



Disclaimer:

Intellectual Disability and Dementia

Evidence Review

The information contained in this PowerPoint presentation, is directly related to the work of the project on:

“Canadian Best Practice Guidance for Quality Community Supports and Care for Adults with Intellectual Disabilities and Dementia and Their Caregivers”



Intellectual Disability and Dementia

Evidence Review

Overview

- The brief
- Professionals and families
- Screening and assessment tools
- Training
- Individuals with intellectual disability
- Academic review
- Canadian guidelines
- Discussion

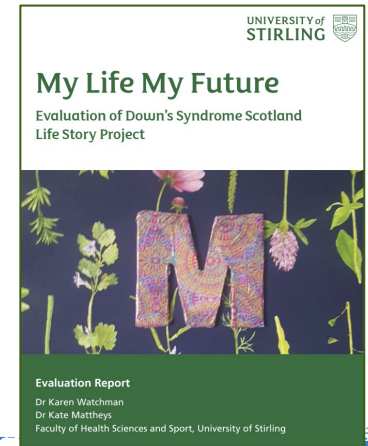
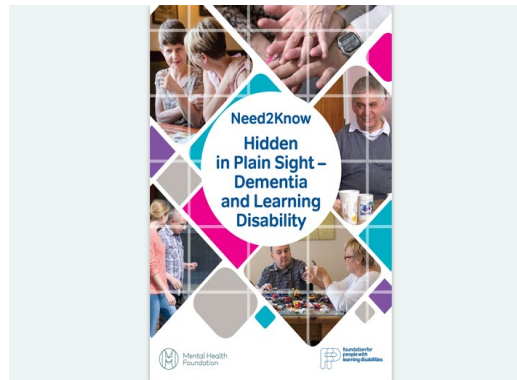
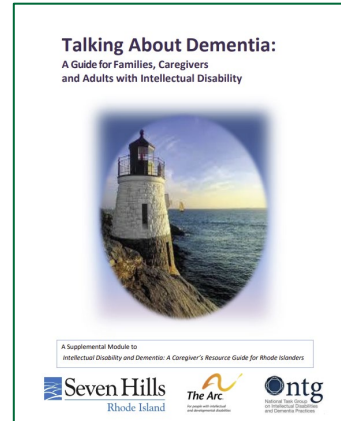
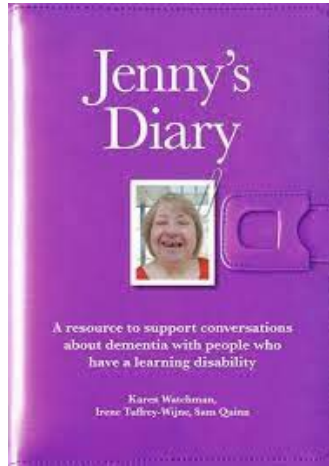
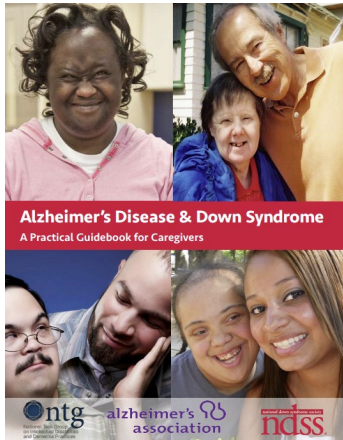


Image reproduced with permission from Stand by Me (Watchman et al., 2023)

The brief

- Summary of freely available resources and tools – practice based information:
 - for professionals, families and people with intellectual disability
 - overview of screening and diagnostic tools
 - training courses or resources available
- Rapid review of academic databases, 2016-2023, searching for:
 - interventions, community support, service provision
 - experiences of people with intellectual disability and caregivers
 - screening and assessment tools (non clinical)

Sample of resources and tools – all links provided



Information for health and social care professionals and family members - consensus

- Training required
- Multidisciplinary approach
- Need to communicate about dementia
- Palliative care
- Typically used assessment tools not appropriate
- 'It might not be dementia'
- Pain management
- Co-morbidity and medication review
- Ageing in place (stay at home) as first option, but...
- Environmental changes
- Focus on the persons strengths and choices, maintaining independence for as long as possible
- Communicate in the way the person wants
- Non-drug support
- Reminiscence including music and life story

Sharing positive experiences and memories can be important to people with a learning disability



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Lack of consensus

- Age of first baseline assessment for people with Down's syndrome
- Where someone lives as dementia progresses – referral out seen as last choice, but...
- Care home
- Best practice?
- Who provides support?
- Memory clinics/services
- Training – what and for who?
- Recognition/awareness of differences when person with dementia has an intellectual disability

What may be different?

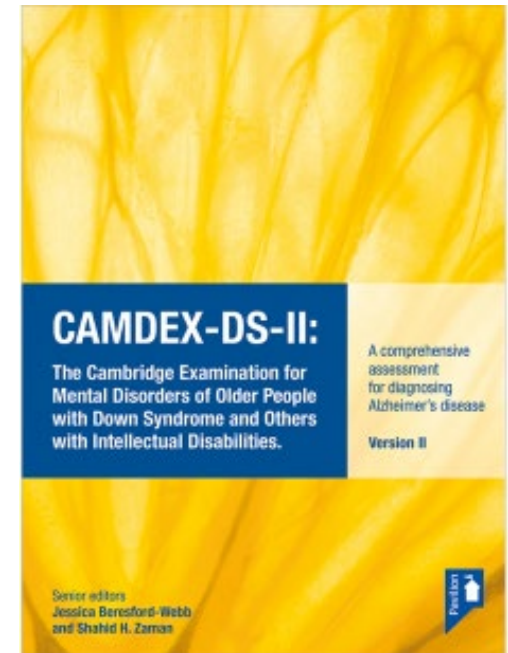
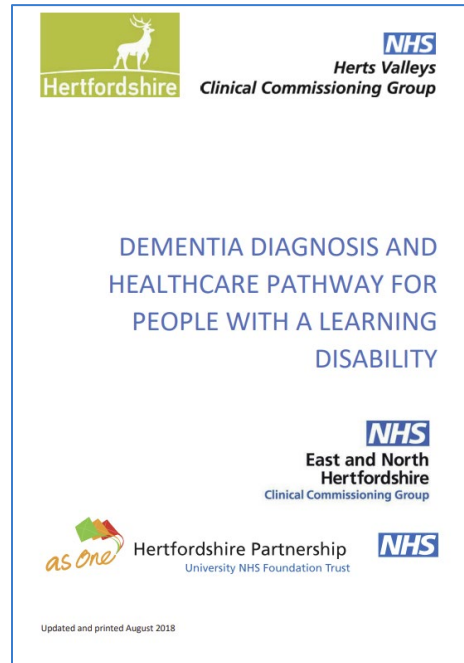


*Image reproduced with permission from Jenny's Diary
(Watchman et al., 2015)*

- Previous cognitive ability
- Process of diagnosis
- Increased misdiagnosis
- Age at diagnosis and early signs
- Disclosure of diagnosis
- Diagnostic overshadowing
- Progression of dementia
- Change in gait/walking
- Family support
- Where people live
- Apparent change in personality
- Frequency of medication review
- Late onset seizures

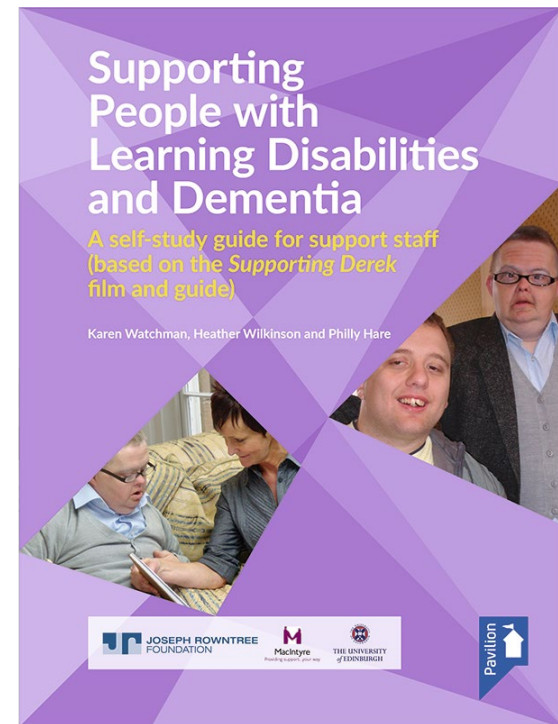
Screening and assessment tools

- Mostly screening information, some locally adapted or developed
- Baseline assessment
- Range of assessment tools – limited evidence base

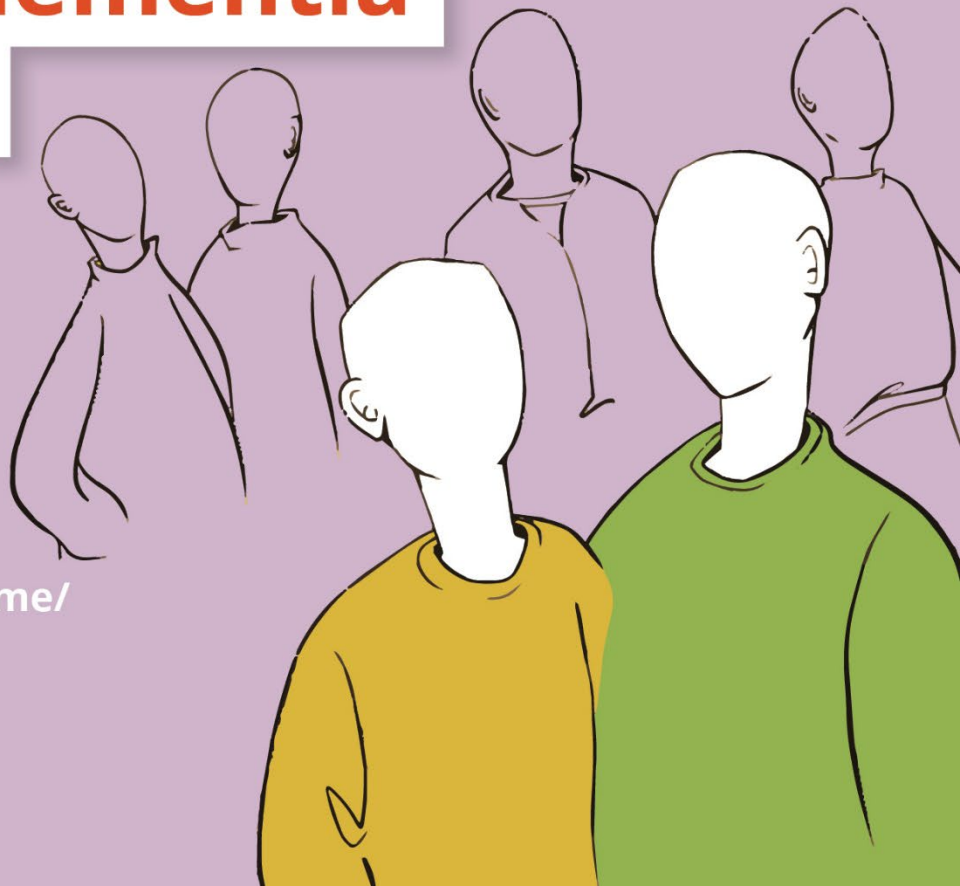


Training

- Some PowerPoint presentations online however, evidence base not always clear
- US, Canadian, UK and Ireland
- Some 'off the shelf' packages, limited face to face/real time online



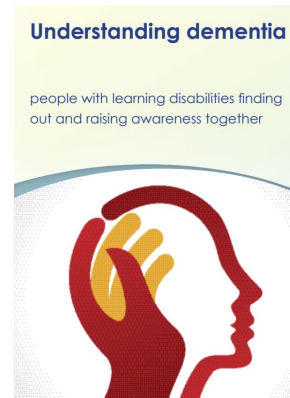
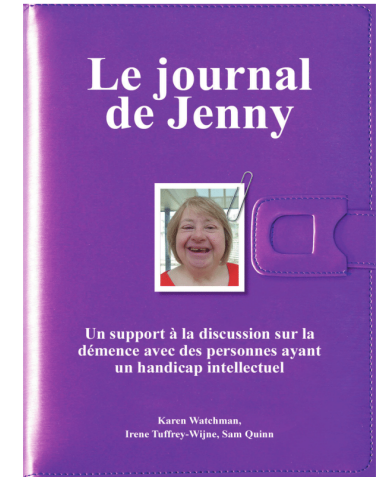
Let's talk about dementia with people who have a learning disability



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Information for people with intellectual disability

- Range of pictorial booklets and guides to explain dementia
- Resources for peers and friends
- Resources for couples
- Mostly in English language



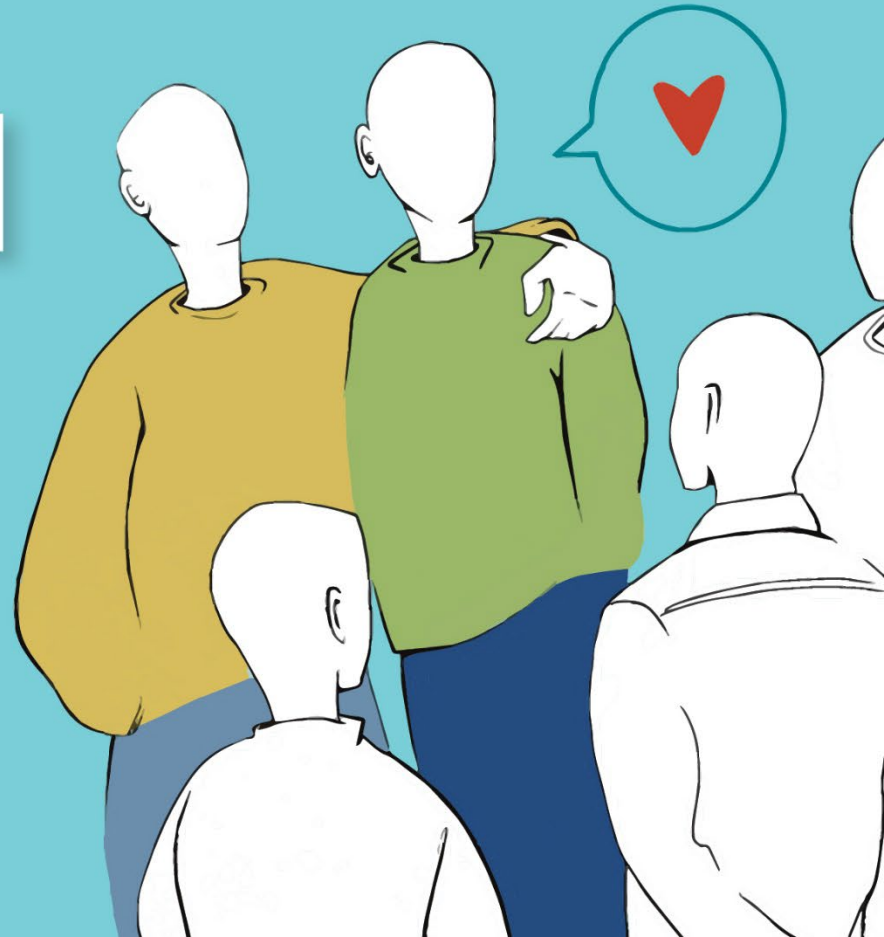
Rapid review of academic studies

- Lack of co-production
- Staging of dementia may not be appropriate
- Role of allied health professionals
- Importance of training
- Lack of advanced dementia awareness
- Impact of transitions on people with intellectual disability
- Reinforces gap between intellectual disability and dementia services/supports
- Lack of recognition in dementia national plans and strategies

What is new?

- Brain health and dementia risk reduction
- Care home (how the 'referral out' option may be supported)
- Talking about/sharing the diagnosis
- Strengths/asset/rights based
- Increased focus on end of life care
- Wider knowledge of health inequalities
- Inclusion of people with intellectual disability and dementia in research
- People with intellectual disability as carers
- Recognising couples and the importance of relationships/marriages
- Concurrent mental health problems

People with a learning disability are carers too



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Updating the Canadian Guidelines – further discussion points

- In isolation or as part of more holistic approach to aging?
- Caution over some specific service provider information
- Baseline and NTG screening tool
- Voice of people with intellectual disability
- Impact on peers
- Timeline?
 - Edinburgh Principles, 2001
 - My Thinker's Not Working report, 2012
 - Glasgow summit, 2016
 - Toronto summit, 2023

People with a learning disability can **live well** with dementia



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Thank you

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