



SYDNEY NORTH
Health Network

WELCOME

Considerations for End-of-Life Planning for People with Intellectual Disability

Tuesday 21 June, 2022

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ACKNOWLEDGEMENT OF COUNTRY



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The Sydney North Health Network wishes to acknowledge Australia's Aboriginal peoples – the traditional custodians of the land on which we meet and work.

We pay our respects and recognise their continued connection to land, water and community and honour their ancestors, Elders past, present and emerging.



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HOUSEKEEPING



- ◆ **Chat** we will use this for discussion during the presentation
- ◆ **Q&A** please use this for questions you might like to have answered at the end of the presentation. If we don't get to all the questions, we will email a summary of all questions and answers
- ◆ **Please be respectful** of other participants and behave as you would at a face-to-face meeting.
- ◆ **If your screen freezes** during the presentation, it could be your WiFi connection is limited – try moving closer to your WiFi router
- ◆ **Evaluation** – This will be available via QR code at the completion of this webinar. Please ensure that you submit this to ensure that we can adhere to our RACGP reporting requirements



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COVID ADVICE PHONE LINE

For GPs



- ◆ The GP COVID clinical advice line allows GP's to seek clinical advice for escalation and/or referral to Sotrovimab clinic from GPs working in the Virtual Hospital.
- ◆ Available from Mon-Fri between 9am-5pm until June 2022.

 0418 579 373



For referral for monoclonal antibody treatment

NSLHD-COVID@health.nsw.gov.au



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COVID HOME SERVICE

WiSE Mobile Doctor



 Mobile medical service for people in isolation due to COVID-19 to access clinical assessment and treatment for COVID and non-COVID related matters.

 Available to all household members at no cost.

 GP referral only via Healthlink, Fax or Phone.

 0412 617 276

 02 9216 7677

 WISEMEDM (Healthlink)

For more information contact SNEOC@snhn.org.au



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COVID HOME ISOLATION SUPPORT SERVICE

PCCS



 Offer social support for individuals in isolation due to COVID-19 to access local support services and community resources.

 Provide practical assistance with daily living and lifestyle needs, support to access services etc.

 No cost to patient

 Referral required. Available at pccs.org.au/chiss

 9477 8700

 02 9477 8799

 GPSOCIAL (Healthlink)

For more information contact SNEOC@snhn.org.au



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HEALTH NAVIGATORS



Health Navigators is a completely free to access hotline which is staffed by experienced nurses. Health Navigators makes it easy for health, aged and social care professionals to find local services for their frail, older or vulnerable patients/clients.

For more information visit

snhn.org.au/health-navigators

Or call 1800 271 212

Phone lines are open Monday to Friday, from 11am to 3pm.



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HealthPathways

A WAY FORWARD



HealthPathways is an online health information website which supports GPs, hospital doctors, nurse practitioners, pharmacists, allied health and other clinicians.

HealthPathways supports:

- ✓ Condition management
- ✓ Service navigation
- ✓ Referral to specialists, facilities, public and private services
- ✓ Access to reference materials
- ✓ Access to patient educational resources



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SPEAKER INTRODUCTION



◆ **DR SEETA DURVASULA | CLINICAL DIRECTOR, NSLHD INTELLECTUAL DISABILITY HEALTH SERVICE**

Seeta Durvasula is a medical practitioner who has been consulting in intellectual disability medicine for more than 25 years. She is the Clinical Director of two specialised multidisciplinary health clinics in Sydney for children and adults with intellectual disability. She is a Senior Lecturer in Developmental Disability Health, Northern Clinical School, Faculty of Medicine and Health, University of Sydney. Seeta's research interests are in mortality, ageing and frailty, and health outcomes in people with intellectual disability.

◆ **NICOLA GUY | SENIOR SOCIAL WORKER, NSLHD INTELLECTUAL DISABILITY HEALTH SERVICE**

Nicola has experience providing social work services across a range of health care and community settings including disability services, aged care, oncology and palliative care.

◆ **CATHERINE O'HEA | CLINICAL NURSE CONSULTANT, NSLHD INTELLECTUAL DISABILITY HEALTH SERVICE**

Catherine has over 30 years' experience in the disability sector and is passionate about supporting people with Intellectual Disability to be involved in their health management and decision making throughout their life including at the end of life stage. She is also enjoys assisting mainstream health/allied health staff to further develop the skills, confidence and experience in meeting the health needs of people with intellectual disability.



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Considerations for end of life planning in people with intellectual disabilities (ID)

Considering health, psychosocial factors and Quality of Life

21 June 2022

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Northern Sydney Intellectual Disability Health Service (NSIDHS)

- Specialised multidisciplinary consultative intellectual disability health service for children and adults
 - Clinical staff - medical (paediatric and adult), nursing, social work and paediatric psychology
- Clinical consultative services to community health, inpatient, ED and GP practice teams
- Clinical and capacity building focus
- Outreach to Northern NSW and Mid-North Coast LHDs

Introductions

- Professional background?
- Experience in end of life planning?

Learning Outcomes

1. Describe how mortality, avoidable deaths and co-morbidities differ in people with intellectual disability, compared to others in the population
2. Identify the main health and psychosocial factors to consider in end of life planning for people with intellectual disability
3. Recognise how the concept and perceptions of Quality of Life influence end of life planning people with intellectual disability

Questions for reflection

- When do you start end of life planning?
- Who should be involved in end of life decision-making?

How do mortality, avoidable deaths, and comorbidities differ in people with Intellectual Disability (ID)?



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Mortality / life span of people with ID

- Mortality rates higher than general population
 - SMR 3.15 in NSW population ([Florio & Trollor, 2015](#))
 - Large population based NSW study ([Trollor et al, 2016](#))
 - Main causes of death – diseases of respiratory system, circulatory system, malignancy, diseases of nervous system, injury and poisoning
 - Median age at death – 54 years
 - 38% deaths avoidable (17% avoidable deaths in comparison general population) – infections, cancer, circulatory system
- Life expectancy increasing, but up to 20 years less than in general population ([Glover, Williams, Heslop, 2017](#); [O'Leary, Cooper & Hughes-McCormack, 2018](#))
- People with ID have a high rate of avoidable deaths
- Prevention includes routine health screenings (immunisations, cancer screenings, etc) and a comprehensive annual health assessment

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Health Status

- Multiple and complex health conditions ([Liao et al., 2021](#))
 - More common than in general population
 - Epilepsy (20-30%)
 - Mental health conditions (up to 40%)
 - Depression (3 times more common), anxiety, OCD, bipolar disorder
 - Dementia - earlier onset in people with Down syndrome
 - Gastrointestinal disorders – GORD, constipation, dysphagia
 - Vision and hearing impairments (50%)
 - Endocrine disorders – hypogonadism, osteoporosis, hypothyroidism
 - Respiratory infections
 - Musculoskeletal conditions – scoliosis, contractures
 - Oral health conditions – periodontal disease
 - Polypharmacy



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Multi-morbidity and ageing

- Multi-morbidity - ≥ 2 chronic conditions
- Higher levels of multi-morbidity at younger age than in general population
 - Irish longitudinal study – 71.2% of people with ID > 40 years had multi-morbidity, compared to 58.6% of people >65 years in general population ([McCarron et al., 2013](#))
- Ageing process starts at younger age
 - 45-50 years. Younger in people with Down syndrome or cerebral palsy
 - e.g. dementia, osteoporosis, frailty develop at younger age
 - Pre-existing conditions may worsen - e.g. dysphagia, sensory impairments



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Challenges for health professionals providing end of life planning with people with ID

What do you think are the factors that need to be taken into account in end-of-life planning

- for the general population?
- for people with intellectual disability?



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What do you think are the factors that need to be considered in end-of-life planning for the General Population?

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What do you think are the factors that need to be considered in end-of-life planning for people with Intellectual Disability?

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What are the main **health factors** to consider in end of life planning for people with ID?

- Early onset of ageing and frailty
- Complex multi-morbidity
- Complexity of medical conditions
- Pre-existing conditions
- Co-existing conditions
- Diagnostic overshadowing



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Diagnostic Overshadowing

- Diagnostic overshadowing is also a contributing factor in the premature mortality and high rates of avoidable death among people with intellectual disability
- It occurs when a health professional makes the assumption that the behaviours of concern of a person with intellectual disability is a part of their disability without exploring other factors

What are the main health factors to consider during the end of life stage?

- Accurate pain assessment and management
- Skin integrity: increased pressure injury (PI) risk due to e.g. incontinence, weight loss
- Increasing risk of falls
- Constipation from pain management medication, immobility, and dehydration
- Decreasing swallowing ability – choking, aspiration, aspiration pneumonia
- Increase in distress, confusion and fear
- Fatigue
- Dementia – rapid on-set and decline (Dementia is now recognised as a terminal condition for which palliative care is appropriate)

Defining ‘Psychosocial’

- The term psychosocial denotes the psychological, spiritual and social aspects of a person’s life and may describe the way people make sense of the world
- Psychosocial care, as defined by the National Council for Hospice and Specialist Palliative Care Services, is care concerned with:
 - the psychological and emotional well-being of the patient and their family/carers (including issues of self-esteem)
 - insight into an adaptation to the illness and its consequences
 - communication
 - social functioning and relationships

What are the main psychosocial factors to consider in end of life planning for people with ID?

- Communication needs and abilities – what knowledge can be built?
- Health literacy levels – Knowledge and experiences of illness, death and dying
- Support networks – family, friends, carers, social networks, (important people)
- Family/caregiver dynamics/perceptions
- Attitudes towards death and dying of family/care givers – informal and formal
- Decision making abilities
- Expressing desires/wishes
- Level of care, accommodations, supports and capacity to meet changing needs
- Spiritual beliefs and supports
- Cultural beliefs and supports
- Emotional and mental health needs
- Existing supports – professional/formal and their attitudes and beliefs
- What is important to the patient?

Video: Talking about death and dying – the experiences of people with ID

Talking End of Life

Interviews with people with intellectual disabilities: What is it like talking about death and dying?

<https://vimeo.com/259797538>



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Communication strategies to support engagement and understanding:

- Building knowledge
- Social Stories
- Easy Read information



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Resources

- Talking end of Life...with People with a intellectual disability – An online toolkit of resources to help you to teach PWID about the end of life:
<https://www.caresearch.com.au/tel/tabid/4881/Default.aspx>
- Breaking Bad News – The Guidelines
<https://breakingbadnews.org.au>
- Palliative Care Easy Read Resources
https://www.health.nsw.gov.au/palliativecare/Pages/easy-read-resources.aspx?utm_source=CID+contacts&utm_campaign=e122ddb36-enevs_Nov19&utm_medium=email&utm_term=0_6edf5012ca-e122ddb36-46003771#bookmark1
- The Books Beyond Words Series includes a range of titles including: ‘Am I Going to Die?’ ‘Anne has Dementia’ and ‘Getting on with Cancer’
<https://booksbeyondwords.co.uk/bookshop/paperbacks/am-i-going-die>
- What matters to me: conversation guide
<https://www.health.gov.au/resources/publications/what-matters-to-me-conversation-guide>



Resources



What is Quality of Life?

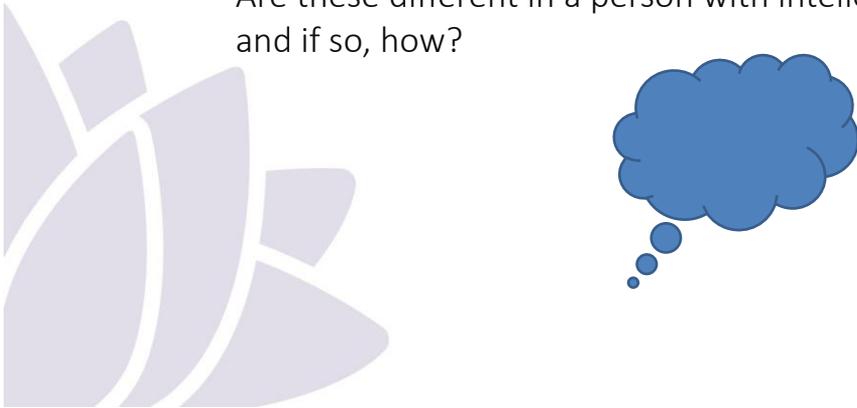


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Quality of Life & End of Life Planning

What aspects of a person's life would you take into account when determining their quality of life?

Are these different in a person with intellectual disability, and if so, how?



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What aspects of a person's life would you consider when determining their quality of life?

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Are these different in a person with intellectual disability, and if so, how?

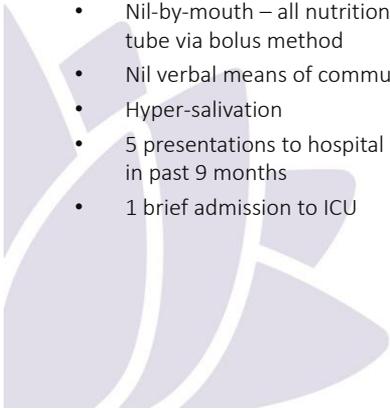
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Perceptions of Quality of Life

CASE STUDY – SARAH

- 35-year-old female
- Severe physical disability (cerebral palsy)
- Nil-by-mouth – all nutrition/fluids via gastrostomy tube via bolus method
- Nil verbal means of communication
- Hyper-salivation
- 5 presentations to hospital for aspiration pneumonia in past 9 months
- 1 brief admission to ICU
- Lives in a purpose-built group home with 3 other women
- Attends day program 5 times a week
- Participates in art and music programs
- Has many friends and a boyfriend
- Close with family, loves her nieces and nephews
- Loves watching AFL football, attending concerts



Considerations for Quality of Life

Assessing medical decisions and their impact on the person’s quality of life requires reflection and much thought

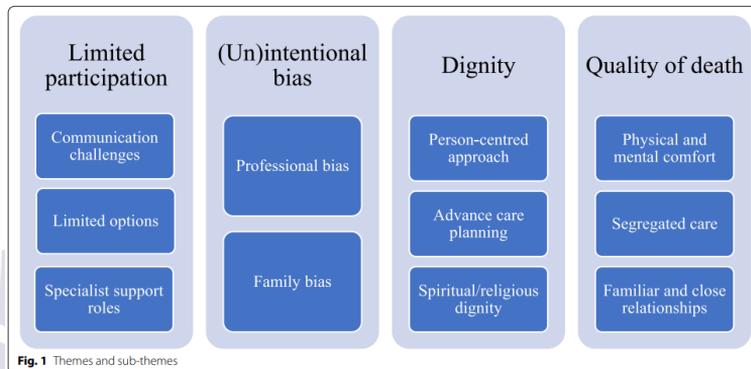


Fig. 1 Themes and sub-themes
(Voss et al., 2021, p3)

Summary

- People with intellectual disability have reduced life expectancy, experience complex multi-morbidity and early ageing
- End of life planning may need to start earlier than for others in the community
- The planning needs to take into account health and psychosocial factors, as well as a holistic view of the person's quality of life

Role of the NSIDHS

How can the NSIDHS support health professionals with end of life planning with people with ID?



Considerations for end of life planning in people with intellectual disabilities (ID)

Part 2

- Next webinar - August 23rd 2022
- Consent and supported decision making
- Applying an Ethical Decision Making Framework to end of Life Planning
- Role of appropriate and timely referrals for palliative care



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Question and Answer

Please add your questions using
the Q&A feature



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