

Appendix A: Glossary

Term	Definition
Acute deterioration	Physiological, psychological or cognitive changes that may indicate a worsening of a person's health status: this may occur across hours or days. ²⁵
Advance care directives	Sometimes referred to as a living will. It is something a person ('person concerned') creates and involves documentation of their preferences for future care. It can include the person values, life goals and preferred outcomes and directions about care and treatments. An Advanced care directive can only be completed and signed by a competent adult. A substitute decision maker can be formally appointed. It is used only when the person concerned lacks capacity to participate in decision-making. ²⁶
Advance care planning	Is about understanding what is important to the individual. Advance care planning is a process of planning for future health care, for a time when the person is no longer able to make their own health care decisions. It relates to a person's future health care and medical treatments. It may include conversations about treatments they would or would not like to receive if they become seriously ill or injured. It includes identifying the person they want to make these decisions and how they want those decisions to be made. It has many benefits for the person (care aligned with preferences), loved ones and treating clinicians. ²⁷
Adverse event	An incident that results, or could have resulted, in harm to a person in receipt of care or support. A near miss is a type of adverse event. ²⁸
Allergy	Occurs when a person's immune system reacts to allergens in the environment that are harmless for most people. Typical allergens include some medicines, foods and latex. An allergen may be encountered through inhalation, ingestion, injection or skin contact. A medicine allergy is one type of adverse drug reaction. ²⁹
Assistive technology	Physical supports that help people do something more easily or do something that a person cannot do because of their disability. ³⁰
Avoidable death	A death from a condition that could have been prevented through provision of individualised care and/or treatment through existing primary or hospital care. ³¹
Bad news	Any news that drastically and negatively alters a person's view of his or her future. A person's experience of news as 'bad' is dependent upon their concept of time and future as well as their capacity for abstract thinking. ³²
Care	The process of providing what a person needs.
Carers	People who provide personal care, support, and assistance to people with a disability, mental condition, medical condition, or frailty due to age. The term carer does not include people who provide care for payment. ³³

Term	Definition
Clinical communication	The exchange of information about a person’s care that occurs between treating clinicians, the person, their, carers and families, and other members of a multidisciplinary team. Communication can be through several different channels, including face-to-face meetings, telephone, written notes or other documentation, and electronic means.
Clinical governance	An integrated component of corporate governance of health service organisations. It ensures that everyone – from frontline clinicians to managers and members of governing bodies, such as boards – is accountable to the person in receipt of care and support and the community for assuring the delivery of safe, effective and high-quality services. Clinical governance systems provide confidence to the community and the healthcare organisation that systems are in place to deliver safe and high-quality health care. ³⁴
Clinician	A healthcare provider, trained as a health professional, including registered and nonregistered practitioners. Clinicians may provide care within a health service organisation as an employee, a contractor or a credentialed healthcare provider, or under other working arrangements. They include nurses, midwives, medical practitioners, allied health practitioners, technicians, scientists and other clinicians who provide health care, and students who provide health care under supervision. ³⁵
Communicating for safety	Having systems and processes in place to ensure timely, purpose driven and effective communication and documentation that support continuous, coordinated and safe care and support for people in need and receipt of care. ³⁶
Compassionate communities	A palliative care framework that aims to promote and integrate social approaches to dying, death and bereavement in the everyday life of individuals and communities. ³⁷
Continuous improvement	A systematic, ongoing effort to raise an organisation’s performance as measured against a set of standards or indicators.
Coordination of care	The goal of coordination of care is to meet the person’s needs, goals, and preferences in the delivery of high-quality health, community, and disability services. Coordination of care relies on all providers to work together in partnership with the person with disability.
Diagnostic overshadowing	A process where health or disability professionals wrongly presume that present physical symptoms are a consequence of the persons disability, when they actually represent a physical illness. ³⁸
Disability	Any limitation, restriction or impairment which restricts activities and has lasted or is likely to last, for at least six months. ³⁹
Disability Support Worker	Disability supports workers are people who provide care, physical assistance, emotional support, and supervision for people with disability.

Term	Definition
Diversity	The varying social, economic and geographic circumstances of people who use or may use the services of a health or disability organisational, as well as their cultural backgrounds, religions, beliefs, practices, languages spoken and sexualities which is currently referred to lesbian, gay, bisexual, transgender, intersex, and queer (LGBTIQ).
Easy English	Further simplified accessible communication that includes images that help understand concepts. It is used for people with learning disabilities or those who have trouble reading. This affects a little less than half of Australian adults. For Easy English you need the same as plain English plus a simple font or typeface, layout and design, and images that are relevant to the message and enhance understanding of it. ⁴⁰
Easy read	A way of making information easy to understand. It uses simple text; pictures to explain text; lots of white space.
End of life	The period when a person is living with, and impaired by, a [terminal] condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of people with chronic or malignant disease, or very brief in the case of people who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma. ⁴¹
End-of-life care	Includes physical, psychological, and spiritual assessment, care and treatment delivered by disability support workers, healthcare professionals and other staff. It includes the care and support of family, and carers, and the care of the person's body after death. People are approaching end of life when they are likely to die within the next 12 months.
Family	Includes people who a person identifies as family and may include people who are biologically related and people who have joined through relationships, marriage as well as family of choice and friends. ⁴²
Feedback	Opinions, expressions and comments of interest in the services provided. This may involve, complaints, compliments and suggestions.
Goals of care	Clinical and other goals or a person's episodes of care that are determined in the context of a shared decision-making process. Goals of care may change over time, particularly as the person enters the terminal phase and during end-of-life care. ⁴³
Health care	The prevention, treatment and management of illness and injury, and the preservation of mental and physical wellbeing through the services offered by clinicians, such as medical, nursing and allied health professionals. ⁴⁴
Health services	<p>For the purpose of the healthy dying for people with disability project health services includes the following:</p> <ul style="list-style-type: none"> ▪ Primary care (for example General Practitioners, nurses) - Primary health care is typically a person's first contact with the health system and broadly encompasses care that is not related to a hospital visit. It includes a range of activities, such as health promotion, prevention, early intervention, treatment of acute conditions, and management of chronic

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	<p>conditions. It can be considered as the ‘gateway’ to the wider health system.</p> <ul style="list-style-type: none"> ▪ Primary health care is delivered in a variety of settings, including general practices, community health centres, allied health practices, and through communication technology such as telehealth and video consultations. Primary health care services are delivered by various health professionals, including general practitioners, nurses, nurse practitioners, allied health professionals, midwives, pharmacists, dentists, and Aboriginal and Torres Strait Islander health workers. ▪ Secondary care - (e.g.: allied health professionals, district nurses, community nursing, disability services; support coordination providers, specialist palliative care services). Secondary care is medical care provided by a specialist or facility upon referral by a primary care physician.⁴⁵ ▪ Tertiary care - Hospital services provided by private and public hospitals. Hospital emergency departments are a critical component of hospitals and of the health system. They provide care for patients who have an urgent need for medical or surgical care. Palliative care is also provided in tertiary health settings.
Intellectual disability	<p>A form of developmental disability characterised by impaired mental abilities and reduced ability to manage common demands of day-to-day life (adaptive functioning). A person with intellectual disability may have difficulty with thinking skills that impact planning, problem solving, abstract thinking and learning. They may also experience difficulties with communication, social skills and independently managing daily activities.⁴⁶</p>
ISOBAR	<p>A communication tool used widely in the health and community sector, prompting minimum information requirements to improve a person’s safety at the points of transitions of care and reduce the risk of adverse events. The acronym ISOABR - Identify, Situation, Observations, Background, Assessment, Recommendation- summarises the components of a checklist adapted to promote effective communication. Handovers must include the transfer of responsibility and accountability of a person’s care.^{47 48}</p>
Life-limiting illness	<p>A life-limiting illness is a condition or chronic disease that will not respond to curative treatment.</p>
Medical goals of care	<p>Medical assessment of appropriate treatment or limitations of treatment (incl Not For Resuscitation), on admission to hospital and during hospital stay, and for people in community settings where limitation of treatment is requested or appropriate. Medical Goals of Care should be assessed as either: A. curative; B. restorative with specific limitations of treatment; C. palliative; or D. comfort measures for dying people.^{49 50} The Medical Goals of Care are completed by a qualified medical professional or similar.</p>
National Disability Insurance Scheme (NDIS)	<p>An insurance scheme that provides support to people with disability their families and carers.</p>
National Disability Insurance Scheme	<p>An independent agency established to improve the quality and safety of NDIS supports and services. The commission regulates NDIS providers,</p>

Term	Definition
Quality and Safeguards Commission	provide national consistency, promote safety and quality services, resolve problems and identify areas for improvement. ⁵¹
Palliative care	An approach to treatment that improves the quality of life of people and their families facing life-limiting illness, through the prevention and relief of suffering. It involves early identification, and impeccable assessment and treatment of pain and other problems (physical, psychosocial and spiritual). ⁵²
Palliative care providers	All organisations providing palliative care, including health and social service providers and community members and networks.
Person-centred care	Person-centred care is respectful of, and responsive to, the preferences, needs and values of the individual person in receipt of care. It involves seeking out, and understanding what is important to the person, fostering trust, establishing mutual respect, and working together to share decisions and plan care. Key dimensions of person-centred care include respect, emotional support, physical comfort, information and communication, continuity and transition, care coordination, involvement of carers and family, and access to care.
Policy	A set of principles that reflect the organisation's mission and direction. All procedures and protocols are linked to a policy statement.
Procedure	The set of instructions to make policies and protocols operational, which are specific to an organisation.
Quality improvement	The combined efforts of the workforce and others – including participants, consumers, and their families, researchers, planners, and educators – to make changes that will lead to better outcomes (health), better system performance (care) and better professional development. Quality improvement activities may be undertaken in sequence, intermittently or on a continual basis.
Reasonable adjustments	The way mainstream services makes their services available to people with disabilities, to make them as accessible and effective as they would be for people without disabilities. ⁵³
Referral pathways	Describe the order in which people access palliative care services and the mechanism by which they connect with new services within an existing model of care.
Restrictive practice	Any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with disability. ⁵⁴
Risk	The chance of something happening that will have a negative impact. Risk is measured by the consequences of an event and its likelihood.
Service providers	Any professionals involved in the provision of palliative care services or referral to palliative care services. This may include specialist palliative care

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	providers but also General Practitioners, health professionals at local Hospitals, geriatricians, disability and aged care providers.
Shared decision making	A consultation process in which a clinician and a person jointly participate in making a health decision, having discussed the options, and their benefits and harms, and having considered the person's values, preferences and circumstances. ⁵⁵
Specialised 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. ⁵⁶
Standard	Agreed attributes and processes designed to ensure that a product, service, or method will perform consistently at a designated level.
Transitions of care	Situations when all or part of a person's care is transferred between healthcare locations, providers, or levels of care within the same location, as the person's conditions and care needs change. ⁵⁷

²⁵ Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. 2nd ed. Version 2. Sydney: ACSQHC; 2021

²⁶ Better Access to Palliative Care Program

²⁷ Advance Care Planning Australia, Instruction guide, advance-care-plan_full-name.pdf (advancecareplanning.org.au)

²⁸ *ibid*

²⁹ Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. 2nd ed. Version 2. Sydney: ACSQHC; 2021

³⁰ Assistive technology explained | NDIS

³¹ Falster, M and Jorm, L. A guide to the potentially avoidable deaths indicator in Australia. Centre for Big Data Research in Health, University of New South Wales in consultation with Australian Commission on Safety and Quality in Health Care and Australian Institute of Health and Welfare: Sydney 2017

³² Tuffrey-Wijne, I & Watchman, K, 2015, Breaking bad news to people with learning disabilities and dementia, Art and Science, Vol. 18, no. 7.

³³ The Parliament of Australia. Carer recognition Act No.123, 2010.

³⁴ *ibid*

³⁵ *ibid*

³⁶ Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. 2nd ed. Version 2. Sydney: ACSQHC; 2021

³⁷ External link to Compassionate communities' network website

³⁸ Diagnostic overshadowing: see beyond the diagnosis, University of Hertfordshire. Diagnostic Overshadowing: See Beyond the Diagnosis | Intellectual Disability and Health

³⁹ Australian Bureau of Statistics Disability, Ageing and Carers, Australia: Summary of Findings, 2018 | Australian Bureau of Statistics (abs.gov.au)

⁴⁰ Primary Health Tasmania

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- ⁴¹ Australian Commission on Safety and Quality in Health Care. National Consensus Statement: essential elements for safe and high-quality end-of-life care. Sydney: ACSQHC, 2015 Consensus Statement: Essential Elements for safe and high-quality end-of-life care (safetyandquality.gov.au)
- ⁴² Palliative Care Australia. Palliative care Service Development Guidelines, 2018.
- ⁴³ National framework for advance care planning documents, 2021, National framework for advance care planning documents | Australian Government Department of Health
- ⁴⁴ Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. 2nd ed. Version 2. Sydney: ACSQHC; 2021
- ⁴⁵ Secondary Care | Definition of Secondary Care by Merriam-Webster
- ⁴⁶ Trollor, J, Submission to the Royal Commission into violence, abuse, neglect and exploitation of people with disability
- ⁴⁷ Australian Commission on Safety and Quality in Health Care (2010). The OSSIE Guide to Clinical Handover Improvement. Sydney, ACSQHC.
- ⁴⁸ Guidelines for Shared Transfer of care, 2016, Primary Health Tasmania, Guidelines-for-Shared-Transfer-of-Care.pdf (primaryhealthtas.com.au)
- ⁴⁹ Better Access to Palliative Care Program
- ⁵⁰ Medical Goals of Care Plan | Palliative Care (dhhs.tas.gov.au)
- ⁵¹ Home | NDIS Quality and Safeguards Commission (ndiscommission.gov.au)
- ⁵² *ibid*
- ⁵³ Tasmanian NDIS Disability-Health Advisory Group, October 2017. Policy proposal for the operational interface between the National Disability Insurance Scheme (NDIS), disability and health in Tasmania for: adult NDIS participants with intellectual disability during hospitalisation. Appendix 2- Examples of NDIS and health values.
- ⁵⁴ NDIS Quality and Safeguards Commission: Regulated restrictive practices. Available: Regulated restrictive practices | NDIS Quality and Safeguards Commission (ndiscommission.gov.au).
- ⁵⁵ Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. 2nd ed. Version 2. Sydney: ACSQHC; 2021
- ⁵⁶ Exploratory Analysis of Barriers to Palliative Care - Issues Report on People with Disabilities (health.gov.au)
- ⁵⁷ Australian Commission on Safety and Quality in Health Care. National Safety and Quality Health Service Standards. 2nd ed. Version 2. Sydney: ACSQHC; 2021