



The Hearing Aid Podcasts



Episode 9.07

Learning Disabilities in Later Life

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Learning Outcomes

Knowledge

- Understand the difference between learning disabilities, learning difficulties, and cognitive impairment acquired later in life.
- To be aware of some of the reasons people with LD may have worse health outcomes than people without.

Skills

- To be able to adjust communication techniques where appropriate, to suit the needs of people with sensory impairment or lower intellectual ability.

Attitudes

- Recognise the importance of supporting people with LD to be involved in decisions about their care.
- Consider how a person's emotional and relationship experiences may be affected by having a LD.

Definitions

According to NICE guidance (2018) a learning disability is defined as an individual having:

- Lower intellectual ability (usually an IQ of less than 70)
- Significant impairment of social or adaptive functioning
- Onset of these features in childhood

An individual's learning disability may be identified as either mild, moderate, severe or profound in severity.

According to the Joseph Rowntree Foundation (2013) individuals diagnosed with Down's syndrome make up 15–20% of people with a known cause for their disability.

Learning **disabilities** are different from specific learning **difficulties** such as dyslexia, which do not affect intellectual ability.

People with learning disabilities may also develop other forms of cognitive impairment later in life, for example due to Alzheimer's or vascular dementia.

Main Discussion

- According to NICE, older people with a learning disability are now living 'significantly longer'.
- Estimates suggest that, by 2030, the number of adults aged over 70 using learning disability services is likely to have doubled.

[Emerson and Hatton, 2008](#)

Health and social care

As they age, this group will have many of the same health and social care needs as other older people, but are likely to face significant additional challenges due to their LD.

These challenges include:

- Higher rate of dementia among people with Down's syndrome
- Difficulty expressing their needs, which may negatively affect the accuracy and suitability of care provided to them
- Increased difficulty identifying symptoms and signs leading to missed/incorrect/suboptimal diagnoses
- Disadvantages when trying to access health and social care services -Many people with milder LD may never have received additional support).
- Poor lifestyle choices can contribute to poorer health.

The Confidential Inquiry into Premature deaths of people with learning disabilities ([CIPOLD 2013](#)) identified that the median age of death for people with learning disabilities (65 years for men; 63 years for women) was *significantly* lower than for the UK population (78 years for men and 83 years for women).

The report goes on to identify that, at the time of their death “64% lived in residential care homes, most with 24-hour paid carer support”.

[Emerson, E. and Hatton, C. \(2008\) 'Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England', CeDR Research Report, 2008:6](#)

<https://www.nice.org.uk/guidance/ng96/chapter/Context>

http://www.bris.ac.uk/media-library/sites/cipold/migrated/documents/final_reportexecsum.pdf

[Public Health England, 2014](#)

From a clinicians perspective, is there anything that explains the disparity in median age of death between adults with LD and the wider population?

This has been looked at extensively in Downs Syndrome, as the most common learning disability in the UK.

- Respiratory disease is the leading cause of death in patients with DS, with the burden of cardiac causes of death similar to that in the wider population (despite high prevalence of congenital heart disease)
- Dementia is significant in individuals with DS, with estimates suggesting at least half of individuals are affected and presenting at an earlier age than in patients without DS (though usually only over the age of 40)
- In fact, it was by looking at patterns of neuropathology in patients with DS and recognising similarities to those seen in patients with Alzheimer's disease that was a factor in the identification of the amyloid precursor protein as playing a role in the pathology of AD. The gene encoding APP is found on chromosome 21 (that which DS patients have 3 copies of).

What can we do as HCP when looking after older adults with LD, and is there anything we should be particularly mindful of?

- The learning disabilities register exists as a record of all patients with learning disabilities that have registered this with their GP. However there are 1 million people in the UK living with LD and only 200,000 on the register.
- if patients with LD are not identified, they can miss out on access to the healthcare and support - such as the annual health checks (which all LD patients are entitled to with their GP).
- Encourage patients and carers to ensure they are registered - and this can be done at any age!

- The Downs syndrome association has lots of useful resources for HCP looking after patients with DS covering topics like....
 - respiratory disease (perhaps related associations between smaller lung and airway size amongst other things)
 - continence
 - mental health
 - ageing in general.
- Be aware that the diagnosis of conditions of older age can be very hard in patients with LD. This may be related to
 - communication barriers
 - a functional impairment can be erroneously put down to a person's disability (particularly when carers change regularly or family are not around to advocate).
 - Daily carer support in everyday tasks can mask a slow loss of function over time.
- As with a patient without LD, reversible causes for decline must be ruled out when problems are brought to your attention, particularly because mimicking conditions like hypothyroidism and depression occur at higher rates in these individuals.

[Hithersay R, Startin C, Hamburg S et al. Association of dementia with mortality among adults with downs syndrome older than 35 years. JAMA Neurol 2019 Feb 1;76\(2\):152-160. PMID30452522](#)

<https://www.downs-syndrome.org.uk/for-professionals/health-medical/annual-health-check-information-for-gps/>

[Jensen K, Bulova P. BMJ 2014; 349: g559. PMID: 25269800](#)

[Strydom A, Coppus A, Blesa R, Danek A et al. Alzheimers Dement 2018; 4: 703–713. PMID: 30581976](#)

The need for a joined-up approach can be clearly seen in relation to the topic of death and dying, and the often unique experience and needs that patients with LD and their families have at the end of life.

Grief:

- Research indicates that experiences of grief are more complicated for people with learning disabilities than for the general population, and it is important that they receive good support.

- For some people it may take them a much longer period of time to realise the full implications of what has happened and therefore they may take longer to grieve.
- It is important that people working with this group are able to recognise that someone is still grieving.
- If this is having a significant impact on the person's ability to get on with their life, even some time after the event, the need for specialised therapy should be considered.

This specialised approach when providing assessment and care for individuals with learning disabilities must be considered when addressing any need or issue, for eg. in the case of memory assessment, and the need to find the right professional to perform memory assessments of patients with LD.

[Dodd, P. C. and Guerin, S. \(2009\) 'Grief and bereavement in people with intellectual disabilities'. Current Opinion in Psychiatry, Vol. 22, pp. 442-446](#)

Supporting older people with learning disabilities to make end-of-life plans:

Raise points/questions such as

- where I live
- who is important to me
- likes and dislikes
- what happens when I get ill
- what happens when I die
- my funeral
- what happens to my things.

Ward, C. 2012. Perspectives on ageing with a learning disability. Available at:
<https://www.irf.org.uk/report/perspectives-ageing-learning-disability>

Dynamics of the Caring Relationship:

A small, Canadian, qualitative study by Baumbusch et al found that ageing concurrently with a community-dwelling relative with LD is a unique experience for older adults and challenges traditional views of familial caring relationships. Relationships in these circumstances are characterised by evolving patterns of care and exchange.

There is also a sense of urgency about securing future care arrangements for the adult relative with LD. Advanced care-planning can be complicated by that person's understanding of death and dying.

[Baumbusch, J. Mayer, s. Phinney, A. & Maumbusch, s. 2015. Aging Together: Caring Relations in Families of Adults With Intellectual Disabilities. The Gerontologist, 2017, Vol. 57 \(2\),pp 341–347 doi:10.1093/geront/gnv103.](#)

So practically what can we do to optimise how we care for individuals with LD?

- we need to be aware of the laws that both protect individuals with LD and guide us when we assess, treat and work with these patients

Legal mandate:

As with any adult, the needs of this group of people are covered by the same legal mandate:

[The Care Act \(2014\)](#) - for assessing the individual's care needs.

[The Mental Capacity Act \(2005\)](#) - to assess the individual's ability to make their own decision with respect to their care and health needs

[The Equality Act. \(2010\)](#) - ensures that health and social care services (including housing) are accessible to people with protected characteristics, such as older age and disability.

We should mention at this point the Clinical Frailty Scale or CFS, which is topical at the time of the recording - during the second peak of the COVID-19 pandemic in the UK.

- NICE produced guidelines to help clinicians identify which patients with COVID-19 were at risk of more severe disease and poorer outcomes, and to identify who would benefit from critical care admission
- These guidelines included use of the CFS to help stratify patients
- There was some understandable concern from HCPs working with adults with learning disabilities that relying on the CFS to guide management in a high pressure environment would not be appropriate in this cohort of patients.
- NICE and the specialised clinical frailty network have since been clear that the CFS has not been widely validated in either the under-65s or in patients with learning disabilities, and advise against its use in these contexts.
- A patient with a stable long term disability who at face value scores the same as an older frail patient with a progressive decline may have very different outcomes from and goals regarding treatment of their illness.

<https://www.nursingtimes.net/opinion/covid-19-the-clinical-frailty-scale-and-people-with-learning-disabilities-26-03-2020/>

<https://www.scfn.org.uk/clinical-frailty-scale>

Communication:

The [Accessible Information Standard \(2016\)](#), sets out a consistent and specific approach to identifying and meeting the information and communication support needs of people with disabilities or impairments.

This can include the following:

- Seeking input from a speech and language therapist whenever needed.
- Use of an interpreter so that people can communicate in their first language, or consider the use of an advocate.
- Finding out before an appointment how the person prefers to communicate and receive information. During the appointment use visual aids and short, clear sentences to aid understanding.
- Extending appointment times to give more time for discussion.
- Giving people written information (such as appointment letters and reminders) in different languages or in an accessible format of their choice, for example Easy Read, audio books, films or by using online resources such as specialist learning disability websites.

Useful resource: [Books Beyond Words](#) link in show notes

Came across these in a webinar during lockdown by Irene Tuffrey-Wijne, who is a professor of intellectual disability and palliative care. The webinar was about helping people with learning disabilities to cope with illness, dying, death and bereavement during the COVID-19 outbreak, but the content was applicable to any time.

Housing:

The Confidential Inquiry into Premature deaths of people with learning disabilities ([CIPOLD 2013](#)) which was mentioned earlier identified that the majority of people with LD lived in residential care at the time of their death.

What are the practical implications of ageing with a LD on housing and independence?

- Much of the literature indicates that older people with a LD continue to live with their ageing parents, and are often providing care to them.
- This indicates the importance of forward planning to ensure that the whole family's needs are considered and appropriate support provided, as and when the situation changes.
- If their parents have died, it is likely they are receiving care from other family members or have had to move into some other form of accommodation i.e. residential or supported housing
- Research continues to show that many people with learning disabilities are being placed in older people's nursing or residential care at a much younger age and with a lower threshold of need ([Thompson et al., 2004](#)).

- According to Turner (2015) it should be possible to support individuals to continue to live in the family home, with careful planning and responsive services.
- Thompson and King (2001) identify the use of discretionary trusts of gifting of the property to enable this to happen and the use of disabled facilities grants to adapt the property as appropriate to do so.
- However, living alone in their own property can lead to increased vulnerability, for example bullying or the growing impact of county lines and 'cuckooing' practices in which the home of a vulnerable person is taken over by drug gangs

According to the Department of Health (2014) there are three main strands to housing policy for older people with a disability:

1. Providing support to enable people to remain in their own home
2. Ensuring that people have access to appropriate information
3. Strengthening choice for those individuals who wish to move into specialist care

[Thompson, D. J., Ryrie, I. and Wright, S. \(2004\) 'People with Intellectual Disabilities Living in Generic Residential Services for Older People in the UK', Journal of Applied Research In Intellectual Disabilities, Vol. 17, No. 2, pp. 101-107.](#)

[Turner, S. 2015. Current Policy and legislation in England regarding older people -what this means for older people with a learning disability: a discussion paper. British Journal of Learning Disability](#)

Turner, N & King D. 2001. Giving people with learning disability the chance to continue to live in the family home. Update Vol 2. Issue 17. London. The Foundation for people with a Learning Disability.

<https://www.nationalcrimeagency.gov.uk/who-we-are/publications/257-county-lines-drug-supply-vulnerability-and-harm-2018/file>

Social Isolation:

- Current policy continues to recognise the impact of social isolation on individuals. According to Turner (2015), whilst policy has recognised the specific needs of people with a learning disability there is no specific recognition of the needs of *older people* in this group.
- She goes on to suggest that there may be an assumption amongst professionals that this is a group of people already receiving support, and that alternative interventions therefore do not need to be considered.
- However, research indicates that loneliness is not necessarily related to company but to the *nature and quality* of social interactions, or a mismatch

between the relationships that individuals desire and the company they currently receive (Robins and Allens, 2013).

- Gravel (2012) identified that people who are particularly lonely are more likely to get involved in relationships which are detrimental or destructive.

[Robins, T & Allen, S. 2013. *Loneliness Resources Pack*: Joseph Rowntree Foundation.](#)

[Gravel, C. 2012. *Loneliness and Cruelty*. Lemos and Crane with FPLD and Esmee Fairbairn Foundation.](#)

Curriculum Mapping

NHS Knowledge Skills Framework

- Core 1 Level 3
- Core 2 Level 1
- Core 6 Level 1
- HWB2 Level 2
- HWB3 Level 2
- HWB4 Level 3

Foundation Programme

- Sec 1:2 Patient centred care
- Sec 1:3 Mental capacity
- Sec 1:3 Vulnerable groups
- Sec 1:4 Self directed learning
- Sec 2:6 Comm. patients/ relatives
- Sec 3:10 Support for pts

Core Medical Training

- Managing long term conditions and promoting patient self-care
 - Models of disability
 - Health and social service provision
- Health promotion and public health
 - Factors affecting health
- Principles of medical ethics and confidentiality
 - MCA

Internal Medicine Stage 1

- Generic CIPs - Category 1:1
 - Learning & teaching
- Generic CIPs - Category 1:2
 - Safeguarding
- Generic CIPs - Category 2:3
 - Barriers to communication
 - Shared decision making
- Neurology
 - Dementia and cognitive disorders
- Public health and health promotion

- Mental health
- Social deprivation

GPVTS

- 3.05 Maintaining an ethical approach
- 3.05 Communication and consultation
- 3.05 Clinical management - support services, care and accommodation
- 3.05 Managing medical complexity - recognise how comorbidity may affect recognition of adverse clinical patterns
- 3.05 Maintaining performance, learning and teaching
- 3.05 Practising holistically and promoting health
- 3.05 Community orientation - be aware of inequalities, understand key government policies, be aware of statutory and voluntary services.

Geriatric Medicine Specialty Training

- Managing long term conditions and promoting patient self-care
 - Models of disability
 - Health and social service provision
- Health promotion and public health
 - Factors affecting health
- Principles of medical ethics and confidentiality
 - MCA
- 27. Comprehensive Geriatric Assessment
- 29. Diagnosis and Management of Chronic Disease and Disability
- 30. Rehabilitation and Multidisciplinary Team Working
- 40. Community Practice Including Continuing, Respite and Intermediate Care
- 49. Dementia and Psychogeriatric Services