

# People with a Learning Disability LEDER & Health Inequalities

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# LEDER Programme

Learning from Life and Death Reviews – people with a learning disability and autistic people



- People with a Learning Disability and or Autism continue to face increased inequity in healthcare. We know the gap in health inequality widened as a result of COVID 19.
- The Learning Disability and Autism Life and Death Review Programme (LeDeR) reviews the life and deaths of all people with a learning disability aged 4 years + and adults, diagnosed as Autistic
- The 2021 LEDER report shows data relating to the deaths of people with a learning disability.
- Autism deaths are yet to be reported on.

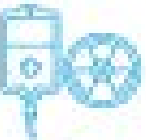
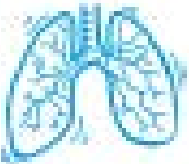
## What do we know about those who died in 2021

- 3304 deaths were reported to LEDER in 2021
- People die on average 22yrs & 26yrs younger than the general population.
- The median age of death for men and women in 2021 was 61yrs of age
- Over 50% of people who died lived in the most socially deprived areas of England.
- If you came from a black or minority ethnic group, had recently been treated for DVT or had epilepsy, you are likely to die much younger than those without. (DVT new finding)

# What did people die from in 2021?

Top 5 causes of death:

- Covid 19 21.3%
- Diseases of Circulatory system 14.3%
- Diseases of the respiratory system 12%
- Cancers 11.4%
- Diseases of the nervous system (11%



# Causes of death

## COVID

- In 2021 COVID 19, was the leading cause of death in people with a learning disability.
- Although deaths have reduced from 2020, 34.3% they still remain double of numbers seen in the general population (21.5% v 10.4% gen pop)

28% of people who were unvaccinated died from COVID 19 compared to 3.4% who were.

Men and women with a learning disability died in similar numbers. This varies from the death rates in the general population where men appeared to be at greater risk.

Vaccination continues to play significant factor in protecting people and reducing further deaths.

## Bacterial Pneumonia & Aspiration Pneumonia

- ▶ Had been the leading causes of death prior to COVID.
  
- ▶ There has been a significant reduction in numbers and proportions of deaths due to pneumonia ( (52%) in 2018; to 21%) in 2021).
  
- ▶ This may in partly due to the effect of measures taken to control COVID-19 (social distancing, face coverings, reduced number of large gatherings), that also had a positive impact on pneumonia, though could also be due to some pneumonia deaths being classified as COVID-19.
  
- ▶ The 3 most common respiratory causes of death for people that died in 2021, were:
  - COVID 19 63.9%
  - Pneumonia, organism unspecified 21.2 %
  - Pneumonitis due to solids and liquids 3.5%

## Cancer

In LeDeR data for 2021, the top 6 cancers were:

- ▶ stomach cancer, 34.7%
- ▶ bowel cancer 13.6%
- ▶ cancer of the blood 11.2%
- ▶ lung cancers, 8.4%
- ▶ breast 8.4%
- ▶ ovarian cancer, 8.0%
  
- ▶ Most common sub cancers: Colon and rectum, Oesophageal & Pancreatic

## Avoidable medical causes of death - Learning

- ▶ In 2021 people died from an avoidable medical cause of death more than twice as seen in the general population (49% vs 22%). NEY 47%
- ▶ 33% of avoidable deaths were linked to epilepsy, 31% cardiovascular conditions, 17% to diabetes and 17% to respiratory conditions, 14% to hypertension
- ▶ Deaths were more likely to be assessed as being avoidable with increasing age, which remained an important predictor after taking account of other factors.
- ▶ The highest risk for avoidable deaths were seen in “middle aged” groups (age 50 - 64), before decreasing for those aged 65+.
- ▶ The 50-64 age group were nearly five times as likely of having a death classified as avoidable.



## Medical Certificate of Cause of Death - Learning

- ▶ Continued inaccuracy of the coding of the underlying causes of death continues to be seen in the deaths reviewed within LEDER
- ▶ This includes recording of learning disability, Downs syndrome and cerebral palsy, as a direct contributory factor or the direct primary cause of death of the person (diagnostic overshadowing)  
Examples seen include: 1a Learning Disability / 1a Pneumonia, 1b Downs syndrome
- ▶ Coding underlying causes of death as being from congenital and chromosomal causes, conceals the more specific causal sequence of events leading to the person's death.

# Coroners referrals –Learning

- ▶ In 2020 and 2021, a lower proportion of all deaths were reported to a coroner than in previous years (This may partly be due to COVID-19)
- ▶ Pre COVID- 19 - Having a learning disability made you less likely to have your death reported to the coroner (32%) than people in the general population (41%).
- ▶ However more likely to have a post-mortem (50%) than those in the general population (39%)
- ▶ More likely to have an inquest (28%) in comparison to a those in the general population (13%).

**\*Despite this not all deaths are referred to the Coroner which should be. This appears linked to the quality and accuracy of causes of death cited on the MCCD.**

## DNACPR - Learning

64% of people who died in 2021 had a DNACPR in place at the time of death. Reviewers judged that this was followed appropriately for 60% of deaths.

In comparison to previous years, there was an increase in the proportion of deaths in which the reviewer was unable to determine whether the process for making a DNACPR decision had been correctly followed and a slightly larger proportion with non-compliance to DNACPR protocol around the time of death.

There remains concerns around a number of issues linked to DNACPR including:

- ▶ Lack of awareness by the person or their NOK, that a DNACPR had been put in place
- ▶ lack of use of the Mental Capacity Act, to confirm the person didn't have capacity to be involved in the discussion about placing a DNACPR and not using the Act to make a Best Interest Decision, involving carers and families.
- ▶ The clinical rationale for its application was the person had a learning disability, down's syndrome or cerebral palsy

# The Challenges of Recognising Early Deterioration In Physical Health

- ▶ The following factors can impact on early intervention and diagnosis:
  - Physical illness manifesting itself as a change in behaviour in the person, changes can be both subtle or significant and overshadow the actual physical illness
  - Playing down or indicating an absence of pain
  - Inability to describe symptoms, or recognise in themselves, that they are very unwell.
  - Fear and anxiety
  - Not wanting to be examined or seen by a doctor
  - Not having the capacity to make treatment decisions for themselves
  - Not being able to self report illness
  - We know that families and carers who know a person well, are often the best placed at recognising an individual is 'unwell' but their invaluable insight can be ignored
  - Using the support of Acute LD Liaison Nurse / LD teams can have a significant impact on outcome
  - Staff using and referring to Hospital / Health passports

## Inequity In Access To Services

Leder continues to highlight concerns across a number of areas which impact on mortality & health and wellbeing.

- ▶ Delays in diagnosing and treating illness
- ▶ Delay in appropriate investigations
- ▶ Delay in the timely provision of medical care
- ▶ Delay in processes related to the Mental Capacity Act
- ▶ A lack of Reasonable adjustments in line with the Equalities Act
- ▶ Appropriateness / good documentation of DNACPR orders
- ▶ Diagnostic overshadowing impacting on treatment offered

# Useful Links

[National LEDER Annual Report 2021](#)

[leder-main-report-hyperlinked.pdf \(kcl.ac.uk\)](#)

[See Me \(miXiT\) YouTube: Human: https://youtu.be/-jxKZ5HNMeA](#)

[Easy read booklets \(mariecurie.org.uk\)](#)

[Mental capacity in palliative care | Information for professionals \(mariecurie.org.uk\)](#)

[https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf](#)

[Learning Disability Palliative Care Network: PCPLD Network – Palliative Care of People with Learning Disabilities Network](#)

[LDA North Health Inequalities Community of Practice – email \[maria.foster2@nhs.net\]\(mailto:maria.foster2@nhs.net\)](#)

QUESTIONS?

# Reflecting as you travel home

Reflecting on all the sessions you have heard today take a moment to consider.

- ▶ What have you learnt that you did not know before or what inspired you the most ?
- ▶ What will you take back to your workplace and consider implementing or improving in practice ?
- ▶ What from what you heard today might be key priorities for your organisation?
- ▶ What could be the challenges to meeting these priorities ?



# Future Sessions - Lunch and Learn

▶ 19 October 2022

Sue Bottomley National Programme Director palliative and end of life care  
Topic- ICB statutory guidance PEOl and commissioning and contracting

▶ 9 November 2022

HEE colleagues

Topic- Nurse apprenticeships and nursing associate opportunities

▶ E mail Stephanie Beal [stephaniebeal@nhs.net](mailto:stephaniebeal@nhs.net) for the link



## Evaluation

Please help us by completing the evaluation for the conference by using the QR code attached. (Copies are also on the tables).

We welcome your feedback!



**Scan me!**

# Staying up to date

NHS Futures National End of Life Care Practitioners Network

E mail: [Sherree.Fagge@nhs.net](mailto:Sherree.Fagge@nhs.net) to join

To be added to the SCN distribution list for future webinars,

E mail: [stephaniebeal@nhs.net](mailto:stephaniebeal@nhs.net)

To suggest topics for future *Lunch and Learn* webinars,

E mail: [marie.hancock2@nhs.net](mailto:marie.hancock2@nhs.net)

Please use our website.

<https://www.yhscn.nhs.uk/palliative--end-of-life-care-clinical-network>