APPENDIX B

LLR LeDeR Annual Report 2023

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Reviews of deaths in 2022/23

83 deaths of people with a LD and Autistic people were reviewed by the LLR LeDeR Programme in 2022/23

Of those

- 3 were autistic
- 6 were children with LD
- 72 were adults with LD
- 2 were out of scope

Ethnicity

- 82% were ‘White’
- 12% were ‘Asian or Asian British’
- 1% were ‘Black, African, Caribbean or Black British’

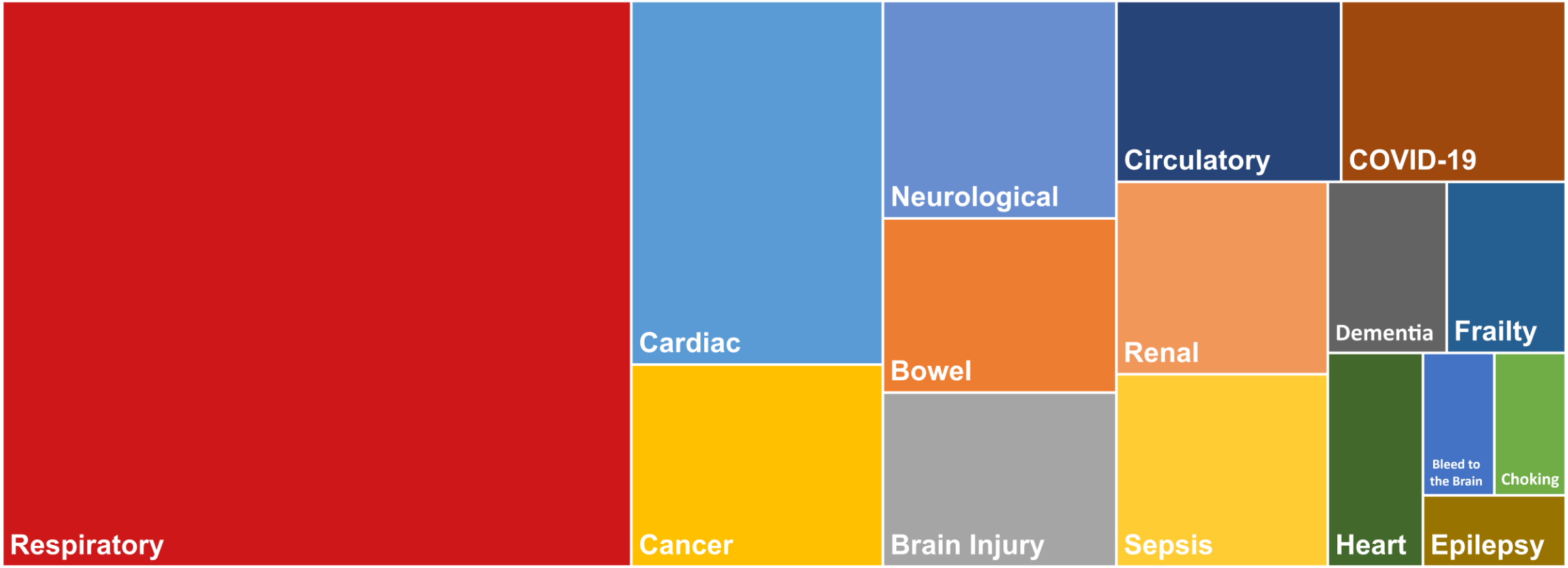
Age at death

Median age at death for those whose deaths were notified to LeDeR in 2022/23, was **62**

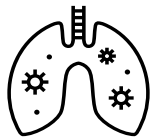
- **34% of deaths from aspiration pneumonia were <u>avoidable</u>**

Causes of death

Respiratory remains the leading cause of death for those in LLR



Deeper analysis and areas of focus



Aspiration Pneumonia

Covid-19

Weight management

Mental Capacity Act assessment

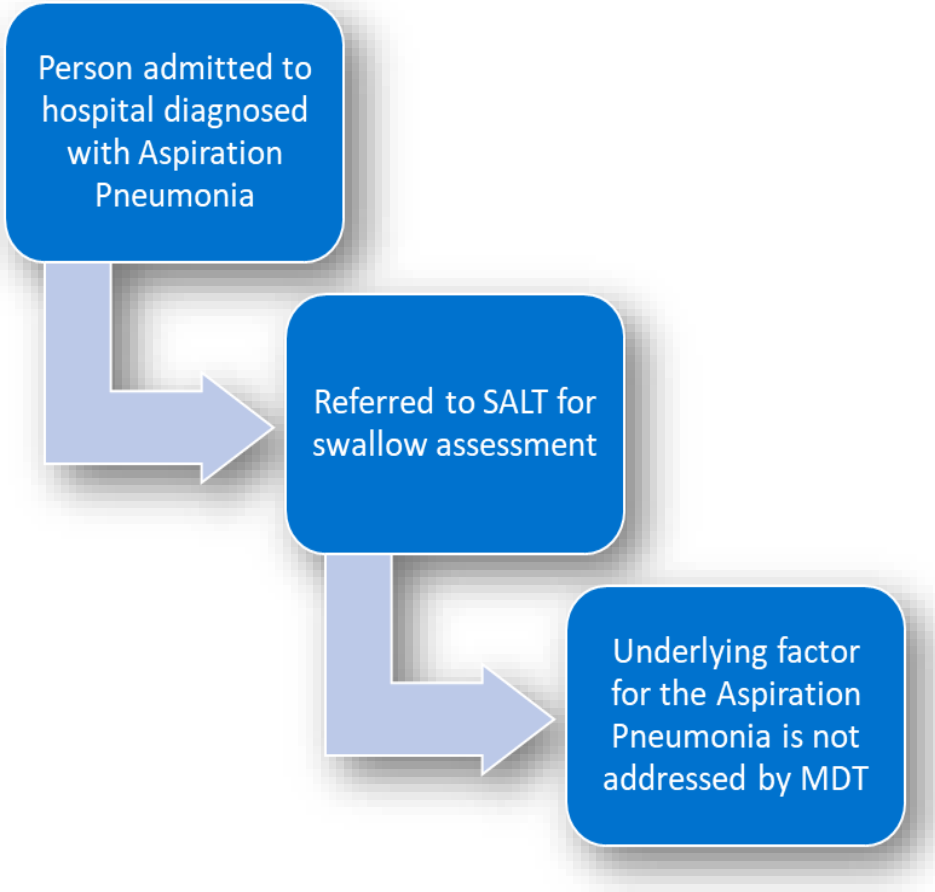
Inequalities

Venepuncture

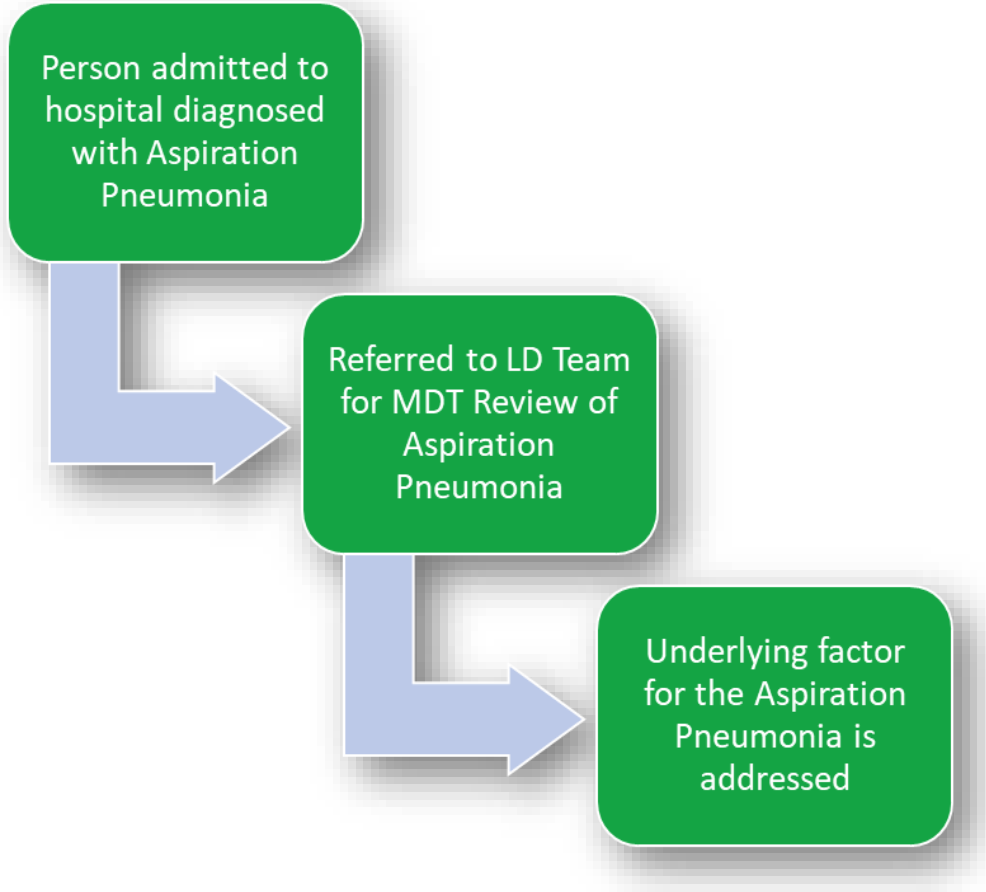
- Can be extremely challenging if a person is not compliant with the blood taking procedure and carries risks
- LLR is seeking to establish a venepuncture service appropriate for those who have received all support currently available, but require more restrictive intervention under the MCA in community care
- Successful trial with two people who had not had bloods taken for several years

Avoiding deaths from aspiration pneumonia

Current Aspiration Pneumonia pathway



Proposed Aspiration Pneumonia pathway



LeDeR 2023 TOP TEN things you can do to help

to prevent deaths of people with a learning disability and autistic people (aged 18 and over)

1. **Tell us when an autistic person dies. Deaths of autistic people are significantly under-reported.** We cannot learn from someone's life and death if we don't know they have died. Report all deaths of autistic people (with or without a learning disability) to the LeDeR Programme. This is easy to do and takes 2 minutes at https://leder.nhs.uk/report
2. **Deaths from some places and ethnic groups are under-reported. Deaths of people in Leicester City area, and of people from diverse ethnic backgrounds are not being referred to the LeDeR Programme**. This means we are unable to learn whether place of residence or ethnic background affects someone's life expectancy. Please refer all deaths to https://leder.nhs.uk/report
3. **Mental Capacity Act Assessments really do make a difference. There is widespread under-use and inappropriate use of the Mental Capacity Act across health and social care**. Please review your own practices to ensure compliance with this important legislation and share your experience with others.
4. **Weight: don't estimate, measure and record accurately. Many of those who die early have not had their weight measured accurately or managed well.** The practice of estimating someone's weight is a significant risk for people, but it is common. People **must** be weighed using appropriate weighing equipment and the weight should be recorded accurately.
5. **Plan support for people well in advance. Clear plans should be created for every person with behaviour that challenges highlighting the support they require and anticipating the support they are likely to need in the years ahead.** The needs of people with learning disabilities as physical health and nursing care increase, particularly towards the end of their life.

Top ten continued…

6. **Talk about End of Life well in advance. Care providers must be competent and confident in talking about end-of-life matters.** Have these meaningful conversations at the right time; when people are still able to take an active part in conversations about their care.
7. **Screening, screening, screening! Screening inequities exist, and every effort should be made to improve uptake**. Barriers to non-invasive bowel screening should be rectified. Speak to your Primary Care Liaison Nurse for support.
8. **Stop prescribing psychotropic medications unless they are absolutely necessary. The** STOMP/STAMP **agenda is well-established, but there's much to do**. Generic, physical, and mental health services all need to understand the need to reduce unnecessary medications. In the 12 months to October 2023, over 700 people with a learning disability and autistic people in LLR have had their medications reviewed and reduced as a result.
9. **30% of deaths from aspiration pneumonia are preventable. Aspiration pneumonia happens as a consequence of a precipitating event**. Early identification of risk factors and ongoing management save lives. The learning from LeDeR shows that changing of pathway at discharge to LD MDT rather than to SALT only, **will** prevent deaths.
10. **Blood tests save lives…if you can, take some blood! If you can't, there is help available.** There is specialist support for people in the community who have been unable to have blood taken from standard phlebotomy.

And finally…**spread the word!**

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