



The Learning Disabilities Mortality Review
(LeDeR) Programme

How old is 'older' for people with learning disabilities?



Professor Pauline Heslop

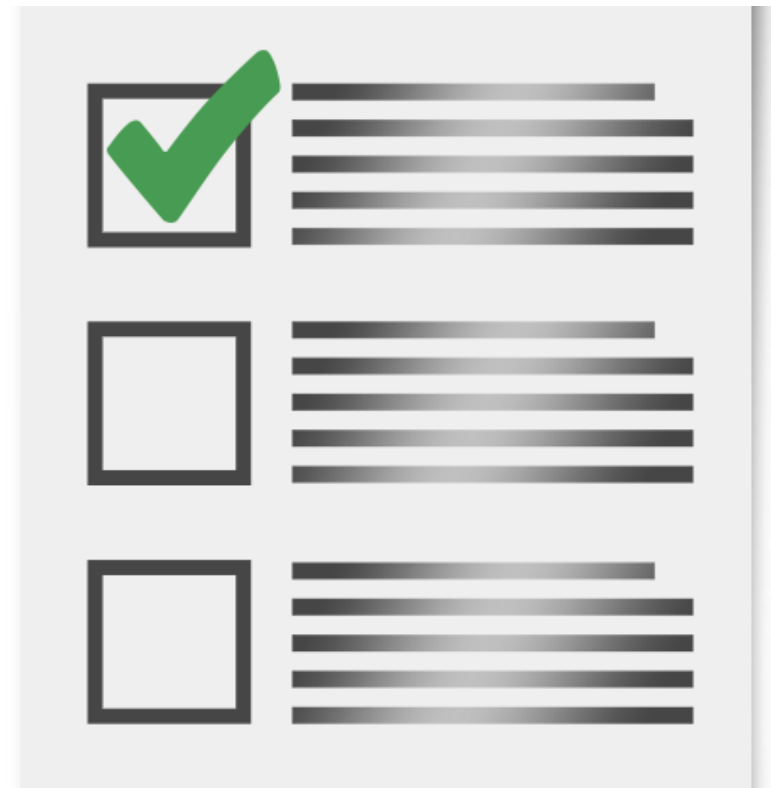


The Learning Disabilities Mortality Review (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England.



What I will be covering in this presentation

- Reminder about the Learning Disabilities Mortality Review (LeDeR) programme
- What do we know about old age in people with learning disabilities?
- Questions and discussion





The Learning Disabilities Mortality Review
(LeDeR) Programme

Reminder about the Learning Disability Mortality Review (LeDeR) programme





Background

- Department of Health (2001) Valuing People
- Mencap (2004) Treat me right
- Mencap (2007) Death by Indifference
- Michael (2008) Healthcare for All
- Confidential Inquiry into premature deaths of people with disabilities (CIPOLD) (2013)
- Mazars report (2015)



Each of these reports has documented widespread health inequalities for people with learning disabilities....but little detail about 'old' people with learning disabilities



Deaths of adults with learning disabilities

- Early deaths of people with learning disabilities: a 20+ year disparity compared to general population (CIPOLD and GPES data)
- Shortfall in age at death compared to people in the general population is 23 years for males and 29 years for females (LeDeR 2018)
- Increasing median age at death over time (now approximately 60 years) but little evidence of any substantial closing of the gap in life expectancy between people with learning disabilities and the general population
- Deaths amenable to good quality care account for a higher proportion of all deaths of people with learning disabilities than of people without, both overall, and at each age group up to age 74 (Glover et al. 2017)

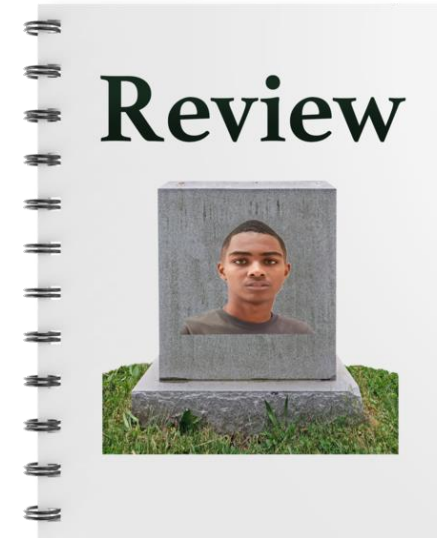


LeDeR programme aims

- a) To support improvements in the quality of health and social care service delivery for people with learning disabilities
- b) To help reduce premature mortality and health inequalities for people with learning disabilities

We do this through:

Supporting local reviews of deaths of people with learning disabilities aged 4 years and over.





LeDeR programme progress

Since the start of LeDeR we have been told about the deaths of over 4,000 people with learning disabilities.

More than a quarter of these deaths have now been reviewed

Last year's annual report was based on 103 completed reviews.

We have now submitted our annual report for 2018, which is based on over 1,000 completed reviews of deaths



NHS Long Term Plan

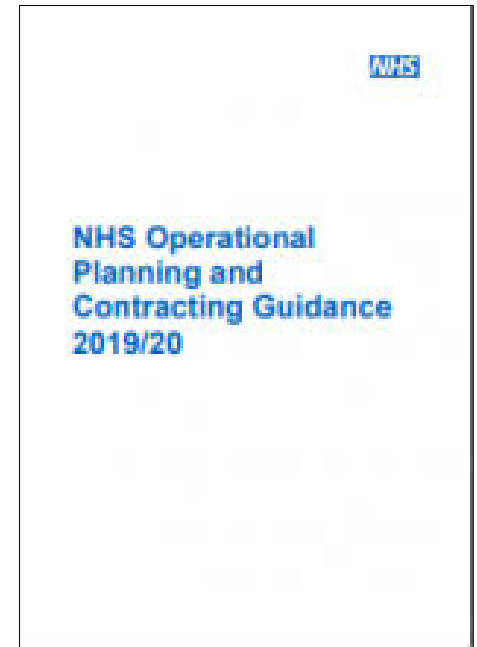
- The NHS Long Term Plan, published earlier this year, supports the continuation of the LeDeR programme
- *‘Action will be taken to tackle the causes of morbidity and preventable deaths in people with a learning disability and for autistic people...’*
 - Continue the LeDeR programme
 - Improve uptake of annual health checks
 - Expand the STOMP/STAMP programme





Planning Guidance 2019/2020

- CCGs are a member of a LeDeR steering group and have a named person with lead responsibility
- There is a robust CCG plan in place to ensure that LeDeR reviews are undertaken within 6 months of notification
- CCGs have systems in place to analyse and address the themes and recommendations from completed LeDeR reviews
- An annual report is submitted demonstrating action taken and outcomes from LeDeR reviews





National Learning into Action group

A Learning into Action group is now established at national level

Work streams cover some of the issues identified in the LeDeR report 2016/17, including: Mental Capacity Act; constipation; sepsis; identifying deterioration early

For examples of local actions see the LeDeR programme Learning into Action newsletters at:

<http://www.bristol.ac.uk/sps/leder/news/learning-into-action-newsletters/>



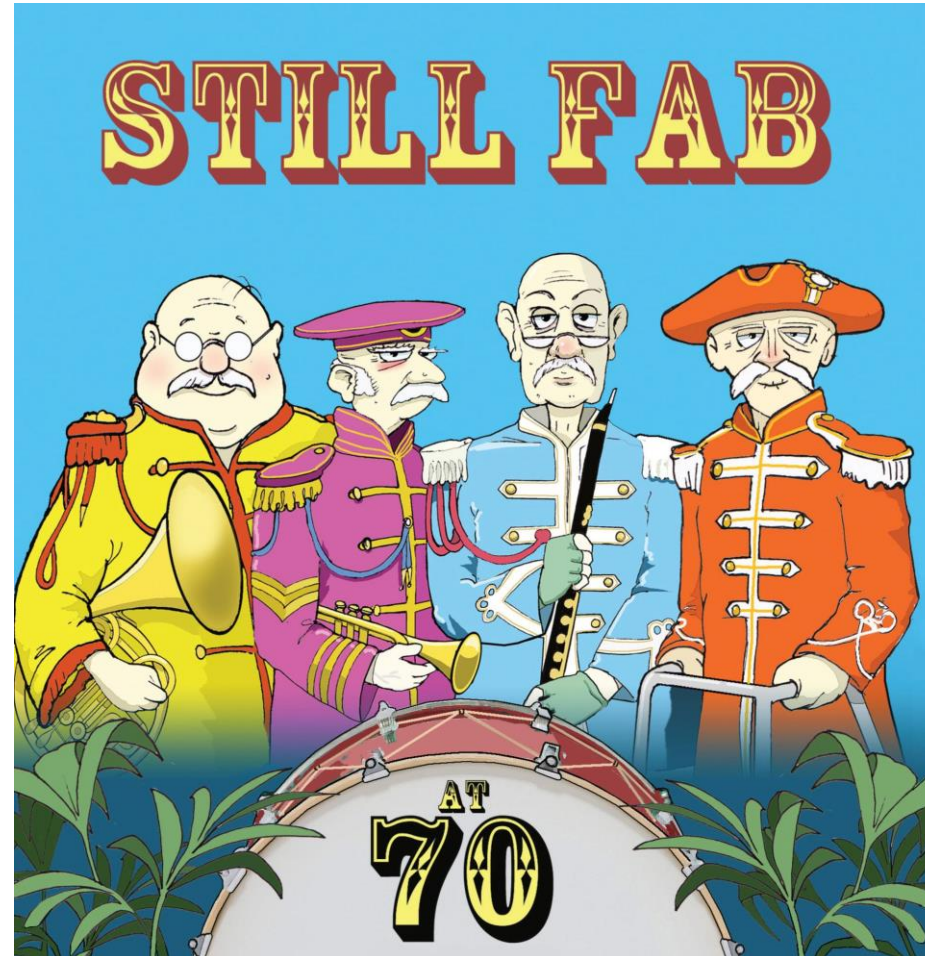


So what about older people with learning disabilities?



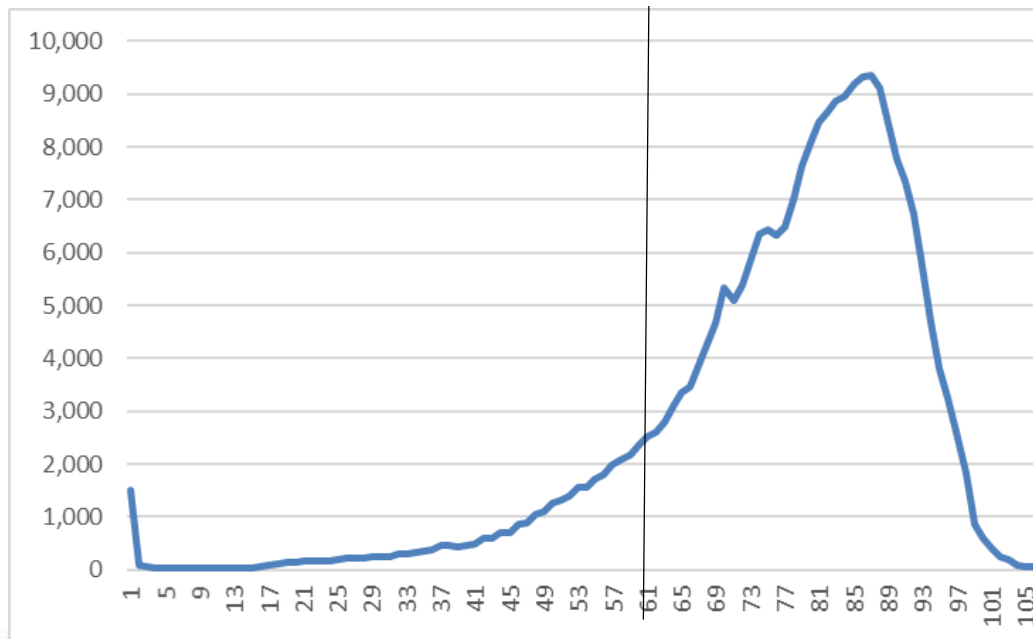


How old is 'old'?

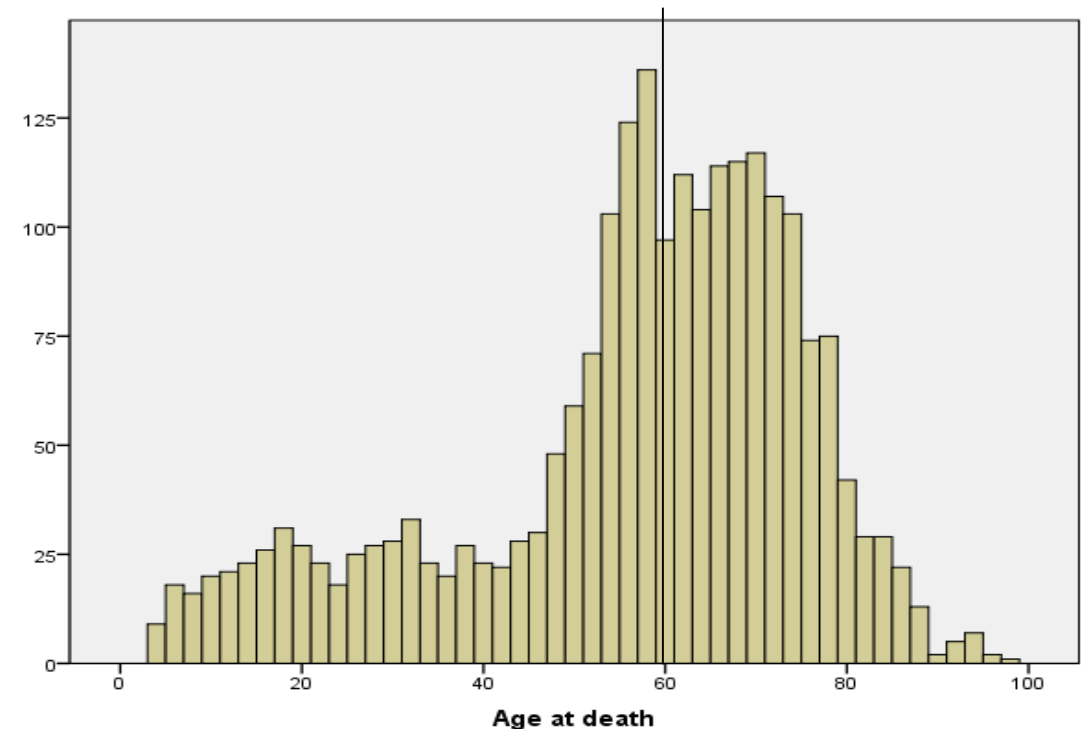




Age at death General population England and Wales 2017 (Males)

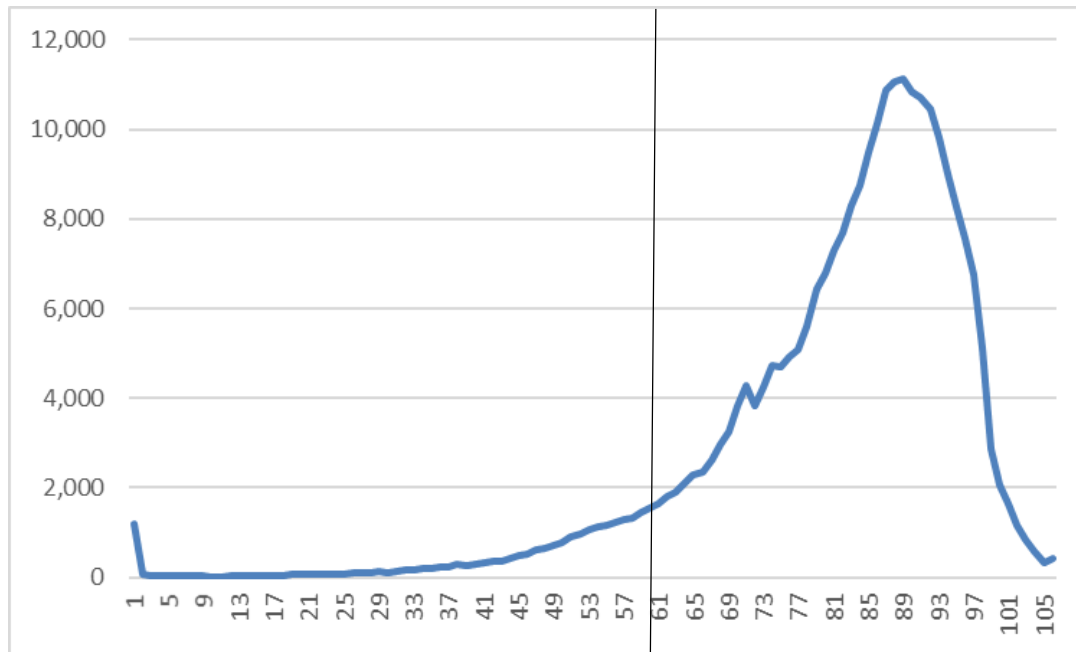


Age at death People with learning disabilities in England 2016-2018 (Males)

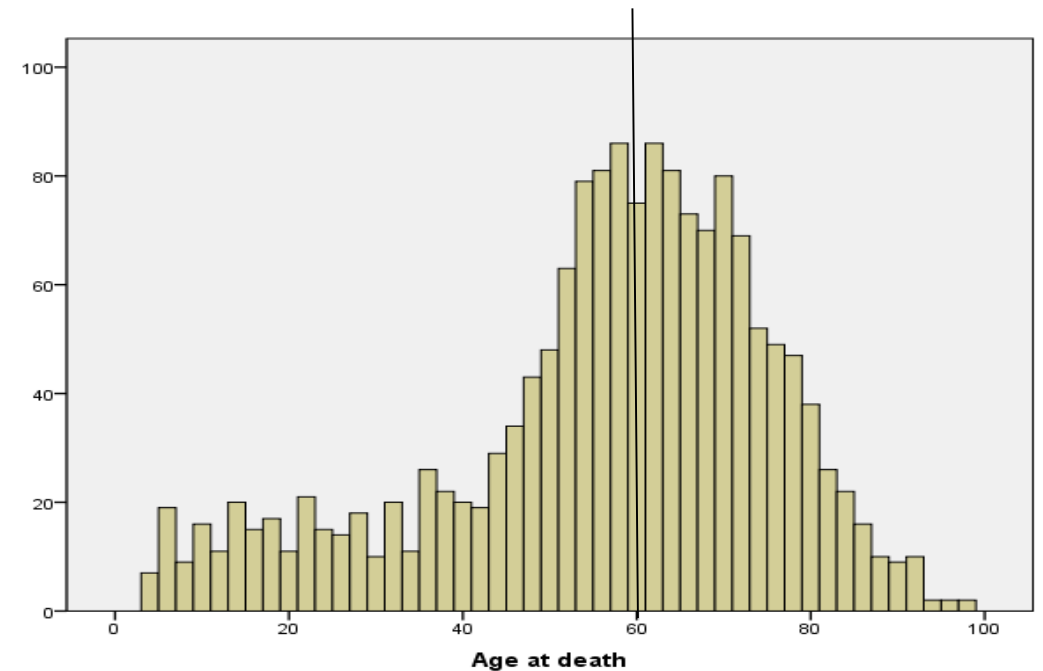




Age at death General population England and Wales 2017 (Females)



Age at death People with learning disabilities in England 2016-2018 (Females)





People with learning disabilities aged 65 and over (n=578)

- Gender
60% male, compared with 57% aged less than 65
- Ethnicity*
96.5% White British, compared to 87% aged less than 65
- Severity of learning disabilities*
72.5% mild/moderate, compared to 54% aged less than 65



Guidelines for Medical Certificate for Cause of Death (MCCD)

INTERNATIONAL FORM OF MEDICAL CERTIFICATE OF CAUSE OF DEATH

Cause of death		Approximate interval between onset and death
I Disease or condition directly leading to death*	(a) due to (or as a consequence of)
Antecedent causes Morbid conditions, if any, giving rise to the above cause, stating the underlying condition last	(b) due to (or as a consequence of)
	(c) due to (or as a consequence of)
	(d)
II Other significant conditions contributing to the death, but not related to the disease or condition causing it

**This does not mean the mode of dying, e.g. heart failure, respiratory failure. It means the disease, injury, or complication that caused death.*



Underlying cause of death

'a) the disease or injury which initiated the train of morbid events leading directly to death, or

b) the circumstances of the accident or violence which produced the fatal injury'

(WHO, 1967).



People with learning disabilities aged 65 and over

Underlying cause of death – most frequently reported

26% respiratory system

18.5% circulatory system

15% neoplasms (cancer)

8.5% nervous system





People with learning disabilities aged 65 and over

Underlying cause of death, compared to under 65s

26% respiratory, compared to 15% aged less than 65

8.5% nervous system, compared to 15% aged less than 65

7% congenital and chromosomal, compared to 21% aged less than 65





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People with learning disabilities aged 65 and over

Individual conditions on Part I of Medical Certificate of Cause of Death

Pneumonia (bacterial): 28% aged 65 and over; 23% less than age 65

Dementia: 8.5% aged 65 and over; 5% less than age 65

Down's syndrome: 6.5% aged 65 and over; 16% less than age 65

Epilepsy: 2.5% aged 65 and over; 7% less than age 65





People with learning disabilities aged 65 and over

Quality of care measures

No significant difference between people aged 65 and over and those who died younger in relation to:

- Grading of the quality of care
- Gaps in service provision
- Problems with organisational systems and processes
- Delays in service provision
- On end of life care pathway





Summary

- Median age at death of people with learning disabilities is 59 years.
- The disparity in age at death between people with learning disabilities and the general population is 23 years for males and 29 years for females.
- People aged 65 years and older with learning disabilities are predominantly of White ethnicity and with mild/moderate learning disabilities.
- People aged 65 years and older with learning disabilities are more likely to die from pneumonia and dementia than their younger counterparts.





Questions and discussion





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