

End of Life Care for people with learning disabilities



Louise Jenkins
Strategic Liaison Nurse Secondary &
Tertiary care
Hertfordshire Health and Community
Services



Learning Objectives

- Overview of health risks for people with a learning disability
- Identifying strategic changes required to increase engagement with seldom heard communities
- Describing specific challenges experienced by some seldom heard groups
- Identifying useful skills, tools and resources to help overcome some of these challenges

Definition of a Learning Disability:

Impaired Intelligence (IQ below 70)

Reduced ability to understand new or complex information and impaired ability to learn new skills

Impaired Social Functioning

Reduced ability to cope independently

Started in childhood

Before the age of 18

Life long

With lasting effect on development

Valuing People Now (2009)



eQUALITY

for people with learning disabilities

Health Statistics - Did you know?

Life expectancy for people with learning disabilities is considerably lower than that of the general population (CIPOLD .2013)

The average life expectancy for **women** with learning disabilities is 63 years (Compared to the general population of 83 years).

The average life expectancy for **men** with learning disabilities is 65 years (Compared to the general population of 78 years).

People with intellectual disabilities have a shorter life expectancy and increased risk of early death when compared to the general population: figures published in 2013 showed that 22 per cent of people with an intellectual disability were under the age of 50 when they died, compared to 10 per cent of the general population.



Health Statistics - Did you know?

Respiratory disease is the leading cause of death for people with learning disabilities accounting for 46% - 52% as opposed to 15% - 17% for the general population.

Coronary Heart Disease is the second most common cause of death amongst people with learning disabilities, 14% - 20% .

People with learning disabilities have proportionally higher rates of **Gastrointestinal Cancer** 48% - 58.5% versus 25% for general population of cancer deaths.

The incidence of **dementia** amongst people with learning disabilities increases from 10-25% for ages 40 -49yrs up to 20-50% for ages 50 -59yrs and 30-75% for ages 60yrs and above.

Royal College of Psychiatrists (2009)
CIPOLD (2013)



Confidential Inquiry (2013) findings on End of Life Care

42% of deaths were considered to be premature. The most frequent reasons given for a death to be premature was because of delays or problems with treatment, or because of problems with assessing or investigating the cause of illness.

“A lack of recognition of the approaching end of life commonly led to problems in coordinating end-of-life care and providing support to the person and their family. Difficulties in obtaining Continuing Healthcare (CHC) funding were also reported”.

“People with learning disabilities were

- less likely to have access to specialist palliative care services
- received less opioid analgesia in their final illness.

So why don't you get more referrals?

What's stopping the referrals from coming through?

How can we improve this?

Identifying strategic changes required to increase engagement with seldom heard communities

- Improve understanding about what a hospice can offer with
 - People with learning disabilities
 - Families
 - Paid carers
 - Community learning disability nurses
 - GP's
- Learning from Deaths of people with Learning Disabilities (LeDeR) themes
- Purple Star Strategy accreditation

Describing specific challenges experienced by some seldom heard groups

Let's hear from Gavin

Identifying useful skills, tools and resources to help overcome some of these challenges

- Assessing what's the right approach for that person- "Breaking Bad News model" Irene Tuffrey-Wijne
- Bereavement support for people with learning disability
- Joint working between palliative care colleagues and learning disability colleagues
- Purple Star Strategy

Identifying useful skills, tools and resources to help overcome some of these challenges

Easy Read resources;

- <https://be.macmillan.org.uk/be/s-850-screening-and-diagnosis.aspx>
- <https://booksbeyondwords.co.uk/>
- <https://www.youtube.com/watch?v=gJCzKLEx6Mw>

Learning tools;

- <https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone>

Thanks for listening...any questions?



References

Ayub M, Glover G (2010) *How people with learning disabilities die. London: Improving Health and Lives* London: Learning Disability Observatory.

Baines S, Emerson E (2010) *Health Inequalities & People with Learning Disabilities in the UK: 2010*. London : Improving Health and Lives: Learning Disability Observatory.

Department of Health (2001) *Valuing people: a new strategy for learning disability for the 21st century*. London: The Stationery Office

Department of Health (2008) *Healthcare for all: report of the independent inquiry into access to healthcare for people with learning disabilities*. London: The Stationary Office.

Heslop.P, Blair.P, Fleming.P, Hoghton.M, Marriott.A, Russ. L (2013) *Confidential Inquiry into the premature deaths of People with Learning Disabilities (CIPLD) Final Report*. London: The Stationery Office