

KEY OVERALL DEMOGRAPHICS FROM THE LEDER REPORT

SEX

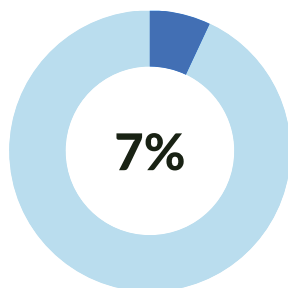
54.7% of adults notified with a learning disability who died in 2023 were male.



79.5% of autistic adults who died in 2021-2023 were male.



ETHNICITY



7% of adults notified to LeDeR in 2023 were from an ethnic minority group.

AGE AT DEATH

In 2023, adults with a learning disability on average die 19.5 years younger than the general population.

MEDIAN AGE AT DEATH OF ADULTS WITH A LEARNING DISABILITY WHOSE DEATH WERE NOTIFIED TO LEDER BETWEEN 2018 - 2023

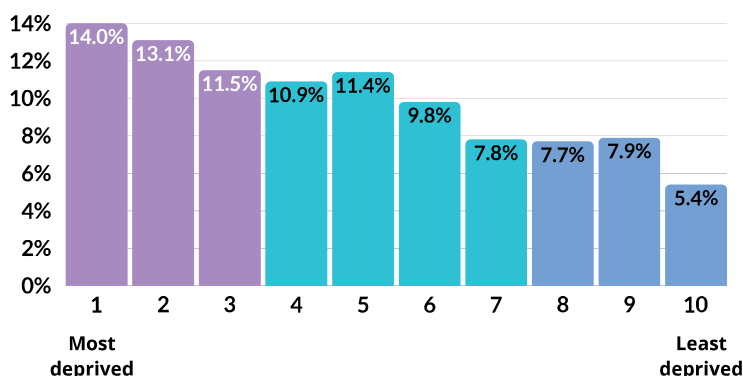
62.5

*Note: Age at death is not the same as life expectancy.

DEPRIVATION

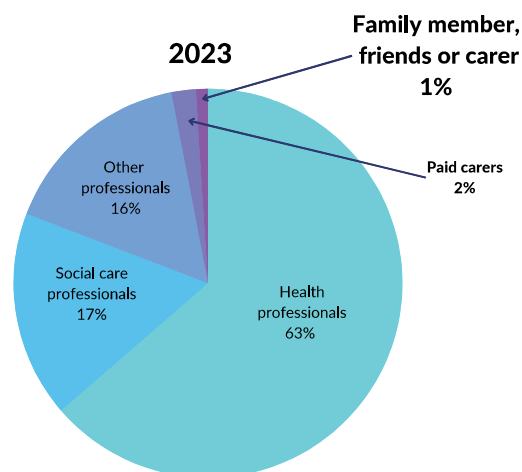
- 38.6% of adults who died lived in most deprived areas (1-3).
- 21% of adults who died lived in the least deprived areas (8-10).

2023



WHO NOTIFIED LeDeR?

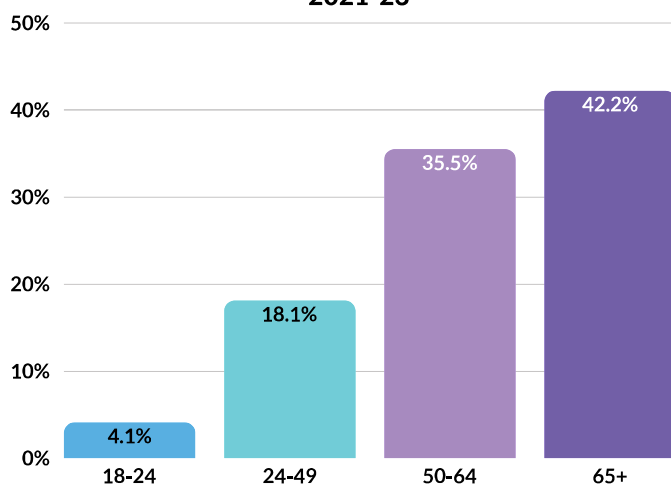
1% of deaths notified to LeDeR were made by a family member, friend or carer.



DEATHS BEFORE 65

Nearly 60% of adults with a learning disability who had a LeDeR review died before the age of 65 years.

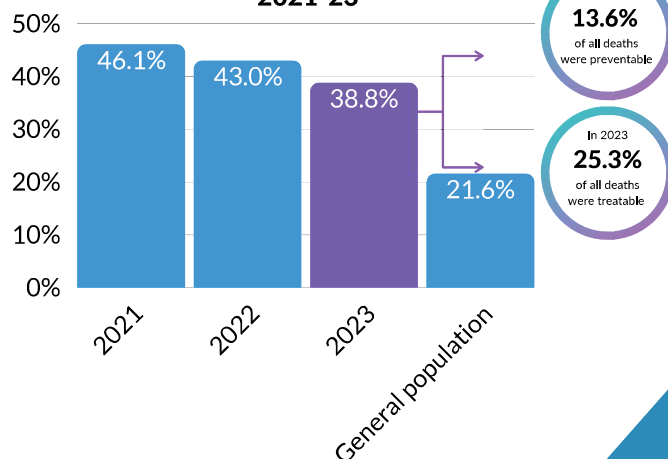
2021-23



AVOIDABLE DEATHS

Avoidable deaths have declined since 2021, however, the rate for adults with a learning disability who died in 2023 is still nearly **double the rate compared to the general population** (data for 2022).

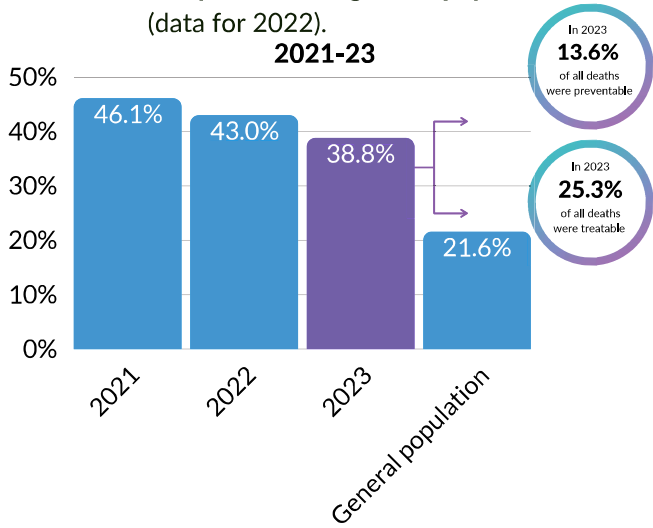
2021-23



CHAPTER 1 - REVIEW OF THE LIVES AND DEATHS OF PEOPLE WHO DIED BETWEEN 2021 AND 2023 WHO HAD A LEDER REVIEW COMPLETED BETWEEN JUNE 2021 TO JULY 2024

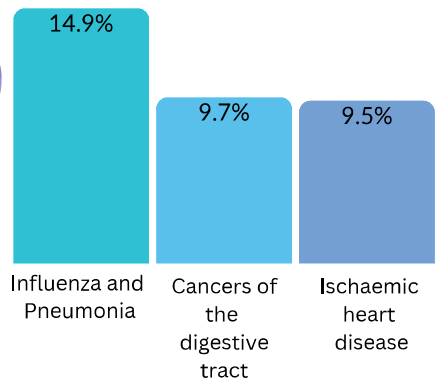
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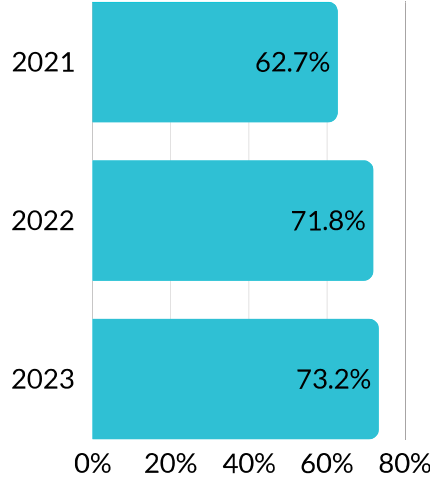
MOST COMMON AVOIDABLE DEATHS (2023)

The 3 most common causes of avoidable deaths are influenza and pneumonia (14.9%), cancers of the digestive tract (9.7%) and ischemic heart disease (9.5%)

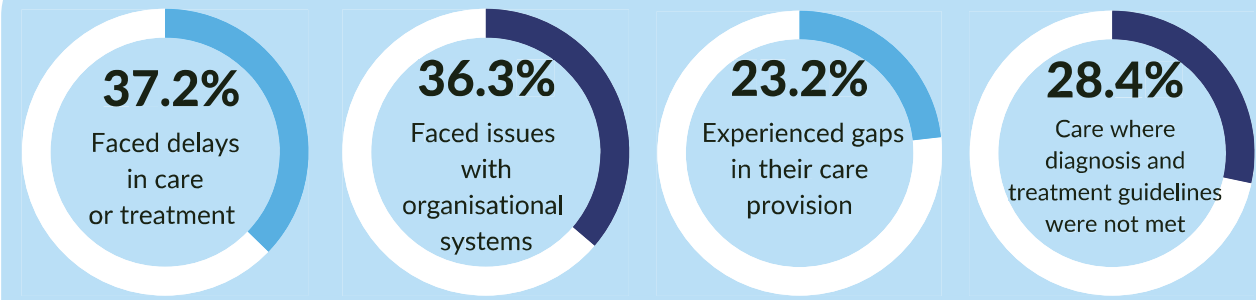


IMPROVEMENTS IN POSITIVE PRACTICE

The % of reviews identified with good practice has increased year on year.



KEY CARE FINDINGS OF 2023



MEDIAN AGE AT DEATH

The median age at death has remained similar since 2021. The median age peaked in 2020 to 63.0 years, and was lowest in 2019 at 61.7 years.

When comparing 2018 to 2023 the median age at death has increased by 7 months.

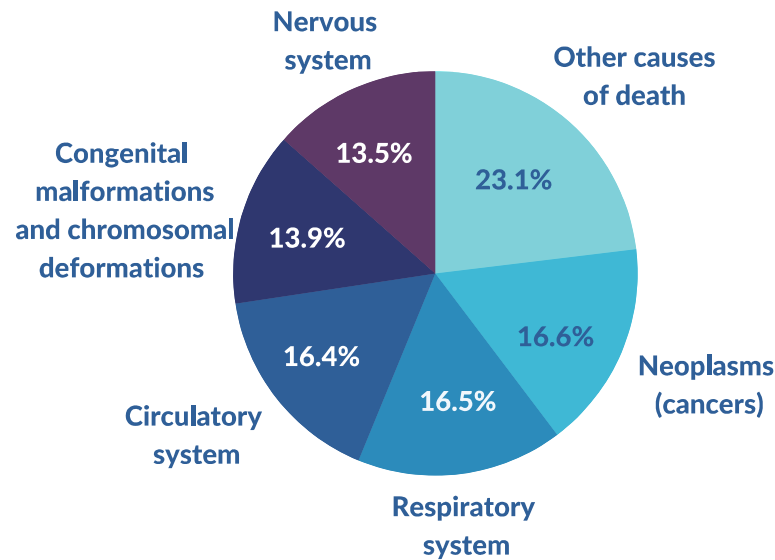
The median age at death for people with a learning disability who were reported to LeDeR is around **20 years lower than for the general population.**

Year of death	Median age at death (years)	IQR
2018	61.8	52.2 to 71.1
2019	61.7	50.8 to 71.1
2020	63.0	53.3 to 72.3
2021	62.1	51.9 to 71.8
2022	62.2	51.4 to 71.8
2023	62.5	52.5 to 72.0

*note median age at death is not life expectancy.

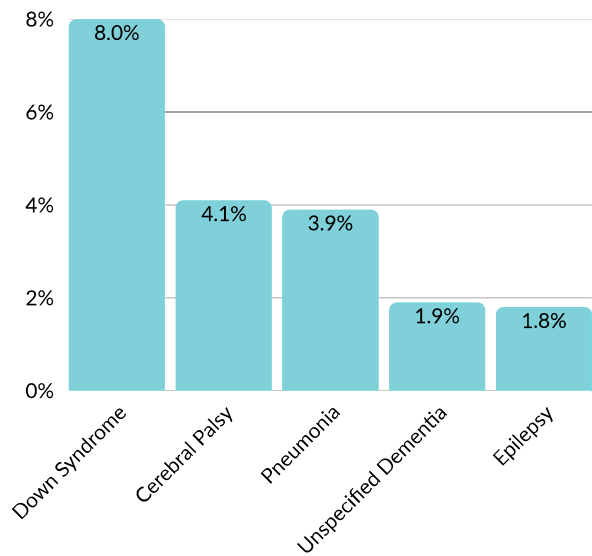
MOST COMMON ICD-10 CODE CAUSES OF DEATH IN 2023 OF ADULTS WITH A LEARNING DISABILITY WHOSE DEATHS WERE REVIEWED

76.9% of deaths in 2023 occurred within 5 ICD-10 groupings.



MOST COMMON UNDERLYING CAUSES OF DEATH IN 2023 OF ADULTS WITH A LEARNING DISABILITY WHOSE DEATHS WERE REVIEWED

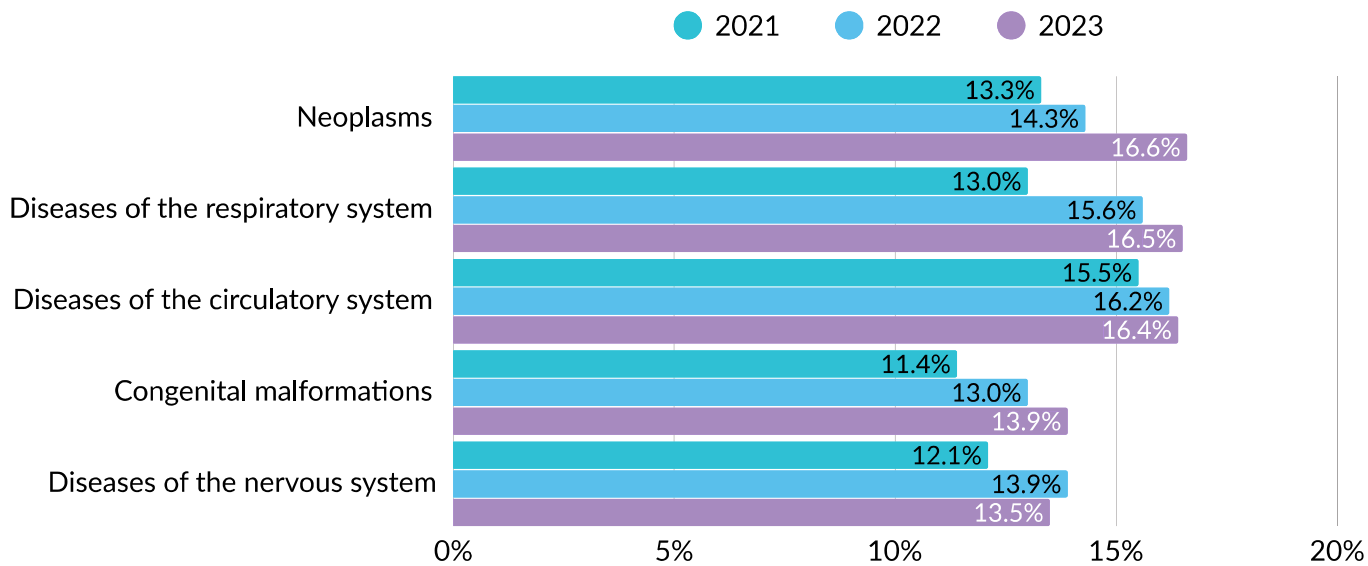
19.7% of deaths in 2023 occurred within 5 reported underlying ICD-10 causes of death..



Although Down syndrome and cerebral palsy should not be listed as the only cause of death on the MCCD, it may be appropriate for them to be listed as the underlying cause of death if the sequence of events or conditions that lead to death is fully recorded, and Down syndrome or cerebral palsy likely resulted in the condition (e.g., if the death was due to a congenital heart defect associated with Down syndrome) (see guidance for completing death certificates).

MOST COMMON GROUPED CAUSES OF DEATH SINCE 2021

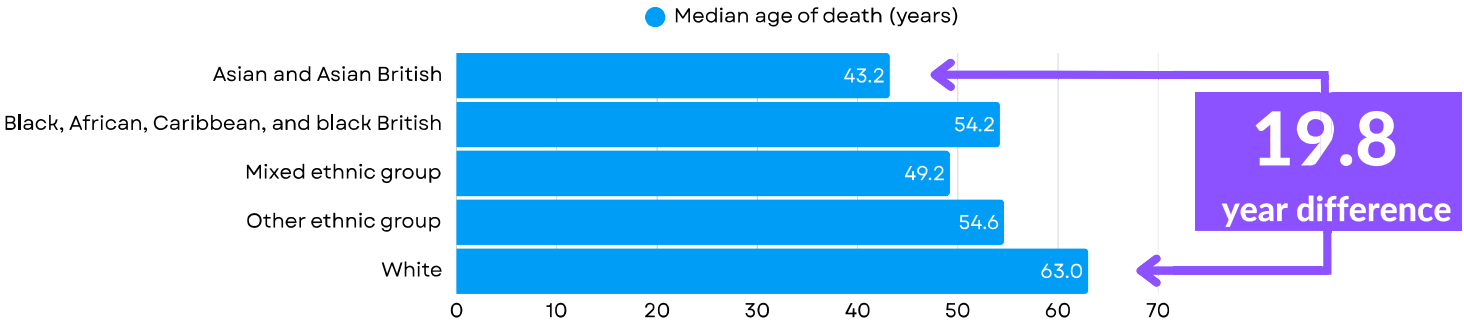
The % of deaths among adults with a learning disability has increased since 2021 for all of the most common causes (except circulatory diseases).



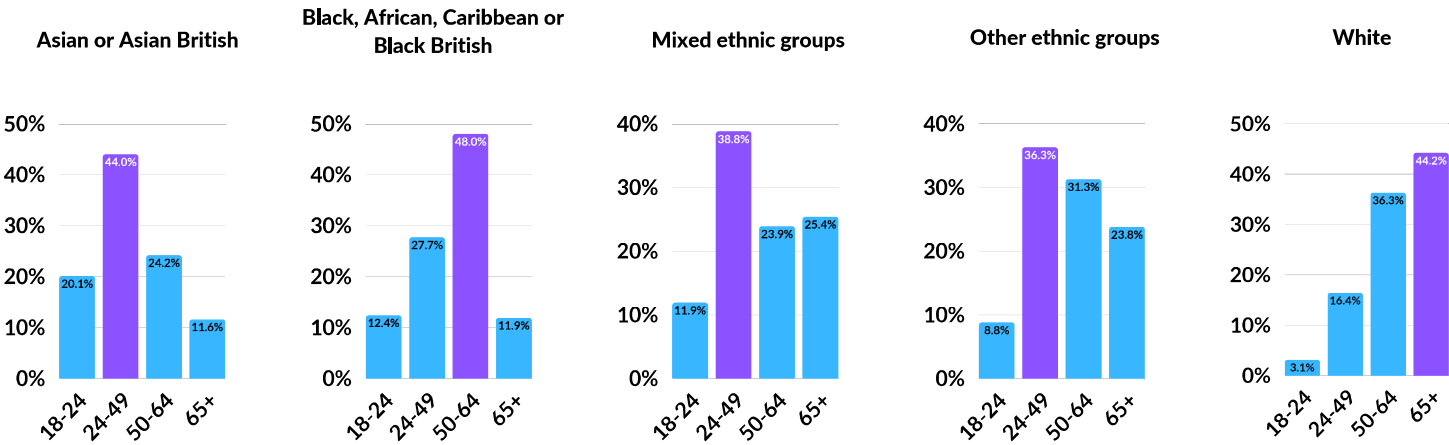
CHAPTER 2 - ETHNICITY OF PEOPLE WITH A LEARNING DISABILITY

AGE AT DEATH

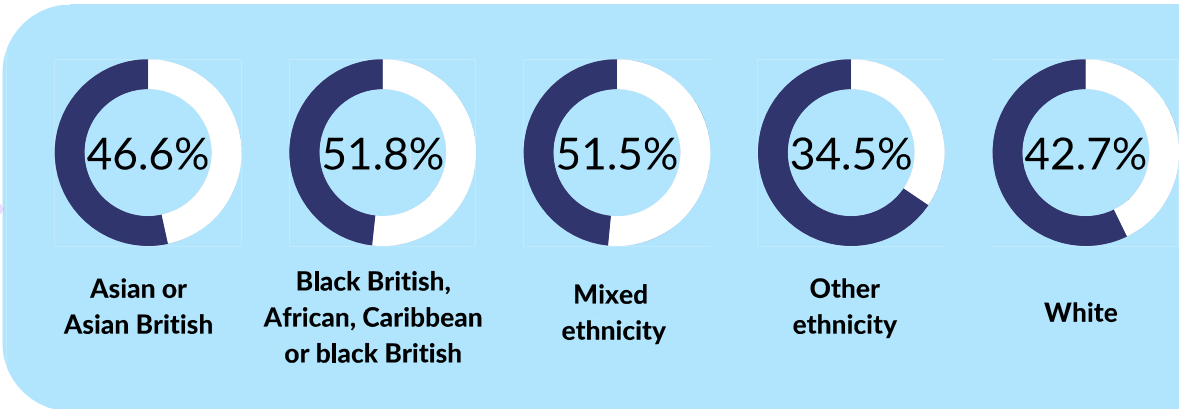
Adults from all ethnic groups who were notified to LeDeR from January 2021- December 2023 had a younger median age at death compared to White adults who died.



AGE GROUP AT DEATH 2021-2023



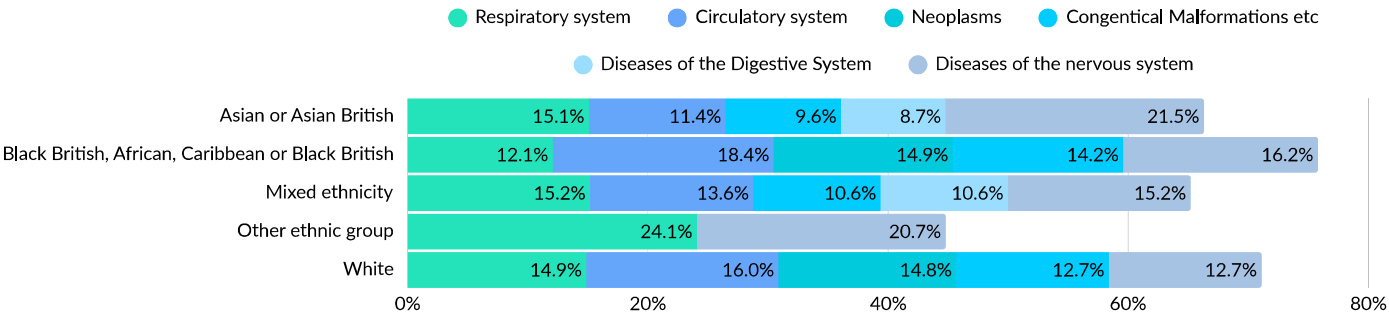
**AVOIDABLE*
DEATHS FOR
2021-23**



*This is based on the OECD preventable/treatable definition (see chapter 1).

MOST COMMON CAUSE OF DEATH BY ETHNICITY 2021-2023

The 5* most common causes of death for adults with a learning disability an by ethnic group.



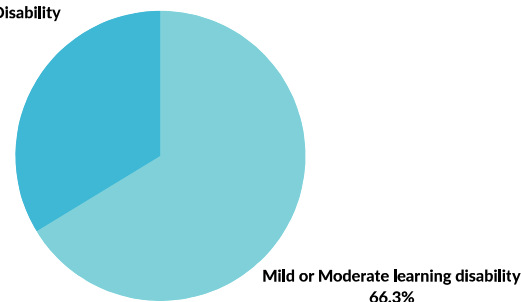
*5 available only when possible to avoid deidentification due to small numbers

CHAPTER 3 - PEOPLE WITH A SEVERE OR PROFOUND LEARNING DISABILITY

LEVEL OF LEARNING DISABILITY IN THE LeDeR DATA BETWEEN 2021-2023

Of the 3,970 adults with learning disability who had a level of learning disability recorded in their initial review form, over two thirds were recorded as having a mild to moderate learning disability, and one third a severe or profound learning disability.

Severe or Profound learning Disability
33.7%



Median age at death

Mild or moderate

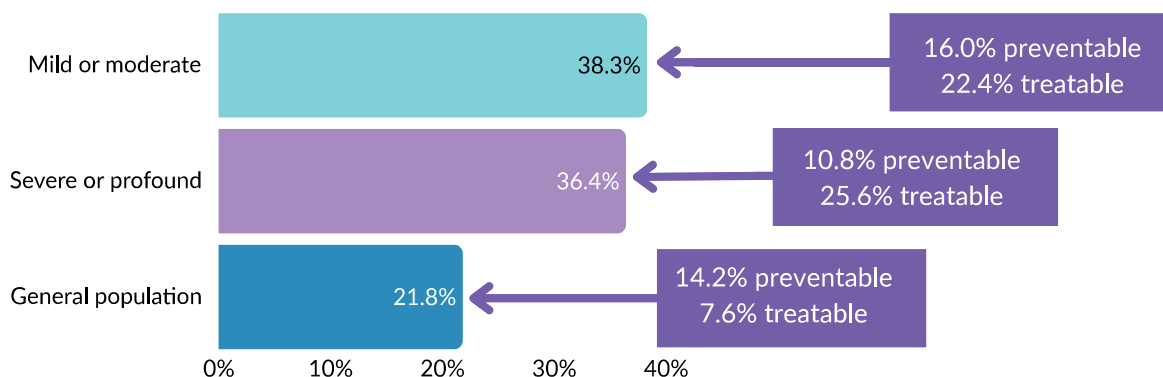
64.9
years

7.3
years
difference

57.6
years

Severe or profound

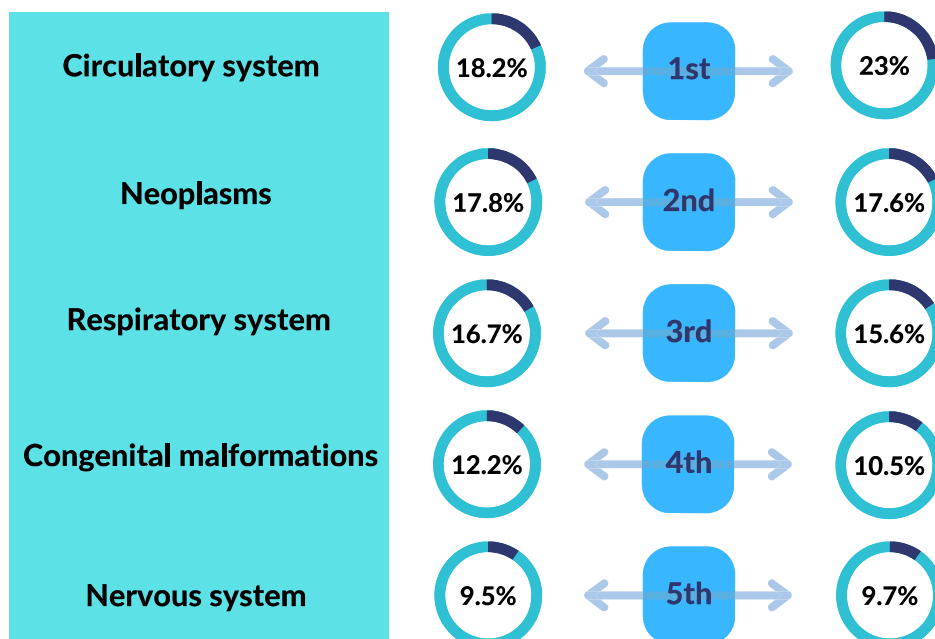
AVOIDABLE* DEATHS FOR 2021-23



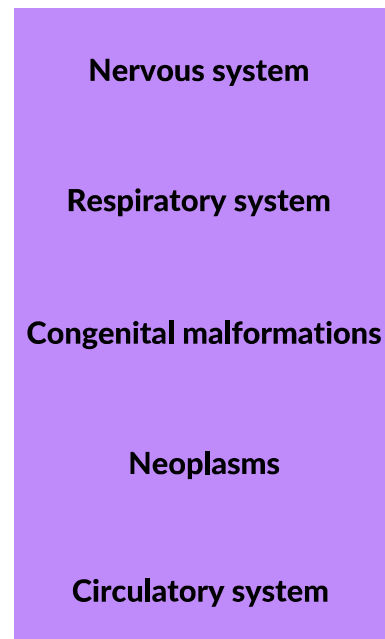
*This is based on the OECD preventable/treatable definition (see chapter 1).

MOST COMMON ICD-10 GROUPED CAUSE OF DEATH BY LEVEL OF LEARNING DISABILITY

MILD OR MODERATE



SEVERE OR PROFOUND

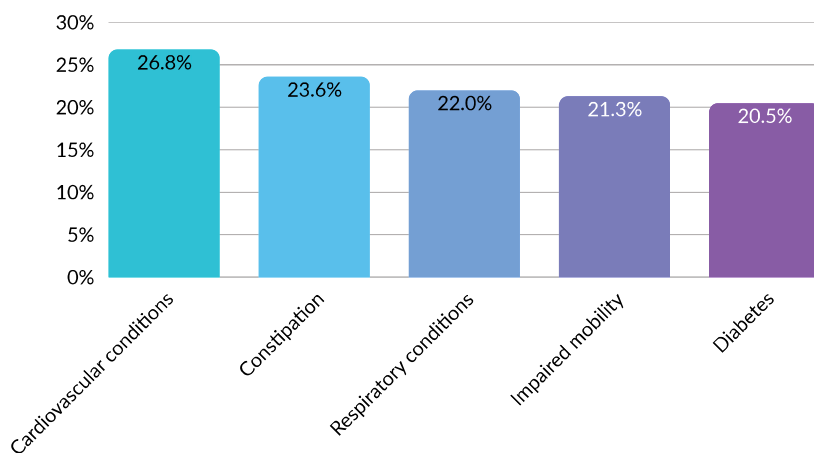


CHAPTER 4 - AUTISTIC ADULTS WITHOUT A LEARNING DISABILITY WHO WERE NOTIFIED TO LeDeR

KEY DEMOGRAPHICS OF AUTISTIC ADULTS WHO HAD A LeDeR REVIEW BETWEEN 2021 - 2023



TOP 5 COMORBID REPORTED PHYSICAL HEALTH CONDITIONS (2021-2023)



MENTAL HEALTH 2021-23

Had a diagnosis of depression

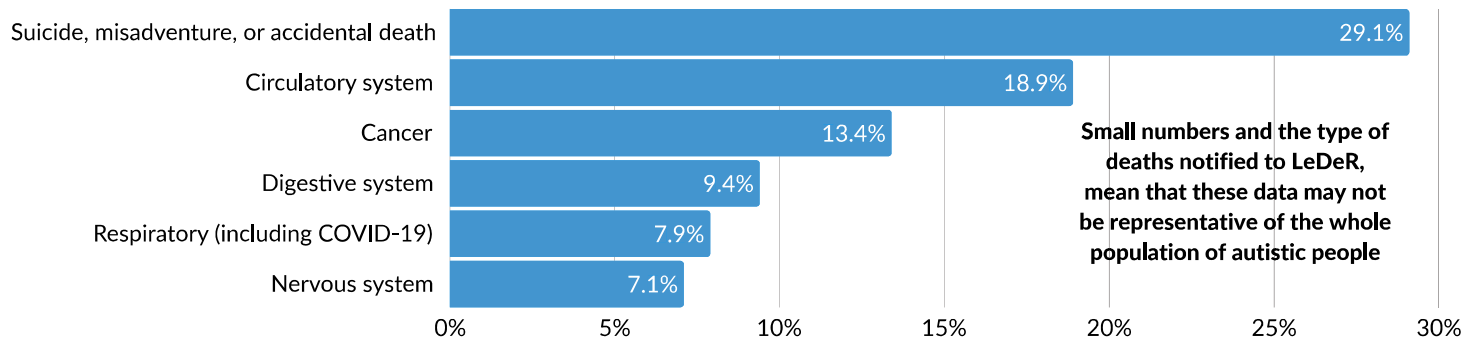
54.3%

Had a diagnosis of anxiety disorder

42.5%

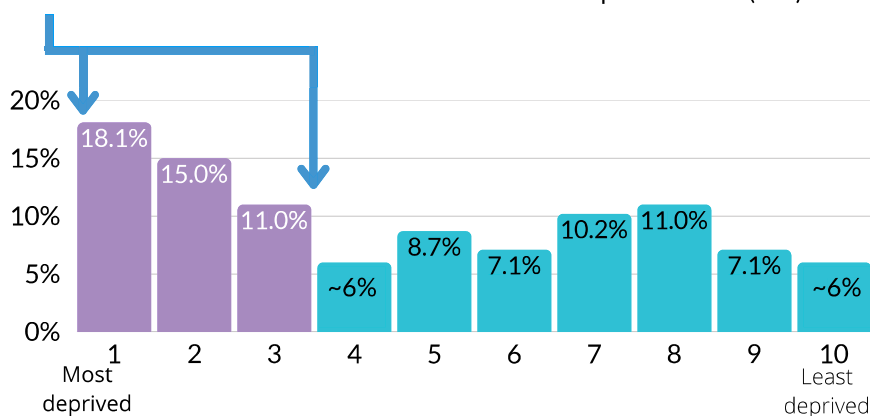
MOST COMMON CAUSES OF DEATH FOR AUTISTIC ADULTS WHO HAVE HAD A LeDeR REVIEW

2021-2023



INDEX OF MULTIPLE DEPRIVATION 2021-23

44.1% of autistic adults who died lived in most deprived areas (1-3).



ISSUES WITH CARE

- Inadequate training for staff around autistic adults needs.
- Lack of awareness of autistic adults' needs.
- Insufficient referrals to autistic specialist services.

Deep Dives and Publications that have arisen from LeDeR

Introduction

The LeDeR academic partnership led by KCL regularly undertakes more in-depth and extensive investigations (“deep dives”) to gain insights into key areas to improve our understanding of the health needs and service improvements needed for people with a learning disability and autistic people. Working in collaboration with NHS England, the academic partnership has investigated several different topic areas that have impacted policy, guidance, and service provision across England. Recently published works are summarised here.

Much of this work uses LeDeR data directly. Some, however, use LeDeR findings as a starting point for further investigation and may use other datasets or gather new information to explore specific questions regarding the health and care of people with a learning disability or autistic people further. The published reports, known as **deep dives**, can be found in full on our website at [Learning from Lives and Deaths - people with a learning disability and autistic people \(LeDeR\) | King's College London](https://www.learningfromlivesanddeaths.org.uk/)

In this section, we will summarise the findings from 6 deep dives completed during the past three years covering. These are: **Diabetes, Bowel Cancer, Impact of Learning Disability Liaison Nurses, Constipation, Pneumonia, and Cardiovascular diseases.**

