Communicating for end of life

A summary of the literature that informed the Healthy Dying for People with Disability project

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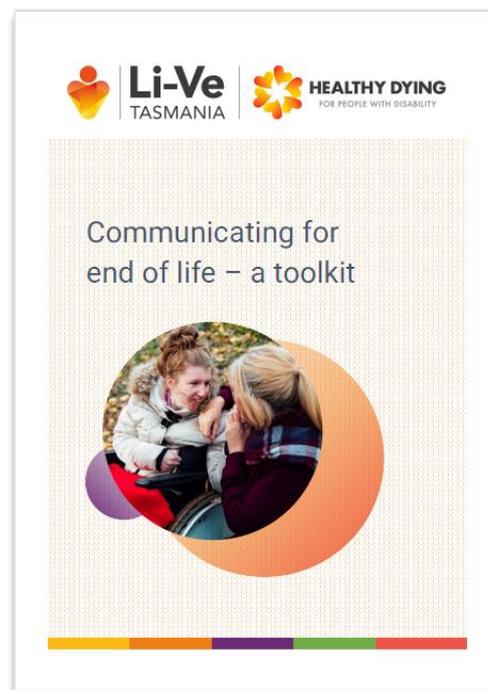
Introduction

This document describes the evidence base and resources used to inform Li-Ve Tasmania's project *Healthy dying for people with disability.*

The project aims to improve the ways that people with intellectual disability or cognitive impairment can communicate their health needs when they are nearing the end of their life. The project aims to do this by promoting and improving the systems and practices that support good communication with people with intellectual disability. Considered, respectful communication supports safe, effective healthcare for those with a life-limiting illness.

Effective communication is a core skill for all people providing end-of-life care. It's a skill that can be developed and improved with practice, support and mentorship, and the use of evidence-based resources*.*

The literature reviewed is grouped by topic, as follows:

Data

Data provides valuable insights into the health trends and needs of people with disabilities, highlighting the health challenges and informing the development of policies and programs to address health disparities and improve people's access to quality healthcare services.

Table 1: Literature reviewed | Data

	Title	Reference	Access	Description
1.	Primary Health Tasmania Needs Assessment 2020	Primary Health Tasmania. Primary Health Tasmania Needs Assessment 2020. Hobart, TAS: Primary Health Tasmania; 2020.	Contact Primary Health Tasmania on 1300 653 169	A summary of a range of statistics, insights, and other information relevant to Primary Health Tasmania's commissioning activity. This assessment provides a snapshot of Tasmanian health trends by noting areas of improvement and identifying areas that continue to pose a challenge to the wellbeing of local populations.
2.	Disability, Ageing and Carers, Australia: Summary of Findings. 2018	Australian Bureau of Statistics. Disability, Ageing and Carers, Australia: Summary of Findings (2018) [Internet]. Canberra: ABS; 2019.	https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2018	National level data and explanatory material. In 2018 there were 4.4 million Australians with disability. This is 17.7% of the population, down from 18.3% in 2015.
3.	Mortality patterns among people using disability support services: 1 July 2013 to 30 June 2018 (Summary)	Australian Institute of Health and Welfare. Mortality patterns among people using disability support services: 1 July 2013 to 30 June 2018 (Summary report) [Internet]. Canberra, ACT; 2020.	https://www.aihw.gov.au/getmedia/de0fc029-4574-4e7b-899c-9818fa482966/aihw-dis-76-summary.pdf.aspx?inline=true	First national mortality report for this population exploring the mortality patterns among people who accessed disability support services during report period.
4.	NDIS Quarterly Report to disability ministers: 30 September 2021 | Appendix K: Tasmania	National Disability Insurance Agency. NDIS Quarterly Report to disability ministers – September 2021 [Internet]. Canberra, ACT: 2021; p. 442–90.	https://www.ndis.gov.au/about-us/publications/quarterly-reports/archived-quarterly-reports-2021-22	The quarterly reports provide disability ministers with information (including statistics) about participants in each jurisdiction and are provided to disability ministers following the end of each quarter. Appendix K provides a data breakdown of Tasmanian NDIS participants, including profile of participants.

	Title	Reference	Access	Description
5.	Investing to save: The economics of increased investment in palliative care in Australia	Palliative Care Australia and KPMG. Investing to save: The economics of increased investment in palliative care in Australia. Canberra, ACT: PCA; 2020.	https://palliativecare.org.au/publication/kpmg-palliativecare-economic-report/	An investigation of the economic value of palliative care, to examine Australia's future palliative care needs and model effective interventions, with recommendations to meet the escalating palliative care needs.
6.	State of Palliative Care: Summary report – Tasmania 2021	Palliative Care Tasmania. State of palliative care: summary report – Tasmania 2021 [Internet]. Hobart, TAS: PCT; 2021.	https://pallcaretas.org.au	Inaugural summary report provides a snapshot of the Tasmanian palliative care workforce, paid and unpaid. Report will be reviewed 3-yearly and will provide insights showing trends and the capability and capacity of the sector.
7.	Health in Tasmania. Primary Health Tasmania Health Needs Assessment 2022–23 to 2024–25	Primary Health Tasmania. Health in Tasmania: Primary Health Tasmania needs assessment 2022–23 to 2024–25 [Internet]. PHT; 2021.	https://www.primaryhealthtas.com.au/wp-content/uploads/2022/04/Primary-Health-Tasmania-Needs-Assessment-2022-25.pdf	Health data across Tasmania. This report sets out priorities to inform PHT primary care commissioning for a 3-year period. Refers to palliative care service demand and disability statistics. Disability data refers to ABS Survey of Disability, Ageing and Carers Summary of Findings (2018) released 2019.
8.	The Health of People with Intellectual Disability: Budget and Federal Election 2019. Commitments sought from Australian political parties	Council for Intellectual Disability, Inclusion Australia (NCID). The health of people with intellectual disability: Budget and Federal election 2019. Commitments sought from Australian political parties [Internet]. NSW: CID; 2019.	https://cid.org.au/wp-content/uploads/2019/06/Intellectual_disability_health_bid_200219.pdf	Submission to political parties outlining proposals to close health inequities for people with intellectual disabilities. Contains specific health data for people with intellectual disabilities to support its proposals.
9.	Appendix 2 - People with disability in Tasmania- at a glance	Tasmanian Government. Accessible island: Tasmania's disability framework for action 2018–2021 [Internet]. Hobart, TAS: Department of Premier and Cabinet; p. 32.	https://www.dpac.tas.gov.au/__data/assets/pdf_file/0027/238095/Accessible_Island_Disability_Framework_for_Action_2018-2021.pdf	Appendix 2 – 'People with disability in Tasmania – at a glance' refers to data from the ABS 2015 Survey of Disability, Ageing and Carers (SDAC) that provides a snapshot of Tasmanians with a disability.
10.	Policy proposal for the operational interface between the NDIS, disability and health in	Tasmanian NDIS–Disability–Health Advisory Group. Policy proposal for the operational interface between the National	https://www.parliament.tas.gov.au/ctee/Council/Submissions/HST%202018/HST%201%20Attachment.pdf	The Tasmanian NDIS Disability Health Advisory Group, disability and health sectors developed this policy proposal. The proposal was informed by an analysis and consideration of possible

	Title	Reference	Access	Description
	Tasmania for: *adult NDIS participants with intellectual disability during hospitalisation*	Disability Insurance Scheme (NDIS), disability and health in Tasmania for: adult NDIS participants with intellectual disability during hospitalisation [Internet]. Hobart, TAS; 2017.		solutions to specific practical problems relating to the NDIS disability–health interface operations.
11.	Statement of Professor Julian Trollor. Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability	Australian Government. Exhibit 4-09 - STAT.0049.0001.0001 - Statement of Professor Julian Trollor [Internet]. Canberra, ACT: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability; 2020.	https://disability.royalcommission.gov.au/system/files/exhibit/STAT.0049.0001.0001.pdf	Data overview and recommendations to support people with intellectual disability in the health and disability sector.

Whole of system

Summary of the literature reviewed that relates to whole-of-system palliative care for people with intellectual disability at end of life.

Table 2: Literature reviewed | Whole of system

	Title	Reference	Link	Summary
1.	The palliative care needs of adults with intellectual disabilities and their access to palliative care services: A systematic review	Adam E, Sleeman KE, Brearley S, Hunt K, Tuffrey-Wijne I. The palliative care needs of adults with intellectual disabilities and their access to palliative care services: A systematic review. Palliative medicine. 2020;34(8):1006-18.	https://journals.sagepub.com/doi/pdf/10.1177/0269216320932774	A systematic review of 5 databases to identify palliative care needs of adults with intellectual disabilities and the barriers and facilitators they face in accessing palliative care. Barriers and facilitators identified were associated with education (staff training, knowledge and experience), communication (staff skill in assessing and addressing needs of people with communication difficulties), collaboration (importance of sustained multidisciplinary approach), and health and social care delivery (staffing levels, funding and management support). The review highlights specific problems in providing palliative care for people with intellectual disability.
2.	End-of-life care in intellectual disability: a retrospective cross-sectional study	Hunt K, Bernal J, Worth R, Shearn J, Jarvis P, Jones E, Lowe K, Madden P, Barr O, Forrester-Jones R, Kroll T. End-of-life care in intellectual disability: a retrospective cross-sectional study. BMJ Supportive & Palliative Care. 2020 Dec 1;10(4):469-77.	https://spcare.bmj.com/content/10/4/469.abstract	UK nationwide population post-bereavement survey to describe the end-of-life outcomes for adults living with intellectual disability in residential aged care in the UK compared with the general population. Quality of care across care settings generally is well-rated, but hospital care and care provided at the time was less well-rated in comparison with general population. Respondents reported: low levels of involvement in care and awareness of approaching death among adults with intellectual disability access to end-of-life care for adults with intellectual disability was constrained by inability to identify approaching end of life.

	Title	Reference	Link	Summary
3.	2019 Report: Scoping review of causes and contributors to deaths of people with disability in Australia	Australian Government. 2019 Report: Scoping review of causes and contributors to deaths of people with disability in Australia [Internet]. Canberra, ACT: NDIS Quality and Safeguards Commission; 2019.	https://www.ndiscommission.gov.au/resources/reports-policies-and-frameworks/research-deaths-people-disability/2019-report-scoping	Research to obtain an Australia-wide perspective on the prevalence of, and factors contributing to, the death of people with disability. Includes a summary of key findings and recommendations.
4.	Statement of Professor Julian Trollor – Royal Commission into Violence , Abuse, Neglect and Exploitation of People with Disability	Australian Government. STAT.0155.0001.0001 - Statement of Professor Julian Trollor [Internet]. Canberra, ACT: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability; 8 September 2020.	https://disability.royalcommission.gov.au/system/files/2020-09/STAT.0155.0001.0001_0.pdf	Evidence-based statement focused on people with cognitive disability.
5.	Palliative Care and Intellectual Disabilities	Tuffrey-Wijne I. Palliative Care and Intellectual Disabilities [Internet]. UK: University of Hertfordshire; 2017.	http://www.intellectualdisability.info/physical-health/articles/cancer,-palliative-care-and-intellectual-disabilities	First published in 2002 and updated in 2017, the article looks at life expectancy, causes of death, palliative care, equity of access, assessment and control of pain and other symptoms, capacity, consent to treatment and end-of-life decision making, communicating about illness, death and dying, family and carers, and collaboration and support services.

Capacity building

Capacity building in the disability sector is crucial for empowering individuals with disabilities, promoting inclusion, improving the quality of services, and strengthening advocacy efforts. It is an important step towards creating a more equitable and inclusive society.

Table 3: Literature reviewed | Capacity building

	Title	Reference	Link	Summary
1.	Providing end-of-life care in disability community living services: An organizational capacity-building model using a public health approach	Grindrod A, Rumbold B. Providing end-of-life care in disability community living services: An organizational capacity-building model using a public health approach. Journal of Applied Research in Intellectual Disabilities. 2017 Nov;30(6):1125-37.	https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12372	Mixed-method research approach (quantitative and qualitative) into the barriers encountered when applying palliative care strategies to the end-of-life care of people with intellectual disability, particularly those in community living services. Research indicates a strong relationship between organisational structure and culture which influences end-of-life practice in community living services. Research paper outlines an organisational model developed from public heath principles to manage end of life in these settings.
2.	Learning Guide for Disability Support Workers	PEPA Project Team (2022). The Program of Experience in the Palliative Approach – Learning Guide for Disability Support Workers. Queensland University of Technology; Brisbane. 2022.	https://pepaeducation.com/wp-content/uploads/2022/02/PEPA_LearningGuide_DisabilitySupportWorkers_OnlineBooklet.pdf	A learning guide used to support workshops and placement learning for disability support workers. Provides overview of palliative care; context of disability and palliative care; palliative care approach; effective communication; advance care planning; recognising and responding to needs; end-of-life care; grief, loss and bereavement; caring for yourself, and a glossary of terms.
3.	Capacity building framework training manual for health services	Summer Foundation. Capacity building framework training manual for health services [Internet]. Box Hill, VIC: Summer Foundation; 2020.	https://www.summerfoundation.org.au/resources/capacity-building-framework-training-manual/	The resource provides a framework for the provision of information, training and mentoring to staff for practice change. It includes the training manual, needs analysis, Summer Foundation NDIS training videos, reflective practice activities, Power Point presentations, FAQs and links to resources for people with disability.

	Title	Reference	Link	Summary
4.	Capacity building and change management. A guide for community services	Victorian Alcohol & Drug Association. Capacity building and change management: A guide for community services [Internet]. Melbourne, VIC: VAADA; 2016.	https://www.vaada.org.au/wp-content/uploads/2018/06/VAADA-Capacity-Building-Change-Management-A-Guide-for-Community-Services.pdf	A manual designed to give an overview on how to equip services with the knowledge and tools needed to successfully implement change to develop the capacity of the organisation. It highlights the shifts in policy and practice, and outlines new approaches to funding to assist community services have greater capability to deliver programs in a more integrated and collaborative way. It outlines governance models and various governance documents and tools which support the functions and processes of collaborations.
5.	Using collaborations as a capacity building tool	Victorian Alcohol and Other Drug Association. Using collaborations as a capacity building tool [Internet]. Melbourne, VIC: VAADA; 2018	https://www.vaada.org.au/wp-content/uploads/2018/11/03_Using-Collaborations-as-a-Capacity-Building-Tool.pdf	A step-by-step guide that provides a focus on the power and value of collaborative relationships and networks not researched in the 2016 version of the same manual. The current guide provides steps to enhance collaboration through the development of relationships and partnerships between service providers by way of systems, such as alliances and networks.

Models of care

A model of care is a framework or approach that outlines how healthcare services are organised, delivered, and evaluated to improve patient outcomes. It is a set of principles, practices, and procedures that guide healthcare professionals in providing patient-centered care that is safe, effective, efficient, and equitable.

Table 4: Literature reviewed | Models of care

	Title	Reference	Link	Summary
1.	Improving end-of-life care outcomes for people with intellectual disabilities living in residential services in Victoria	Grindrod A, Varney H, Rumbold B. Improving end-of-life outcomes for people with intellectual disabilities who live in residential services [Internet]. Bundoora, VIC: LaTrobe University; 2016.	https://www.researchgate.net/publication/307605495_Improving_End_of_Life_Care_Outcomes_for_People_with_Intellectual_Disability_living_in_Residential_Services_in_Victoria	Outlines outcomes from a Partnered Project between North East Primary Care Partnership (NEPCP), DHHS Disability Accommodation Service (DAS) in the North East Metropolitan Area (NEMA), DHHS DAS Policy Development, Centre for Developmental Disability Health (Victoria), Banksia Palliative Care Service Inc. and La Trobe University Palliative Care Unit (LTUPCU).
2.	Healthy End of Life Project (HELP): a progress report on implementing community guidance on public health palliative care initiatives in Australia	Grindrod A, Rumbold B. Healthy End of Life Project (HELP): a progress report on implementing community guidance on public health palliative care initiatives in Australia. Annals of Palliative Medicine. 2018 Apr;7(S2):S73–83.	https://www.latrobe.edu.au/__data/assets/pdf_file/0012/890688/La-Trobe-HELP-Article-Annals-of-Palliative-Medicine-2018.pdf	Outlines a comprehensive community development project that identifies end-of-life needs and how to meet them through the efficient use of community resources.
3.	Care at the end of life knowledge framework: for health professionals and professional care givers	West Moreton Care at the End of Life Collaborative. Care at the end of life knowledge framework: for health professionals and professional	https://www.westmoretoncareconnect.com.au/wp-content/uploads/2020/07/2019432_Knowledge_Framework_Care_at_the_End_of_Life_V2.pdf	This Knowledge Framework has been developed to provide guidance for all health professionals and professional caregivers providing care at the end of life regarding their baseline knowledge needs. The Knowledge Framework is part of a suite of work being undertaken by the Care at the End of Life

	Title	Reference	Link	Summary
		care givers [Internet]. QLD: West Moreton Care Connect; 2019.		Collaborative. The purpose of this work and the collaborative is to work together as a well-connected community of caregivers to ensure quality end-of-life care for all members of our community; regardless of age, cultural background, location or diagnosis
4.	Health Promoting Palliative Care: Developing a Social Model of Practice	Kellehear A. Health-promoting palliative care: Developing a social model for practice. Mortality. 1999 Jan;4(1):75–82.	https://www.tandfonline.com/doi/abs/10.1080/713685967	Discusses the core ideals of health promotion and outlines how these might appear in palliative care practice. The Latrobe University Health Promoting Palliative Care Unit is provided as an example of this public health practice.
5.	Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: A mixed methods survey	McLaughlin D, Barr O, McIlfatrick S, McConkey R. Developing a best practice model for partnership practice between specialist palliative care and intellectual disability services: A mixed methods study. Palliative Medicine. 2014 Sep 19;28(10):1213–21.	https://journals.sagepub.com/doi/10.1177/0269216314550373	This study aims to build a best-practice model to guide and promote partnership practice between specialist palliative care and intellectual disability services. Joint working and learning between intellectual disability and specialist palliative care were seen as key and fundamental. The paper provides new insights into new partnership practices between SPS and intellectual disability services, the key challenges, and ways to overcome the barriers. It proffers a best-practice partnership practice framework to guide service development (such as education for service staff) which could have international applicability.

Navigation

Navigation refers to the process of guiding and assisting people as they navigate through the healthcare system to receive the care and services they need. Navigation can be particularly important for patients who may face barriers to accessing healthcare.

Table 5: Literature reviewed | Navigation

	Title	Reference	Link	Summary
1.	Navigation delivery models and roles of navigators in primary care: a scoping literature review	Carter N, Valaitis RK, Lam A, Feather J, Nicholl J, Cleghorn L. Navigation delivery models and roles of navigators in primary care: a scoping literature review. BMC Health Services Research. 2018 Feb 8;18(1).	https://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-018-2889-0	A scoping literature review to explore the existing evidence on system navigation in primary care that involves community-based services beyond the healthcare system. There is a high degree of variance in the literature, but descriptive studies can inform further innovation and development of navigation innovations in primary care.
2.	Navigation roles support chronically ill older adults through healthcare transitions: a systematic review of the literature	Manderson B, Mcmurray J, Piraino E, Stolee P. Navigation roles support chronically ill older adults through healthcare transitions: a systematic review of the literature. Health & Social Care in the Community. 2011 Oct 13;20(2):113–27.	https://onlinelibrary.wiley.com/doi/pdf/10.1111/j.1365-2524.2011.01032.x	Focus on the transitions between various healthcare services and points of fragmented care, particularly for older adults with chronic conditions. System navigation suggested as an innovative strategy to address complexity of transitions of care for this cohort. Synthesises peer-reviewed literature and documents outcomes on relevant studies. Presents a framework for comparison between identified navigator roles
3.	Care Navigation: A Competency Framework	NHS Health Education England. Care Navigation: A Competency Framework [Internet]. UK: NHS; 2016.	https://www.hee.nhs.uk/sites/default/files/documents/Care%20Navigation%20Competency%20Framework_Final.pdf	Overview of care navigator roles with definitions, evidence and a non-clinical practice framework that sets out key knowledge, skills and behaviours required for an individual to perform day-to-day tasks. Focus on competencies rather than roles, to allow flexibility in developing people. Contains a comprehensive reference list for further research.

Transitions / Pathways

A summary of literature related to transitions or pathways of care. This refers to the process of moving a patient from one healthcare setting or provider to another while ensuring continuity and coordination of care.

Table 6: Literature reviewed | Transitions and pathways

4	Title	Reference	Link	Summary
1.	Safety issues at transitions of care: consultation report on pain points relating to clinical information systems	Australian Commission on Safety and Quality in Health Care. Safety issues at transitions of care: consultation report on pain points relating to clinical information systems [Internet]. Sydney, NSW: ACSQHC; 2017.	https://www.safetyandquality.gov.au/sites/default/files/migrated/Safety-issues-at-transitions-of-care-consultation-report.pdf	The report aims to identify safety issues and pain points related to clinical information systems at transitions of care between the primary care and acute care sectors. Literature review, targeted interviews and stakeholder and consumer workshops were held to identify safety and pain point issues and areas of improvement.
2.	Exploratory analysis of barriers to palliative care: Issues report on people with disabilities	Australian Healthcare Associates. Exploratory analysis of barriers to palliative care: Issues report on people with disabilities [Internet]. Canberra, ACT: Australian Government Department of Health; 2019.	https://www.health.gov.au/resources/collections/exploratory-analysis-of-barriers-to-palliative-care	An analysis of barriers to accessing palliative care for people from under-served populations or people with complex needs. Barriers have been categorised by consumer (individuals/families/communities) and service (health professionals/service/organisations and broader health care system) to provide a framework to enable consideration of a service system. The analysis recognises that the division of responsibility between health and disability sectors is not always clearcut with both sectors required to provide support at the same time. The need for planning and coordination to ensure smooth transitions is required.
3.	Learning disabilities: making reasonable adjustments in hospitals	Phillips L (2019) Learning disabilities: making reasonable adjustments in hospital [Internet]. Nursing Times; 115: 10, 38-42.	https://www.nursingtimes.net/roles/hospital-nurses/learning-disabilities-making-reasonable-adjustments-hospital-16-09-2019/	Two case studies demonstrate the benefits of making reasonable adjustments to the care of people with learning disabilities who receive hospital care. Provides tools to assist nurses in clinical practice. This includes Identifying the needs and learning disabilities of the patient using the Hospital Passport among other things.

4	Title	Reference	Link	Summary
4.	Guidelines for shared transfer of care	Primary Health Tasmania. Guidelines for shared transfer of care [Internet]. Hobart, TAS: PHT; 2016.	https://www.primaryhealthtas.com.au/for-health-professionals/programs/connecting-care/shared-transfer-care/	Sets the standard for transfer of care by promoting a shared approach between organisations, service providers, communities, and healthcare consumers. Designed to support people with chronic/complex health needs who are likely to experience multiple transfers across the healthcare sector and who are subsequently at higher risk of experiencing poor health outcomes, wellbeing and inability to manage chronic illness.
5.	Supporting People with Learning Disabilities through the Palliative Care Journey: NHS Greater Glasgow and Clyde Learning Disabilities and Palliative Care Pathway	Smith L, O'Donnell A. Supporting People with Learning Disabilities through the Palliative Care Journey: NHS Greater Glasgow and Clyde Learning Disabilities and Palliative Care Pathway (Poster Presentation) [Internet]. Scottish Partnership for Palliative Care; 2015.	https://www.palliativecarescotland.org.uk/content/publications/28.-Supporting-People-with-Learning-Disabilities-through-the-Palliative-Care-Journey.pdf	An evaluated pathway that was developed in response to the well-known complexities of caring for people with learning disabilities through the palliative care journey. A pilot of the care pathway was conducted in selected Scottish health boards and it demonstrated that the pathway was easy to follow and effective in assisting practitioners to improve palliative care through partnership and collaborative working.
6.	Transition of care: technical series on safety primary care.	World Health Organization. Transitions of care: technical series on safer primary care [Internet]. Geneva: WHO; 2016.	https://apps.who.int/iris/bitstream/handle/10665/252272/9789241511599-eng.pdf	Summarises the evidence and experience around effective transitions of care for patient safety in primary care, noting that primary care provides an entry point into the health system and directly impacts on people's wellbeing. It lists 10 actions that are most likely to impact on improving safety in primary care: 1. set local priorities 2. systems approach 3. communicate importance of safety in primary care 4. focus on building a positive safety culture 5. strengthen measuring and monitoring of patient safety 6. strengthen use of electronic tools(e.g.: My health record) 7. involve patients and family members 8. strengthen workforce capacity and capability to improve safety 9. focus on those at higher risk of safety incidents 10. celebrate success and share learning with others.

NDIS Interface

A summary of literature reviewed that relates to coordination of care between the National Disability Insurance Scheme (NDIS) and health system interface.

Table 7: Literature reviewed | NDIS Interface

	Title	Reference	Link	Summary
1.	Practice Alert - Transitions of care between disability services and hospitals	Australian Government. Practice alert: Transitions of care between disability services and hospitals [Internet]. Canberra, ACT: NDIS Quality and Safeguards Commission; 2020.	https://www.ndiscommission.gov.au/document/2431	The alert explains how to support NDIS participants during transitions of care to and from hospitals and includes provider obligations.
2.	Insight into design issues in the health and NDIS systems interface: summary report to Department of Health and Human Services	Summer Foundation. Insight into design issues in the health and NDIS systems interface: summary report to Department of Health and Human Services. Box Hill, VIC: Summer Foundation; 2018 Jun.	https://www.summerfoundation.org.au/wp-content/uploads/2018/07/design-issues-health-ndis-interface-june2018.pdf	Examines the capacity, process and structural barriers that prevent coordination between the two systems and the issues specific to the NDIS/health interface. The report provides solutions and recommendations for improving outcomes for NDIS participants with high and complex needs.

Integrated and person-centred care

A summary of the literature reviewed that relates to national and international models of integration of care and person-centred care.

Table 8: Literature reviewed |Integrated and person-centred care

	Title	Reference	Link	Summary
1.	The effects of integrated care: a systematic review of UK and international evidence	Baxter S, Johnson M, Chambers D, Sutton A, Goyder E, Booth A. The effects of integrated care: a systematic review of UK and international evidence. BMC Health Services Research. 2018 May 10;18(1).	https://bmchealthservres.biomedcentral.com/track/pdf/10.1186/s12913-018-3161-3.pdf	Systematic review of the effects of integration and coordination between healthcare services, or between health and social care on service delivery outcomes including effectiveness, efficiency and quality of care. Concluded that integrated care may enhance patient satisfaction, increase perceived quality of care and enable access to services, but evidence for other outcomes not clear.
2.	Lessons from experience: Making integrated care happen at scale and pace	Ham C, Walsh N. Lessons from experience: Making integrated care happen at scale and pace [Internet]. UK: The King's Fund; 2013.	https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/making-integrated-care-happen-kingsfund-mar13.pdf	The aim of this paper is to support the process of 'making it happen' (integrated care) by summarising the steps that need to be taken to make integrated care a reality.
3.	Integrated care. What is it? Does it work? What does it mean for the NHS?	Ham C, Curry N. Integrated care. What is it? Does it work? What does it mean for the NHS? [Internet]. UK: The King's Fund; 2011.	https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/integrated-care-summary-chris-ham-sep11.pdf	This paper describes the different forms of integrated care and summarise evidence on their impact. The paper is based on a major review published by The King's Fund (Curry and Ham 2010).
4.	Person-centred care made simple. What everyone should know about person-centred care	The Health Foundation. Person-centred care made simple. What everyone should know about person-centred care [Internet]. UK: The Health Foundation; 2016.	https://www.health.org.uk/publications/person-centred-care-made-simple	A guide to provide a quick overview of person-centred care for health care professionals and anyone interested in health, healthcare. Includes strategies to put person-centred care into practice.

	Title	Reference	Link	Summary
5.	Enablers and Barriers in Implementing Integrated Care	Maruthappu M, Hasan A, Zeltner T. Enablers and Barriers in Implementing Integrated Care. Health Systems & Reform. 2015 May 19;1(4):250–6.	https://www.tandfonline.com/doi/full/10.1080/23288604.2015.1077301	The article outlines how integration of medical and social care can be achieved with a focus on 3 groups of patients with complex needs that would be benefit with an integrated approach to care: 1. multimorbid patients(2+ chronic diseases); 2. patients with moderate or severe mental conditions 3. the elderly. Provides a definition of integrated care and outlines the need for integrated care due to barriers, factors influencing integration policy, and recommendations for implementing integrated care.
6.	WHO global strategy on people-centred and integrated health services: interim report	World Health Organization. WHO global strategy on people-centred and integrated health services: Interim Report [Internet]. Geneva, Switzerland: WHO; 2015.	https://apps.who.int/iris/bitstream/handle/10665/155002/WHO_HIS_SDS_2015.6_eng.pdf?sequence=1&isAllowed=y	Proposes 5 independent strategic directions to be adopted for health service delivery to become more people-centred and integrated, taking account of the local context, values and preferences: 1. Empowering and engaging (skills, opportunity and resources). 2. Strengthening governance and accountability. 3. Re-orientating the model of care. 4. Coordinating of services at all levels around the needs of people. 5. Creating an enabling environment.

Standards and strategies

A review of national and international standards and strategies of care that govern various aspects of the health, disability and palliative care sectors.

Table 9: Literature reviewed | Standards and strategies

	Title	Reference	Link	Summary
1.	Standards for general practices, 5th edition	Royal Australian College of General Practitioners. Standards for general practices, 5th edition [Internet]. East Melbourne, VIC: RACGP; 2020.	https://www.racgp.org.au/running-a-practice/practice-standards/standards-5th-edition/standards-for-general-practices-5th-ed	The 8 Standards support GPs in identifying and addressing any gaps in their systems and processes.
2.	Communicating for Safety Standard	Australian Commission on Safety and Quality in Health Care. Communicating for safety standard [Internet]. ACSQHC; 2019.	https://www.safetyandquality.gov.au/standards/nsqhs-standards/communicating-safety-standard	The standard aims to ensure timely, purpose-driven and effective communication and documentation that support continuous, coordinated and safe care for patients.
3.	National Safety and Quality Health Service Standards, Second edition	Australian Commission on Safety and Quality in Health Care. National safety and quality health service standards, Second edition [Internet]. Sydney, NSW. ACSQHC; 2017.	https://www.safetyandquality.gov.au/sites/default/files/migrated/National-Safety-and-Quality-Health-Service-Standards-second-edition.pdf	Describes 8 standards designed to improve the quality of health service provision. The standards provide a quality assurance mechanism that tests whether relevant systems are in place to ensure that expected standards of safety and quality are met.
4.	Guidance and Resources for Providers to support the Aged Care Quality Standards	Aged Care Quality and Safety Commission. Guidance and resources for providers to support the Aged Care Quality Standards [Internet]. Canberra, ACT: ACQSC; 2018.	https://www.agedcarequality.gov.au/sites/default/files/media/Guidance_%26_Resource_V14.pdf (September 2022 version - for the latest version and updates refer to the Aged Care Quality and Safety Commission website)	The guidance material has been written for organisations that provide Commonwealth subsidised aged care services. It is designed to support organisations and their workforce to: understand the Quality Eight Standards and what is expected when the Standards are assessed; reflect on everyday practice and areas for improvement; know when

	Title	Reference	Link	Summary
				they are achieved; and undertake ongoing performance reviews against the quality standards. The material provides background information about each Standard; the intent of each Standard; key resources relevant to each Standard; and the legislation relevant to each standard.
5.	National Palliative Care Strategy 2018	Australian Government. National Palliative Care Strategy 2018 [Internet]. Canberra, ACT: Department of Health; 2019.	https://www.health.gov.au/resources/publications/the-national-palliative-care-strategy-2018	The strategy represents national and state and territory commitment to the highest possible level of palliative care. It is guided by the following 6 principles fundamental to palliative care that are expected to be demonstrated in all service delivery, quality improvement, policy and research development activities. 1. Care is person-centred. 2. Death is recognised as part of life. 3. Carers are valued and supported. 4. Care is accessible. 5. Everyone has a role to play. 6. Care is high-quality and evidence-based.
6.	NDIS Practice Standards	NDIS Quality and Safeguards Commission. NDIS practice standards | NDIS Quality and Safeguards Commission [Internet]. www.ndiscommission.gov.au. NDIS Quality and Safeguards Commission; 2022.	https://www.ndiscommission.gov.au/providers/ndis-practice-standards	These standards specify the quality standards to be met by registered NDIS providers to provide supports and services to NDIS participants.
7.	National Palliative Care Standards, 5th edition	Palliative Care Australia. National Palliative Care Standards, 5th edition [Internet]. Canberra, ACT: PCA; 2018.	https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/11/PalliativeCare-National-Standards-2018_Nov-web.pdf	Describes the 9 standards developed to support services to deliver contemporary best-practice palliative care that is person- and family-centred. Standards 1-6 focus on care standards which describes the systems and enablers required to deliver high-quality clinical care. Standards 7-9 focus on governance which describes expectation in regard to quality management, quality improvement and benchmarking.

	Title	Reference	Link	Summary
8.	National Palliative Care Standards for All Health Professionals and Aged Care Services: For professionals not working in specialist palliative care	42. Palliative Care Australia. National Palliative Care Standards for All Health Professionals and Aged Care Services: For professionals not working in specialist palliative care [Internet]. Canberra, ACT: PCA; 2022.	https://palliativecare.org.au/publication/national-palliative-care-standards-for-all-health-professionals-and-aged-care-services/	Developed to compliment the NPCS - 5th edition 2018, with the aim of supporting better experiences and outcomes for people receiving generalist palliative care. The standards are intended to guide health providers to deliver high-quality care in a wide range of settings (in services outside of specialist care services).
9.	The Tasmanian Palliative Care Community Charter	Tasmanian Government. Tasmanian Palliative Care Community Charter [Internet]. Hobart, TAS; Undated. Department of Health and Human Services; undated.	https://doh.health.tas.gov.au/__data/assets/pdf_file/0005/251636/Tas_Palliative_Care_Community_Charter_Brochure.pdf	The charter is an agreement between the Tasmanian community and service providers. The charter promotes a shared responsibility for palliative care informed by a set of guiding principles to advocate a commitment to compassionate and quality palliative care.
10.	United Nations Convention on the Rights of Persons with Disabilities: Article 25 – Health	United Nations. Article 25 – Health. Convention on the Rights of Persons with Disabilities [Internet]. 2006	https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-25-health.html	Statement to recognise that people with disabilities have the right to the highest attainable standard of health without discrimination on the basis of disability.
11.	The Ottawa Charter for Health Promotion	World Health Organization. Ottawa charter for health promotion [promotional flyer] [Internet]. WHO; 1987.	https://www.who.int/publications/i/item/ottawa-charter-for-health-promotion	Collective commitment to the common goal of health for all by the year 2000.

Clinical practice

A summary of the national and international literature reviewed that relates to clinical practice, including diagnostic overshadowing and reasonable adjustments.

Table 10: Literature reviewed | Clinical practice

	Title	Reference	Link	Summary
1.	Nurses are Essential in Health and Aged Care Reform– A White Paper	Australian College of Nursing. Nurses are essential in health and aged care reform – a white paper [Internet]. Canberra, ACT: ACN; 2016. Available from: https://www.acn.edu.au/wp-content/uploads/white-paper-nurses-essential-health-aged-care-reform.pdf	https://www.acn.edu.au/wp-content/uploads/white-paper-nurses-essential-health-aged-care-reform.pdf	Outlines the role of nurses in health and aged care, and the importance of a strong nursing voice in achieving person-centred and sustainable reform. Outlines ACN's role as an Australian professional nursing body, and its ability to provide a conduit to nursing leadership system-wide, and a unified professional nursing voice. Calls on Australian governments to engage with ACN and the nursing profession, ensuring that nurses are represented at all levels and stages of health and aged care reform. Finally, it identifies strategies that would better position the nursing profession to participate in, and contribute to, health and aged care reform.
2.	Reasonable Adjustments	Australian Government. Reasonable adjustments | Comcare [Internet]. www.comcare.gov.au. Comcare; 2021.	https://www.comcare.gov.au/claims/getting-you-back-to-work/reasonable-adjustments	Information page explaining what reasonable adjustments are and what is considered reasonable for an employer when making adjustments so a person with disability can perform the inherent requirements of the job.
3.	Health assessment for people with an intellectual disability: Medicare Benefits Schedule fact sheet	Australian Government. Medicare Benefits Schedule: Health assessment for people with an intellectual disability – Fact sheet [Internet]. Canberra,	https://www1.health.gov.au/internet/main/publishing.nsf/Content/4BD5B41BBE6EDF1ACA257BF0001C682A/$File/Health%20Assessment%20for%20people%20with%20an%20intellect	Fact Sheet that outlines MBS items and components of the health assessment. Provides links to guidelines and resources.

	Title	Reference	Link	Summary
		ACT: Department of Health; [undated].	ual%20disability%20Factsheet%20Final.pdf	
4.	Diagnostic overshadowing: see beyond the diagnosis	Blair J. Diagnostic overshadowing: see beyond the diagnosis [Internet]. Intellectual Disability and Health. University of Hertfordshire; 2017.	http://www.intellectualdisability.info/changing-values/diagnostic-overshadowing-see-beyond-the-diagnosis	Reprint of 2017 British Journal of Family Medicine article. Explains diagnostic overshadowing and considers ways of ensuring key health issues are not overlooked in people with intellectual disabilities.
5.	The health needs of people with learning disabilities: issues and solutions	Blair J. The health needs of people with learning disabilities: issues and solutions [Internet]. Pavilion Health Today. 2016.	https://www.pavilionhealthtoday.com/fm/the-health-needs-of-people-with-learning-disabilities-issues-and-solutions/	Outlines health issues facing people with intellectual disability, the importance of annual health checks by GPs and identifies areas that should be explored. It refers to the Hospital Passport as an important tool to prepare people with intellectual disability for going into hospital. It refers to the need to determine capacity of individual to support decision-making. Describes the UK Mental Capacity Act (5 main principles) and other tools to assist in assessment. For example: • CURB: C-Communicate; U= Understand; R-Retain; B-Balance • BADLIP: B-Best Interest; A-Advanced decision; L-Lasting power of attorney; I-Independent Mental Capacity Act Advocate; P-Proxy.
6.	Disability healthcare	Hayes P. Disability healthcare. Good Practice 2016; (6) 10-12.	https://www.racgp.org.au/download/Documents/Good%20Practice/2016/June/GP2016June-intellectual-disability.pdf	Article outlining the benefits of further education for GPs in the area of treating and advocating for people with intellectual disability. Refers to diagnostic overshadowing.
7.	Diagnostic overshadowing in learning disability: think beyond the disability	Javaid A, Nakata V, Michael D. Diagnostic overshadowing in learning disability: think beyond the disability. Progress in Neurology and Psychiatry. 2019 Apr;23(2):8–10.	https://doi.org./10.1002/pnp.531	Outlines a case study of a 54-year-old male with learning disability who displayed abnormally aggressive behaviours, self-neglect, and had experienced multiple transfers between psychiatric and medical units during inpatient episode. This was partly due to his physical symptoms being misattributed to learning disability and behaviour.

	Title	Reference	Link	Summary
8.	Diagnostic Overshadowing' Amongst Clinicians Working with People with Intellectual Disability in the UK	Mason J, Scior K. "Diagnostic Overshadowing" Amongst Clinicians Working with People with Intellectual Disabilities in the UK. Journal of Applied Research in Intellectual Disabilities [Internet]. 2004 Jun;17(2):85–90.	https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1360-2322.2004.00184.x	Research into the prevalence of diagnostic overshadowing in the UK of people with intellectual disability and mental health problems.
9.	Death by indifference: Following up the *Treat me right!* report	Royal Mencap Society. Death by indifference: Following up the "Treat me right!" report [Internet]. London, UK: RMC; 2006.	https://www.mencap.org.uk/sites/default/files/2016-06/DBIreport.pdf	UK case studies of diagnostic overshadowing.
10.	Death By indifference: 74 deaths and counting. A progress report 5 years on	Royal Mencap Society. Death by indifference: 74 deaths and counting A progress report 5 years on [Internet]. London, UK: RMC; 2012 Feb. Available from: https://www.mybib.com/#/projects/QNeGYG/citations.	https://www.mencap.org.uk/sites/default/files/2016-08/Death%20by%20Indifference%20-%2074%20deaths%20and%20counting.pdf	UK case studies of diagnostic overshadowing.
11.	Practice Alert: Comprehensive Health	Australian Government. Practice Alert | Comprehensive health assessment [Internet]. www.ndiscommission.gov.au. ACSQHC and NDIS Quality and Safeguards Commission; 2021.	https://www.ndiscommission.gov.au/workerresources#paragraph-id-4119	Provides guidance on how to support participants to access regular comprehensive health assessments, and obligations for providers.
12.	The route to success in end of life care– achieving quality in care homes	National Health Service. The route to success in end of life care – achieving quality in care homes [Internet]. UK: NHS; 2010 Jan.	https://www.england.nhs.uk/improvement-hub/publication/the-route-to-success-in-end-of-life-care-achieving-quality-in-care-homes/	The guide was developed in response to the NHS Department of Health's End of Life Care Strategy (2008) that emphasised the need to raise the quality of care provided to dying people in a variety of settings, including care homes. It is shaped around 6 steps, starting with initial discussion about death and future care, on to assessment and the provision of high-quality co-ordinated care and support through to the final days and end of life. Guide includes questions that staff and managers

	Title	Reference	Link	Summary
				should ask about end-of-life care provided in the home and the employees' role in that care.
13.	Health assessment for people with an intellectual disability	Primary Health Tasmania. Health assessment for people with an intellectual disability. HealthPathways [Internet]. 2021 Nov.	https://tasmania.communityhealthp athways.org/95067_1.htm	Primary care pathways to support GPs in the care of people with an intellectual disability. Registered access only.
14.	How social care staff can use reasonable adjustments to support the health of people with learning disabilities	Public Health England. How social care staff can use reasonable adjustments to support the health of people with learning disabilities [Internet]. UK: PHE; 2017.	https://assets.publishing.service.gov. uk/government/uploads/system/upl oads/attachment_data/file/656258/ Social_care_staff_supporting_reason able_adjustments_in_learning_disabi lities.pdf	Outlines why reasonable adjustments are important and provides a learning and remember tool to make reasonable adjustments called TEACH: Time; Environment; Attitude; Communication; Help.
15.	All you see isn't all there is: looking beyond learning disability	Royal Collect of Nursing. All you see isn't all there is | Congress Daily Bulletin | Royal College of Nursing [Internet]. RCN; 2018.	https://www.rcn.org.uk/magazines/b ulletin/2018/may/overshadowing	Discussion around diagnostic overshadowing including case studies of participant and staff. Refers to the 'Treat Me Well' campaign.
16.	Statement of Professor Julian Trollor - Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability	Australian Government. STAT.0049.0001.0001 - Statement of Professor Julian Trollor [Internet]. Canberra, ACT: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability; 11 February 2020.	https://disability.royalcommission.go v.au/system/files/exhibit/STAT.0049. 0001.0001.pdf	Data overview and recommendations to support people with intellectual disability in the health/disability sector. Touches on diagnostic overshadowing.
17.	Defining consensus norms for palliative care of people with intellectual disabilities in Europe, using Delphi methods: A White Paper from the	Tuffrey-Wijne I, McLaughlin D, Curfs L, Dusart A, Hoenger C, McEnhill L, et al. Defining consensus norms for palliative care of people with intellectual disabilities in Europe, using Delphi methods: A White Paper from the European Association of	https://pubmed.ncbi.nlm.nih.gov/26 346181/	The aim of the research was to define norms for palliative care of people with intellectual disabilities in Europe. Eighty experts from 15 European countries evaluated 52 items within the following 13 norms: 1. Equity of access 2. Communication 3. Recognising the need for palliative care

	Title	Reference	Link	Summary
	European Association of Palliative Care	Palliative Care. Palliative Medicine. 2015 Sep 7;30(5):446–55.		4. Assessment of total needs 5. Symptom management 6. End-of-life decision-making 7. Involving those who matter 8. Collaboration 9. Support for family/carers 10. Preparing for death 11. Bereavement support 12. Education/training 13. Developing/managing services. None of the items scored less than 86% agreement, making a further round unnecessary. This white paper presents the first guidance for clinical practice, policy and research related to palliative care for people with intellectual disabilities based on evidence and European consensus, setting a benchmark for changes in policy and practice.
18.	Annual health checks for people with intellectual disabilities in general practice	Baines E. Annual Health Checks for People with Intellectual Disabilities in General Practice [Internet]. Intellectual Disability and Health. University of Hertfordshire; 2015.	http://www.intellectualdisability.info/how-to-guides/articles/annual-health-checks-for-people-with-intellectual-disabilities-in-general-practice	Refers to diagnostic overshadowing and provides scenarios of incidences of diagnostic overshadowing and why health assessments are important.
19.	Practice nurses: Working smarter in general practice	Walker L. Practice nurses: Working smarter in general practice [Internet]. East Melbourne, VIC: RACGP; 2006.	https://www.racgp.org.au/getattachment/b03b763c-df53-4e3f-b356-4c22e7d35740/attachment.aspx	Describes the role of practice nurses (PN) working in general practice, including characteristics of PNs, role of PNs, and business case in support of increased productivity and greater utilisation of PNs in general practice.

Communication

A summary of the literature reviewed that relates to improving communication with people with intellectual disabilities at end of life.

Table 11: Literature reviewed | Communication

	Title	Reference	Link	Summary
1.	Overcoming communication barriers- Working with patients with intellectual disabilities	Tracy J, Chew KL, Iacono T. Overcoming communication barriers Working with patients with intellectual disabilities. Australian Family Physician [Internet]. 2009 Feb;38(1).	https://www.racgp.org.au/afp/2009/january-february/overcoming-communication-barriers	Provides recommendations for GPs to improve communication with people with intellectual disability and practical issues in implementing the recommendations.
2.	Delivering high quality end of life care for people who have a learning disability: Resources and tips for commissioners, service providers and health and social care staff	Palliative Care for People with Learning Disabilities Network. Delivering high quality end of life care for people who have a learning disability: Resources and tips for commissioners, service providers and health and social care staff [Internet]. UK: NHS England; 2017.	https://www.england.nhs.uk/publication/delivering-high-quality-end-of-life-care-for-people-who-have-a-learning-disability/	Provides top tips, resources and good practice examples to support the achievement of the ambitions for people with a learning disability.
3.	A new model for breaking bad news to people with intellectual disabilities	Tuffrey-Wijne I. A new model for breaking bad news to people with intellectual disabilities. Palliative Medicine. 2012 Jan 16;27(1):5–12.	https://journals.sagepub.com/doi/10.1177/0269216311433476	Describes research to develop a model for breaking bad news in a manner that suits the needs of people with intellectual disabilities. The results identified that breaking bad news is best seen as a process, not an event or a linear series of events. Bad news situations usually constitute a wide range of discrete items or chunks of information. 'Building a foundation of knowledge' is central to the model. Information needs to be broken down into singular chunks of knowledge that can be added over time to people's existing framework of knowledge. Three other aspects should be considered at all times: capacity, people and support.

	Title	Reference	Link	Summary
4.	Communicating about death and dying: Developing training for staff working in services for people with intellectual disabilities	Tuffrey-Wijne I, Rose T, Grant R, Wijne A. Communicating about death and dying: Developing training for staff working in services for people with intellectual disabilities. Journal of Applied Research in Intellectual Disabilities. 2017 Jul 5;30(6):1099–110.	https://onlinelibrary.wiley.com/doi/abs/10.1111/jar.12382	The study aimed to assess staff training needs and to develop, trial and evaluate a training course on communicating about death and dying. It was found that staff fear, cultural influences and inexperience with death-related conversations were major communication barriers; and that intellectual disability services must have clear training strategies around death, dying and communication. Evaluation of the course was overwhelmingly positive.
5.	Breaking bad news to people with learning disabilities and dementia	Tuffrey-Wijne I, Watchman K. Breaking bad news to people with learning disabilities and dementia. Learning Disability Practice. 2015 Sep 2;18(7):16–23.	https://journals.rcni.com/learning-disability-practice/breaking-bad-news-to-people-with-learning-disabilities-and-dementia-ldp.18.7.16.e1672	A model that suggests a way of supporting staff and families to have enabling conversations about dementia that centre on the person's current situation and level of understanding and capacity.
6.	Communicating about death and dying with adults with intellectual disabilities who are terminally ill or bereaved: A UK-wide survey of intellectual disability support staff	Tuffrey-Wijne I, Finlayson J, Bernal J, Taggart L, Lam CKK, Todd S. Communicating about death and dying with adults with intellectual disabilities who are terminally ill or bereaved: A UK-wide survey of intellectual disability support staff. Journal of Applied Research in Intellectual Disabilities [Internet]. 2020 Feb 18;33(5):927–38.	https://onlinelibrary.wiley.com/doi/10.1111/jar.12714	The study investigated the extent to which staff communicate about death with people of intellectual disabilities facing terminal illness or bereavement. The report concluded that staff require training and support in communicating about death.
7.	Talking end of life with people with intellectual disability	Wiese M, Stancliffe R, Wagstaff S, Tieman J, Jeltes G, Clayton J. Talking end of life with people with intellectual disability [Internet]. Talking End of Life. Flinders University; 2018.	https://www.caresearch.com.au/tel/	Online version of the Dying to Talk project. Talking End of Life consists of 12 modules that include activities, case studies, videos, resources, and links to research.