respite options for people with disabilities without adequate support being provided within the hospital setting to consistently meet the complex social, emotional, and physical needs of these people.
- Palliative care social workers are frequently called on to assist individuals and families with NDIS applications and navigating this system. This requires a significant time commitment for the social worker to complete administrative tasks, while their time and specialist skills would be better invested in assisting the person to engage in advance care planning discussions and decision-making, supporting families to communicate with the individual, and supporting the person to engage in activities that can optimise their quality of life and help them prepare for the end of life.

## **Residential Aged Care Facilities**

Equitable access to palliative care for people with a disability living in residential aged care facilities (RACFs) is particularly relevant when considering two key statistics. First, 96.1% of older people living in cared-accommodation (which includes hospitals, nursing homes, aged care hostels and other such settings) have a disability.<sup>15</sup> Second, in 2020–21, among people entering permanent residential aged care who were assessed as requiring palliative care under the former Aged Care Funding Instrument, approximately one-third lived in a residential aged care facility for a year or more, and approximately one-fifth for more than 2 years. The primary reason for exiting residential aged care was death.<sup>16</sup> These statistics highlight how the vast majority of older people in residential aged care have a disability and are close to the end of life and therefore are very likely to have palliative care needs.

PCA has received feedback on an emerging issue surrounding the unintended impact of NDIS practice standards on RACFs. RACFs which provide support to NDIS participants are now required to be

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<sup>15</sup> Australian Bureau of Statistics. (2018). *Disability, Ageing and Carers, Australia: Summary of Findings*. ABS. <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>.

<sup>16</sup> AIHW data: Palliative care services Glossary - Australian Institute of Health and Welfare (aihw.gov.au): 1 in 2 exited permanent residential aged care within 8 weeks of admission; 32% within 4 weeks; 50% within 8 weeks; 69% within one year, and 21% after 2 years. For those appraised as requiring other care, 2 in 3 exited after 1 year – 32% within 1–3 years and 34% after 3 years, while less than 9% exited within 8 weeks.

registered with the NDIS Quality and Safeguards Commission. This involves an application and self-assessment against the NDIS practice standards with an independent certification audit in addition to ongoing obligations in standards monitored every 18 months to 3 years. These conditions are listed under [section 73F of the National Disability Insurance Scheme Act 2013](#). While the accreditation process was intended as a safeguard to ensure the safety of people with disability, the result is that some RACFs are deciding against registering with the NDIS Commission due to the additional administrative burden and financial pressures of meeting the legislative requirements. Consequently, many NDIS participants who were receiving care in RACFs have been forced to choose to relocate to other RACFs that are registered providers, transition to a NDIS package in the community (which is not suitable for everyone) or relinquish their NDIS package to stay in the RACF that they call home. This consequently has impacted older people with disabilities accessing RACFs, and with limited RACFs engaging in NDIS accreditation there will be barriers to accessing services including palliative care.

### **CASE STUDY**

*An older person with an intellectual disability, including deafness and the inability to speak, had been living in the same RACF for over 10 years. The person also experienced loneliness and isolation as a result of their conditions. The person received NDIS funding in the RACF. As the RACF did not meet the new requirements for NDIS funding, the person was relocated to another RACF.*

*The person and their care team had spent years developing a strong relationship built on trust, empathy and respect. This supported the establishment of the person's individualised advance care plan. The movement to a new RACF will require the re-establishment of these relationships, at significant detrimental impact on the individual.*

### **Healthcare System**

Key healthcare system barriers for people accessing palliative care are outlined below.

- A shortage of allied health staffing can result in significant delays in the allied health assessments required for a successful NDIS application. This is then compounded by delays once the application is submitted.
- During the transition from primary care to acute care there is a lack of palliative care support, and upon being discharged from acute care often people are unable to locate a palliative care service.
- Some people with a disability are funded through their NDIS plan to receive one-on-one 24-hour care. However, when requiring hospital admission, these staffing ratios can no longer be followed, leaving the person without constant support and therefore at risk of harm.
- Disability providers rely on the health system to provide care to people with disability in supported living environments, however if referrals are not accepted then the disability service has no option but to rely on community health nurses or family and friends for support.
- GPs play a crucial role in referral to palliative care services. Barriers in this process include the critical shortage of GPs in rural and regional Australia, long waiting times to see a GP and

potential diagnostic overshadowing for people with disabilities. This may result in hospital admissions for patients with a disability, when symptoms could otherwise have been managed in a community setting with support from GPs.

### 3. Lack of Awareness/Understanding of Palliative Care

There is a limited understanding of death, dying and the palliative care approach among people with disability and service providers. There is a common belief that palliative care is where you go to die, which can make people reluctant to access palliative care. Family members may be reluctant to talk about death and dying, which can negatively impact the person receiving palliative care. There may also be concerns from family members used to advocating for their loved ones that the introduction of palliative care means the system has 'given up'. There is no easy or single solution to improving community awareness of palliative care and death literacy; it will require public health campaigns and education and training for everyone involved: healthcare professionals including allied health, as well as disability support workers, aged care workers and palliative care volunteers.

A long history of negative experiences with the health system can create distrust and fear of health services, making people with disability reluctant to access care and services. Distrust, feelings of protectiveness and response to previous stigma can impact on the care received by those with disability.

### 4. Communication

Communication issues are a major factor for people with disability when accessing palliative care. Communication challenges affect full disclosure, decision-making, pain management and symptom identification.<sup>17</sup> People with disability may lack the skills or confidence to speak up about symptoms. Some people with disability may need more time to communicate (such as those using electronic communication devices) and the health system often does not make allowances for the time needed. If health professionals are not able to form a clear understanding of a patient's symptoms a diagnosis is difficult. The result may be under-treatment of pain and other symptoms or inappropriate medical interventions at the end of life for people who are not able to verbalise their feelings and needs.

Feedback provided to PCA suggests that many health professionals lack the skills or confidence to tell people with an intellectual disability they are dying and may leave this to someone else, such as a disability support worker or family member. Research highlights that even specialist palliative care staff do not consistently talk with people with intellectual disability about their dying and death.<sup>18</sup> Many disability support workers also lack the confidence and skills to have such conversations. Yet people with intellectual disability have a fundamental right to know about dying and death. Advanced skills are required to ensure that people with intellectual disability can meaningfully engage with end-of-life issues. An unwillingness to engage in conversations around death, dying, grief and loss restricts opportunities for people with disability to explore the topic in ways other people might. Australian

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<sup>17</sup> Velepucha-Iniguez, Josselyn et al. [Barriers to Palliative Care Access in Patients with Intellectual Disability: A Scoping Review](#). Journal of Pain and Symptom Management, Volume 64, Issue 6, e347 - e356

<sup>18</sup> Foo B, Wiese M, Curryer B, Stancliffe RJ, Wilson NJ, Clayton JM. [Specialist palliative care staff's varying experiences of talking with people with intellectual disability about their dying and death: A thematic analysis of in-depth interviews](#). Palliative Medicine. 2021;35(4):738-749. doi:10.1177/0269216321998207

research in 2021 provides evidence that people with an intellectual disability can participate in discussions about end of life and death without undue psychological distress and can self-manage opting out of the conversation and comfort themselves if they become distressed. With this in mind, open discussions about death and dying should not be avoided in order to reduce harm, as in fact anxiety can be reduced by allowing such conversations to occur.<sup>19</sup>

## 5. Service Provider Assumptions about Competence of People with Disabilities

Some health professionals may make assumptions about quality of life and assume that people with disability do not want to be resuscitated or undergo active treatment. The most common issue is that service providers and families often underestimate the decision-making capacity of people with disability, resulting in a lack of person-centred care and a loss of agency for the person. Carers also struggle to communicate effectively with health professionals about issues such as medication, which can lead to confusion and uncertainty. Providers need to have open, direct but sensitive conversations with people with disability about their care preferences. Family members may also make assumptions without checking with the person with disability. In some instances, 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. There may also be confusion around who can provide consent for treatment, participate in advance care planning, and write advance care directives.

## 6. Inadequate Support for Carers, Family and Loved ones

Carers, families and loved ones play a significant role in the support and care of people with a disability and as such need to be considered as partners in care. It is essential that disability service providers and all staff understand critical aspects of palliative care as relevant to their roles, especially those operating and working in group homes. Staff must be able to provide people with a disability who have a life-limiting illness with the care that they need and ensure they remain comfortable and with optimal pain relief in their final days. They should be able to support people with a disability and their carers to talk about death and dying and make decisions around the care they want to receive at end of life. The needs of people with intellectual disabilities are highly variable and can be unexpected, so listening to carers is important, while keeping in mind the preferences of the individual.<sup>20</sup>

Having carers, family members or loved ones who can navigate the health and disability systems and advocate for a person with disability is a key enabler in accessing palliative care. However, many lack adequate support and experience high rates of carer burden, leading to physical and emotional strain. Many carers are also elderly, ill and/or have a disability, adding to this burden. There is a lack of support to care for loved ones at home as they die, especially children, for example due to a lack of adequate aids and equipment.

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<sup>19</sup> Stancliffe, R.J., Wiese, M.Y., Read, S., Jeltres, G., Barton, R., & Clayton, J.M. (2021). Does talking about end of life with adults with intellectual disability cause emotional discomfort or psychological harm? *Journal of Applied Research in Intellectual Disabilities*, 34, 659-669. <https://doi.org/10.1111/jar.12835>

<sup>20</sup> Tuffrey-Wijne I, Curfs L, Deliens L. [\*Developing research, policy and practice in palliative care for people with intellectual disabilities will benefit everyone\*](#). *Palliative Medicine*. 2016;30(7):613-615. doi:10.1177/0269216316648610

## 7. Diagnosis of Palliative Care Needs

Diagnostic overshadowing is when a new health concern is incorrectly identified or ascribed to an existing condition. Further education and training are needed for medical practitioners to facilitate better understanding of the needs of people with disability, in particular intellectual disability, at end of life. Australian research in 2017 found that the support provided by doctors was critical to providing appropriate end-of-life care for people with an intellectual disability.<sup>21</sup> However, concerns were noted by the interviewed disability support workers around the failure to accurately distinguish between existing conditions and emerging health problems and to provide appropriate treatment for the new health condition.

The risk that health professionals may attribute the symptoms of a disease to a person's disability and fail to diagnose or treat it can delay the introduction of palliative care. Consequently diagnostic overshadowing is a contributing factor in the premature mortality and high rates of avoidable death among people with an intellectual disability.<sup>22</sup> Inclusion in health policy, service development and health promotion is required to address premature deaths and health inequalities for adults with intellectual disability<sup>23</sup>. Relevant data is not available in Australia due to the "lack of routine collection and reporting of health outcomes and mortality data for people with ID"<sup>24</sup> which is in contradiction to Australia's commitment under the United Nations Convention on the rights of persons with disabilities (UNCRPD).

Diagnosis of palliative care needs is made more complex by the presence of multiple health and comorbid conditions in people with disabilities. People with life-limiting illnesses often develop significant functional and cognitive limitations as a result of their condition requiring a disability support approach (such as in the case of motor neurone disease or amputations). For this reason, palliative care for people with disability should be delivered by multidisciplinary teams, but evidence suggests that in many instances this does not occur. There may also be a lack of recognition that a person may benefit from palliative care leading to a late referral or no referral at all to palliative care services.<sup>25</sup>

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<sup>21</sup> Wark, S, Hussain, R, Müller, A, Ryan, P, Parmenter, T. (2017) *Challenges in providing end-of-life care for people with intellectual disability: Health services access*. Journal of Applied Research in Intellectual Disabilities. 30: 1151–1159. <https://doi.org/10.1111/jar.12408>

<sup>22</sup> Trollor J, Srasuebkul P, Xu H, et al (2017) *Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data*. BMJ Open 2017;7:e013489. doi: 10.1136/bmjopen-2016-013489

<sup>23</sup> Trollor J, Srasuebkul P, Xu H, et al *Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data* BMJ Open 2017;7:e013489. doi: 10.1136/bmjopen-2016-013489

<sup>24</sup> Trollor J, Srasuebkul P, Xu H, et al *Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data* BMJ Open 2017;7:e013489. doi: 10.1136/bmjopen-2016-013489

<sup>25</sup> Velepucha-Iniguez, Josselyn et al. *Barriers to Palliative Care Access in Patients with Intellectual Disability: A Scoping Review*. Journal of Pain and Symptom Management, Volume 64, Issue 6, e347 - e356

## 8. Physical Barriers

People with disability face a range of physical barriers relating to access, mobility and transportation, including parking, when seeking health services. Individuals with long-standing physical disability are living longer and yet little is known about their specific needs and experiences at end of life.<sup>26</sup> Health and disability care providers play an important role in provision of end-of-life care for people with physical disabilities. However, little is known about their perspectives and experiences and how this might inform improvements to care provision. Further research and data are needed in this space to better understand how access to palliative care can be improved. Research from Belperio et al (2022) highlights “a lack of integration and problems at the intersection of the disability and health system which potentially impacts the experience of death and dying for people with long-standing physical disability.”<sup>27</sup>

The cost of parking at healthcare facilities is often prohibitive and creates a physical barrier for access for carers and families. There is an increasing need for more accessible parking spaces especially in and around acute healthcare facilities. The following case study highlights the impact of inaccessible healthcare carpark facilities for carers with a physical disability.

### CASE STUDY

*An 86-year-old person who uses a wheelchair had difficulty in finding accessible parking when visiting their 90-year-old partner who was dying in an acute care hospital. Invariably, the relatively few accessible parking spaces were full by the time the person arrived at the commencement of visiting hours. Consequently, the person had to rely on family and friends to either drive or accompany them to the hospital. When the person's partner was transferred to an Inpatient Palliative Care Unit within a sub-acute facility there were ample accessible parking spaces, all within a short distance of the hospital entrance. This meant that the person was able to visit and care for their dying partner. The couple were able to be together during this end-of-life journey. This supported advocating on behalf of the dying person to ensure their end-of-life preferences were enacted.*

## 9. Lack of Organisational Support for Dying in Place of Choice

People with a disability have the right to choose the place where they prefer to die. However, there are many barriers to people with disability dying in their place of choice, especially if that choice is their home. Research shows that there is personal significance in the place of death and that the experience

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<sup>26</sup> Belperio I, Devery K, Morgan DD, Rawlings D, Raghavendra P, Walker R. [Health and disability care providers' experiences and perspectives on end-of-life care needs of individuals with long-standing physical disability: A qualitative interview study](#). Palliative Medicine. 2022;0(0). doi:10.1177/02692163221128702

<sup>27</sup> Belperio I, Devery K, Morgan DD, Rawlings D, Raghavendra P, Walker R. [Health and disability care providers' experiences and perspectives on end-of-life care needs of individuals with long-standing physical disability: A qualitative interview study](#). Palliative Medicine. 2022;0(0). doi:10.1177/02692163221128702



of end-of-life care is impacted by the place in which dying occurs.<sup>28</sup> PCA believes that family, carers, loved ones and the primary health doctor are in the best position to support and advocate for those seeking to make choices around the place of death and the care they receive. To achieve this disability support workers who have established relationships and appropriate training should be supported to ensure that a person with palliative care needs has reasonable and necessary supports at a fair cost.

Some palliative care providers lack the confidence to deliver palliative care in community living services such as group homes or supported accommodation because they are unfamiliar with the setting and processes. There is also uncertainty around the intersection between the health system and the NDIS, and what is funded by each system. Disability services may struggle to maintain a suitably qualified workforce, access regular GP support and navigate the complexities of the NDIS. Due to these challenges, PCA is aware of circumstances where service providers send people with disability to hospital to avoid them dying in community living.

For people with disability living in supported accommodation, disability support staff are critical to influencing what services and supports they access. However, many disability support workers are not appropriately skilled or supported to provide palliative care. They may not understand their role as a carer in palliative care or even consider palliative care to be part of their role. There are no compulsory palliative care units in the current Certificate IV in Disability Support.

Further workforce issues include:

- Increasing casualisation and low wages of the disability workforce and resulting lack of continuity in staff.
- Lack of a consistent 'key support worker' for specialist palliative care teams to liaise with. Likewise specialist palliative care teams lack community-facing staff to identify and promote positive work relationships with disability services. Both sectors need to prioritise and fund collaborative work.
- Burnout and grief among disability support workers following the death of a person.
- Inconsistent or incomplete transfer of information between disability and health staff.
- Referrals to specialist palliative care services not being made in timely fashion, not made at all, or may accepted due to service inability to take new patients (due to staffing issues, patient demographics or lack of funding).

PCA envisages that a disability support worker with appropriate training and supports should be able to provide end-of-life care for a person with disability with whom they have an established relationship of care where that care is within the scope of their role. Often disability support workers are the only physical, social and/or emotional supports that people have. Removing people to a different place or service setting for their final days in contradiction of their preferences goes against the founding ethos of the NDIS to provide the reasonable and necessary supports for Australians with disability to lead ordinary lives.

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<sup>28</sup> Belperio I, Devery K, Morgan DD, Rawlings D, Raghavendra P, Walker R. [Health and disability care providers' experiences and perspectives on end-of-life care needs of individuals with long-standing physical disability: A qualitative interview study](#). Palliative Medicine. 2022;0(0). doi:10.1177/02692163221128702

### **CASE STUDY**

*A person had a life-limiting illness, as well as a number of other serious medical conditions, and also had an intellectual disability. The person frequently refused treatment, medication and personal care. The person also found changes in routine and environment very disturbing. After the identification of a serious chronic wound, in consultation with family, a palliative approach was adopted.*

*Unfortunately, the person was not able to be supported by the specialist palliative care service, and due to other staffing and governance issues, there was a complete gap in availability of services for the person. Disability support staff were extremely distressed by seeing the person in significant levels of pain. Fortunately, the person had a family member who was able to take leave to fill this gap and provide care, but the gap in formal care remained until the person's death.*

## **10. Primary Carers Accessing Palliative Care**

Primary carers of a person with a disability can be in receipt of palliative and end-of-life care without service providers being aware that care planning needs to be instigated around the person with the disability in anticipation of their carer dying. Identifying this need early to enable time for care planning that involves the carer and other significant parties is crucial to ongoing stable care, support and decision-making for the person with a disability. Feedback provided to PCA highlights the difficulties faced in situations where a carer is dying, and it is not recognised in time that the person with a disability's ongoing needs have not been addressed. Supports may need to be put in place for housing, finances, legal issues such as inheritance, care, counselling and bereavement care once their carer dies. Timely planning around this is crucial to delivering good outcomes and consistent care for the person with disability.

A PCA member organisation recently supported an autistic man whose grandfather, who he lived with, died suddenly in hospital and nobody was aware of his family situation or needs. In another scenario described to PCA, that organisation worked with an elderly woman in palliative care services who had many adult children, including a son with autism, where the siblings all had varying opinions around what was in the best interests of their brother with a disability.

People who care for a person with intellectual disability require support to help the person with a disability prepare for their loved one's death. Psychosocial and bereavement supports for people with disabilities who have lost a loved one/carer in palliative care are potentially not anticipated, are inadequate, or are not utilised.

PCA received the following feedback from the PCA National Register of Palliative Care Consumers and Carers:

- Carers know the people they care for best and have a long history of advocating with health services for support.
- Decision making at end of life is difficult and it is often hard for loving caregivers to be objective in decision making.



- If information is provided it must be age-appropriate or in a form understood by the person with the disability.
- There should always be someone who can provide objective compassionate advice.
- The timing of conversations about death and dying may be best known by the carers.
- Ethical/moral challenges often emerge, and it is important to consider what decisions people without legal decision-making capacity should be able to make in relation to care.
- Increased support needs to be available to carers at times of emotional distress, for example when news about serious illness is delivered by a healthcare professional.
- Training for all staff in the disability, aged care and healthcare sectors is needed in end-of-life care.
- The definition of 'carer' in disability support can be complex as there can be multiple carers in different contexts and these may differ from those legally tasked with decision-making responsibility.

## 11. Medication Regulations

Medical regulations are a barrier to accessing medications for pain and symptom management, such as breathlessness, for palliative care patients with a disability. Appropriate access to nursing support must be available to deliver clinical care, including the management, distribution and administration of palliative care medications. Palliative care patients may require access to opioid medications at all times of the day based on their pain and symptoms. Many of these medications require a Registered Nurse (RN) to be able to access the medications cabinet and administer these medications. It is critical that there is always a registered nurse on hand to provide this care when needed.

PCA is not aware of how regulations in different states affect access to medication in similar circumstances. However, for palliative patients in Tasmania who are supported by disability support workers, access to medication can be fraught with barriers. When a person with disability is incapable of managing their own medications, and they are dependent on a disability support worker, S8 medications cannot be utilised without the supports of an RN. The Tasmanian [Poisons Act \(1971\)](#) and [Poisons Regulations \(2018\)](#) make it clear that disability support workers are not legally allowed to administer S8 medications (with certain exclusions). This is a large impost on the services available as the funding in their NDIS plan often only allows for regular medication supports. During the last days to weeks of life there is an expected increase in the use of S8 medications as they are *pro re nata* (PRN, or as needed) and frequently used. PRN medication is specifically intended as an 'at a point in time' medication, however under the current legislation the people often providing care, disability support workers, cannot administer the medication at the point in time when it is needed.

Many disability providers do not employ RNs to provide clinical input and care. The alternative is a community nurse, noting that they are not available on call or on weekends and therefore cannot deliver as-needed medication. This is an impossible situation for a patient who wishes to die at home and does not have access to unpaid supports such as family who can stay with the patient and administer the necessary medications. This leaves people with a disability no choice but to die in a hospital or RACF as they have limited or no access to essential medication support in their own home.

In contrast, if these individuals were in an aged care facility, or were fortunate to have family involved, they would be supported by nurses or informal carers. With an ageing population and declining access to informal care, the consequence is people with disability being in pain and discomfort unnecessarily.

### CASE STUDY

*Li-Ve Tasmania have recently had a referral to a palliative care service refused, as it was deemed that the environment the person was living in, was the best environment for them to die. However, disability support workers were unable to administer the medication the person required, to be comfortable and pain free. Li-Ve Tasmania was fortunate enough that the person had a family member who was an RN, and able to come in when required, to administer the medication.*

## 12. Advance Care Planning

The process of advance care planning (ACP) 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.<sup>29</sup> Advance care planning for people with disabilities can promote respect for autonomy in end-of-life care and has the potential to greatly benefit people with disabilities given that health professionals may otherwise make incorrect assumptions about care preferences.

Those who support people with profound intellectual and multiple disabilities to plan for and make decisions about end-of-life care are faced with challenges which are nonetheless important to overcome, not only because of the human rights obligations defined in the CRPD but also due to the evidence demonstrating the importance of autonomy in the creation of a good death. A person's opportunity to express their autonomy at the end of life has been linked to a death that meets the psychological, spiritual, physical, and social needs of the person who is dying. When people are given opportunities to discuss their wishes and preferences, the quality of their end-of-life care is improved.<sup>30</sup>

Understandably, doctors and other healthcare professionals often find it difficult to initiate ACP processes with their patients and families. There are several useful resources available in Australia that health professionals and disability support workers can utilise to prompt ACP discussions.<sup>31</sup> There have been a number of initiatives in the Netherlands and the United Kingdom aimed at making ACP accessible to people with intellectual disabilities, however rigorous evaluation is yet to be completed.<sup>32</sup>

<sup>29</sup> Buck, K. et al. [Prevalence of advance care planning documentation in Australian health and residential aged care services](#), Short Report. (Advance Care Planning Australia, Austin Health, 2017).

<sup>30</sup> Detering K M, Hancock A D, Reade M C, Silvester W. [The impact of advance care planning on end of life care in elderly patients: randomised controlled trial](#) BMJ 2010; 340 :c1345 doi:10.1136/bmj.c1345

<sup>31</sup> <https://livetasmania.org/volumes/images/Communicating-for-end-of-life-A-toolkit-Li-VeTasmania-Appendices-included-18-May-2022.pdf>  
<https://www.caresearch.com.au/tel/tabid/4881/Default.aspx>

<sup>32</sup> De Vleminck A, Pardon K, Beernaert K, et al. [Barriers to advance care planning in cancer, heart failure and dementia patients: a focus group study on general practitioners' views and experiences](#). PLoS One 2014; 9(1): e84905.

Despite Australia's commitment to Article 12 of the CRPD, many people with profound intellectual and multiple disabilities are denied their human right to autonomy in this domain. Unfortunately, too often assumptions are made that self-determination and autonomy are irrelevant to people with intellectual or cognitive disability, due to perceptions about limited decision-making capacity.<sup>33</sup>

Bekkema et al. (2014) reported that while "people with severe intellectual disability had their end of life preferences taken into account only 2.9% of the time, people with mild or moderate intellectual disability had their preferences taken into account 27.8% of the time."<sup>34</sup> This is despite "relatively higher incidence among people with severe intellectual disability of medical conditions (e.g., aspiration pneumonia, respiratory disorders and dysphagia) that require critical decision-making relating to end-of-life care."<sup>35</sup>

### CASE STUDY

*A person over 50 years old had cancer. The person also had an intellectual disability and had limited medical or social support. The person was very distressed by their cancer symptoms and it was only when a family member visited them that the person was taken to visit the GP.*

*The person also had an adult child who lived with them. The child also had an intellectual disability, and had a companion carer to provide support. The person and their child lived independently and were very close.*

*The person experienced functional decline and became distressed again. The person's family member was able to advocate on their behalf to ensure that they received individualised care.*

*To support the person and assist with appropriate pain management, the palliative care team and doctor conducted more frequent 'check-ins', monitoring and symptom assessment than they would normally do for a person living in the community. The person also received additional support from a palliative care social worker, who invested in ongoing discussions about their preferences, advance care planning, and ongoing guardianship for their adult child. The social worker sought to empower the person so that they could make informed decisions about their own life, as well as that of their adult child.*

*The social worker also assisted the adult child with support, in particular ensuring ongoing accommodation following their parent's death. The social worker continued to provide bereavement support to the adult child and family member after the person had died.*

<sup>33</sup> Watson, J., Voss, H., & Bloomer, M. J. (2019). [Placing the Preferences of People with Profound Intellectual and Multiple Disabilities At the Center of End-of-Life Decision Making Through Storytelling. Research and Practice for Persons with Severe Disabilities](https://doi.org/10.1177/1540796919879701), 44(4), 267–279. <https://doi.org/10.1177/1540796919879701>

<sup>34</sup> Bekkema, N., de Veer, A. J., Hertogh, C. M., & Francke, A. L. (2014). [Respecting autonomy in the end-of-life care of people with intellectual disabilities: a qualitative multiple-case study](https://doi.org/10.1111/jir.12023). Journal of intellectual disability research : JIDR, 58(4), 368–380. <https://doi.org/10.1111/jir.12023>

<sup>35</sup> Bekkema, Ibid.

## Recommendations

### Training and Education

PCA recommends:

- Investing in palliative care awareness campaigns to raise community awareness about death, dying and palliative care.
- Specialist palliative care services, healthcare, aged care and disability support staff need to focus on staff developing knowledge and skills in communication strategies relevant to people with intellectual disability. An available resource is the Talking End of Life website [www.caresearch.com.au/TEL](http://www.caresearch.com.au/TEL)
- There are numerous existing options for providers looking to train staff in palliative care, including online tools and resources. These include:
  - [Program of Experience in Palliative Approach \(PEPA\)](#) aims to enhance the capacity of health professionals to deliver a palliative care approach through their participation in either clinical placements in specialist palliative care services or interactive workshops.
  - Indigenous Program of Experience in Palliative Approach (IPEPA). This is a grassroots approach to breaking down the barriers to palliative care for Aboriginal and Torres Strait Islander peoples across Australia.
  - End of Life Directions for Aged Care (ELDAC) provides information, guidance, and resources to health professionals and aged care workers to support palliative care and advance care planning to improve the care of older Australians.
- In addition, disability support workers would benefit from training in grief and loss, as well as in relationship-centered care and building a team that includes the dying person, family and loved ones, peers, spiritual care, and disability and health professionals.

### Workforce

PCA recommends:

- Supporting and growing the palliative care workforce, including the specialist palliative care workforce and primary care workforce.
- Better integration and co-ordination with palliative care social workers and connections with allied health professionals to better provide continuity of care.
- Disability organisations to consider how they can establish realistic healthcare management plans for individuals during end of life that recognise the ongoing need for additional support hours and provide greater flexibility in how these hours can be used to access specialist healthcare services.

## Systems Issues

PCA recommends:

- Greater investment in dedicated palliative care services across Australia including rural and remote areas.
- Providing more support to carers so they can care for their loved ones in the place of their choice.
- Psychosocial and bereavement supports for people with disabilities who have lost a loved one/carer in palliative care.
- Policy and practice changes are needed to address misinformation and assumptions about people with intellectual disability, including the development of guidelines regarding communication about dying and death with people with intellectual disability in palliative care.
- Disability services to consider proactively establishing a linkage with the local palliative care nursing team. A collaborative approach from disability staff may assist nurses within the wider healthcare system to better adapt to the needs of people with intellectual disability during end of life. Evidence shows that the disability sector has strong support for the role of community-based palliative care nurses.<sup>36</sup>
- There is an urgent need for policy and practice changes to enable better integration and continuity of care between the disability and health sectors as well as education and training to improve knowledge and skills in this area for all stakeholders.
- Complaints around palliative care should be addressed in a timely manner and lessons implemented in the workplace.
- Appropriate funding under the Medicare Benefits Schedule (MBS) for GPs to allow time to ensure clear communication and understanding of the wishes of people with disabilities and consideration of the person's capacity for decision-making.
- Tasmanian legislative change to allow disability support workers to administer S8 medications within a palliative care context, or funds need to be made available for disability service providers to engage nurses to address this significant need.

## Data and Research

PCA recommends:

- Augmenting palliative care data and research broadly, noting the lack of quality data, research, evaluation, and monitoring of palliative care usage by people with disability.
- Australian research to examine the personal views of individuals with intellectual disability regarding palliative care, noting that current research focusses on the opinions and perceptions of proxy respondents rather than the actual individual experience

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<sup>36</sup> Wark, S, Hussain, R, Müller, A, Ryan, P, Parmenter, T. (2017) *Challenges in providing end-of-life care for people with intellectual disability: Health services access*. Journal of Applied Research in Intellectual Disabilities. 30: 1151–1159. <https://doi.org/10.1111/jar.12408>

- Further research exploring the experiences and needs of individuals with long-standing physical disability at end of life, including from the perspective of patients and families.

