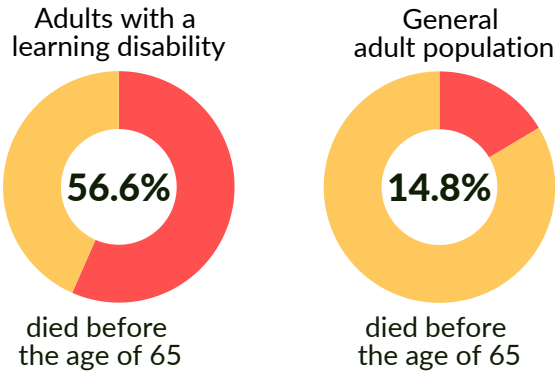


CHAPTER 1 - REVIEW OF THE LIVES AND DEATHS OF ADULTS WITH A LEARNING DISABILITY WHO DIED BETWEEN 2021 AND 2024 WHO WERE REPORTED TO LEDER BY NOVEMBER 2025

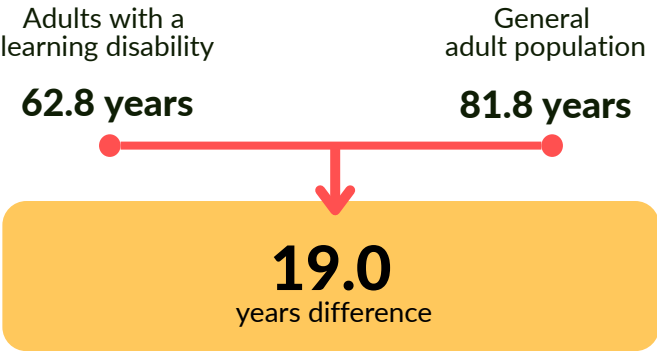
AGE GROUP AT DEATH (2024)

In 2024, more than half (56.6%) of adults with a learning disability notified to LeDeR died before the age of 65.



MEDIAN AGE AT DEATH (2024)

In 2024, the median age at death for adults with a learning disability notified to LeDeR was 62.8 years, 19.0 years lower than the median age at death of the general adult population in 2024 (81.8 years).

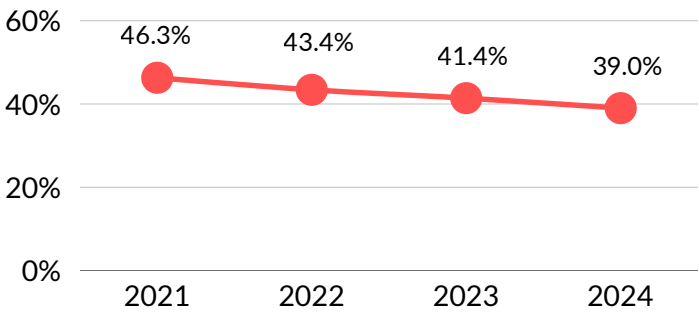


*note median age at death is not life expectancy

AVOIDABLE DEATHS (2021-2024)

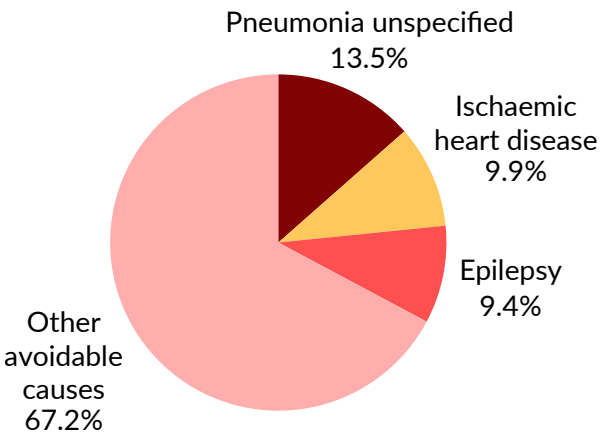
The proportion of avoidable deaths for adults with a learning disability who had a LeDeR review has significantly declined, dropping from 46.3% in 2021 to 39.0% in 2024.

However, the proportion of avoidable deaths in 2024 remains nearly double that of the general adult population (21.1%).



MOST COMMON AVOIDABLE DEATHS (2024)

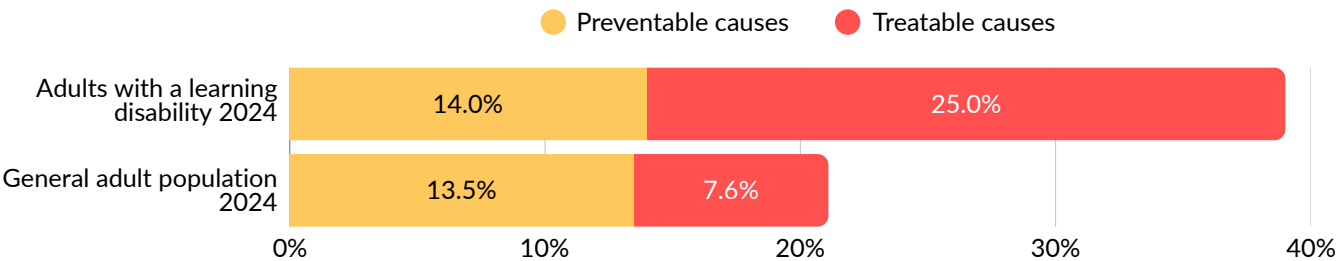
Pneumonia unspecified, ischaemic heart disease, and epilepsy were the leading avoidable causes of death, accounting for nearly one-third (32.8%) of all avoidable deaths.



*categories based on the OECD/Eurostat avoidable mortality list

PREVENTABLE AND TREATABLE CAUSES (2024)

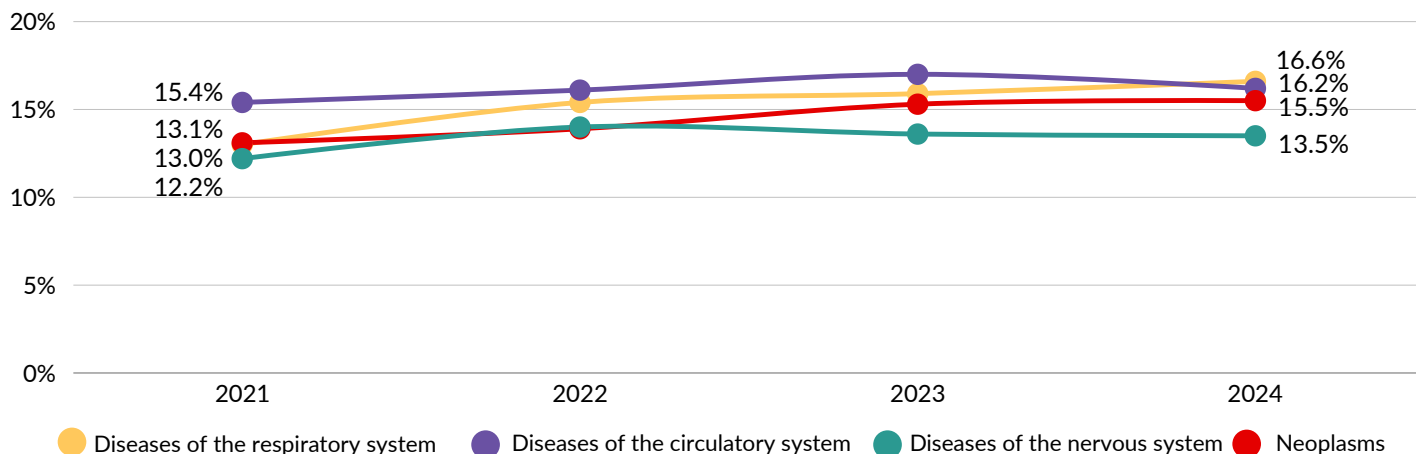
In 2024, treatable deaths accounted for a larger proportion of avoidable deaths than preventable deaths, and were the main driver of differences between adults with a learning disability and the general adult population.



CHAPTER 1 - REVIEW OF THE LIVES AND DEATHS OF ADULTS WITH A LEARNING DISABILITY WHO DIED BETWEEN 2021 AND 2024 WHO WERE REPORTED TO LEDER BY NOVEMBER 2025

MOST COMMON ICD-10 GROUPED CAUSES OF DEATH (2021-2024)

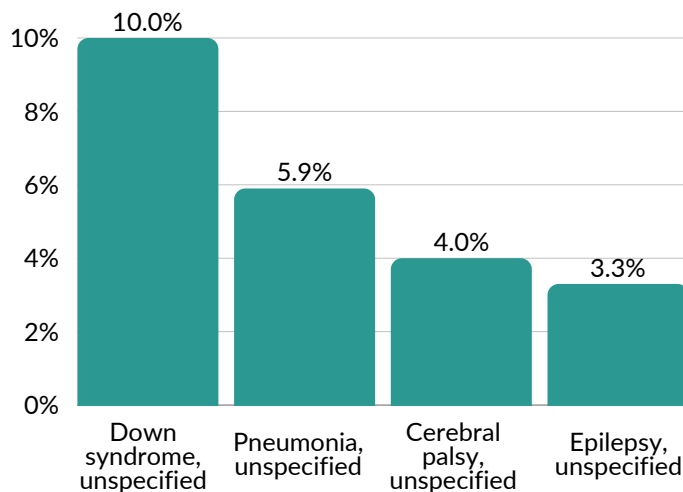
Deaths of adults with a learning disability who had a LeDeR review due to respiratory diseases and neoplasms increased significantly between 2021 and 2024.



Trends should be interpreted with caution due to the high number of COVID-19 deaths in 2021

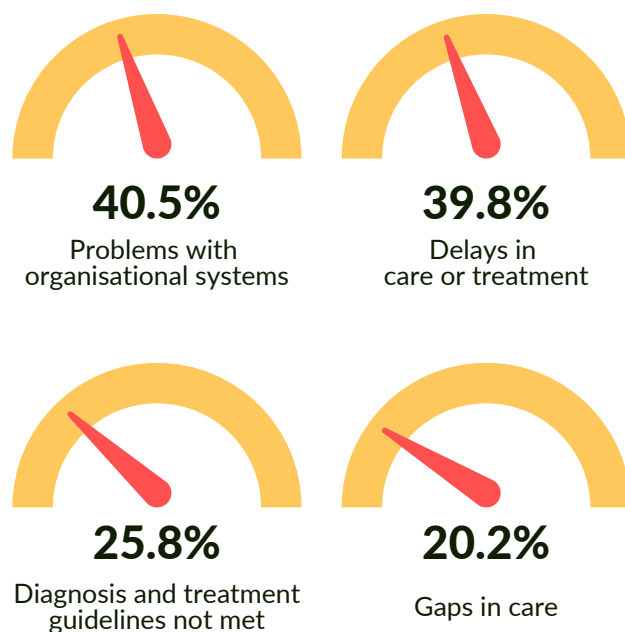
MOST COMMON UNDERLYING ICD-10 CODE CAUSES OF DEATH (2024)

These four causes have been the most commonly reported each year since 2021, with some differences during the COVID-19 pandemic in 2021 and 2022.

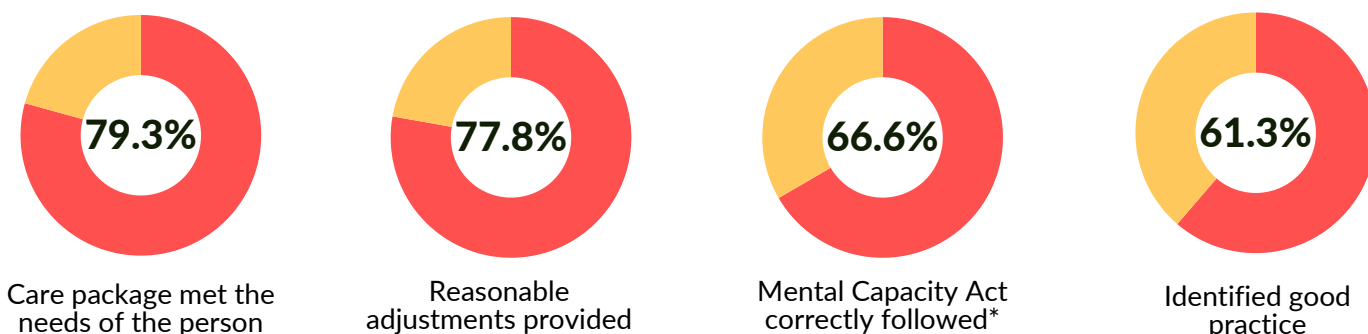


Although Down syndrome and cerebral palsy should not be listed as the only cause of death on the MCCD, it may be appropriate for them to be listed as the underlying cause of death if the sequence of events or conditions that lead to death is fully recorded, and Down syndrome or cerebral palsy likely 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).

PROBLEMS IN CARE (2024)



QUALITY OF CARE (2024)



*Remaining proportion includes both "No" and "not known" responses.

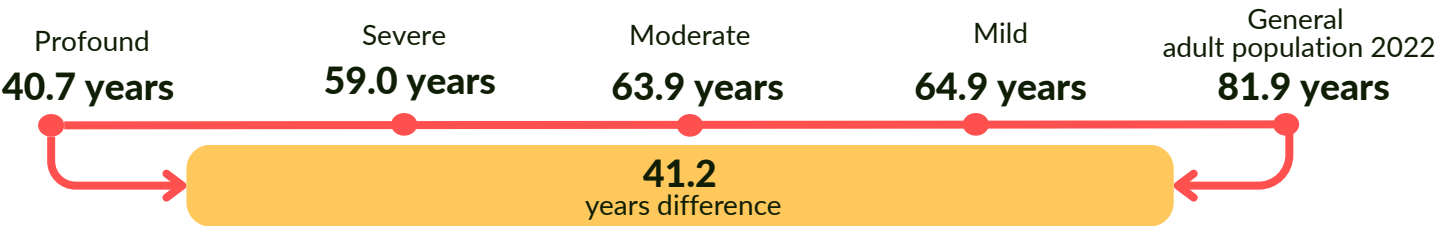
CHAPTER 2 - ADULTS WITH A SEVERE OR PROFOUND LEARNING DISABILITY WHO DIED BETWEEN 2021 AND 2024 WHO WERE REPORTED TO LEDER BY NOVEMBER 2025

LEVEL OF LEARNING DISABILITY (2021-2024)

Among adults with a learning disability who had their level of learning disability recorded, around one in three (35.3%) had a severe or profound learning disability.



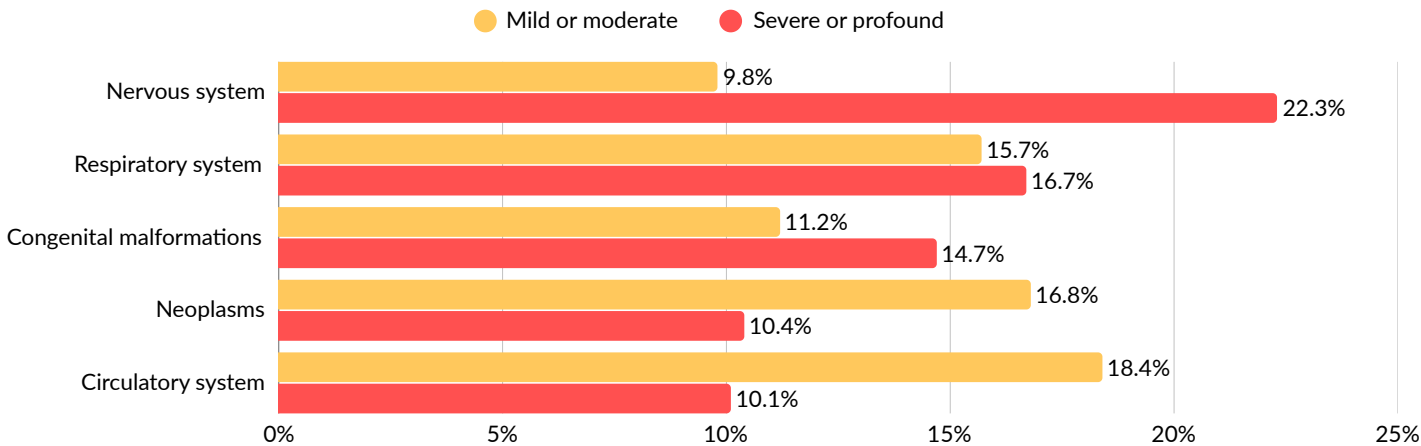
MEDIAN AGE AT DEATH (2021-2024)



*note median age at death is not life expectancy

MOST COMMON ICD-10 CHAPTER CAUSES OF DEATH (2021-2024)

Adults with a severe or profound learning disability were more than twice as likely to die from diseases of the nervous system, and were also more likely to die from congenital and chromosomal conditions, than those with a mild or moderate learning disability.

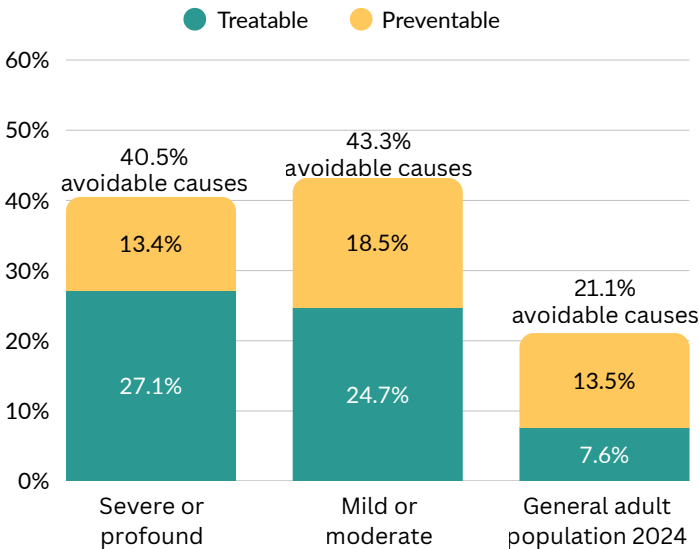


AVOIDABLE DEATHS (2021-2024)

Avoidable mortality was substantially higher in both groups than in the general adult population, and was driven mainly by treatable causes like pneumonia.

Treatable mortality accounted for more than a quarter of deaths (27.1%) among adults with a severe or profound learning disability and was significantly higher than in other groups.

In contrast, preventable mortality was higher among adults with a mild or moderate learning disability than in other groups.

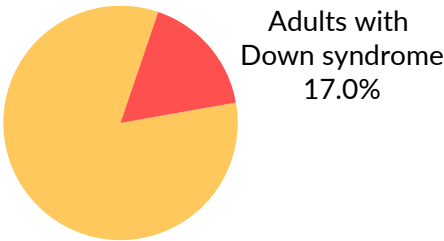


CHAPTER 3 - ADULTS WITH A LEARNING DISABILITY AND DOWN SYNDROME WHO DIED BETWEEN 2021 AND 2024 WHO WERE REPORTED TO LEDER BY NOVEMBER 2025

REVIEWS OF DEATHS OF ADULTS WITH DOWN SYNDROME (2021-2024)

Down syndrome was recorded in 17.0% of the 11,687 reviewed deaths of adults with a learning disability.

Other adults with a learning disability
83.0%



MEDIAN AGE AT DEATH (2021-2024)

Adults with Down syndrome
59.8 years

Other adults with a learning disability
64.1 years

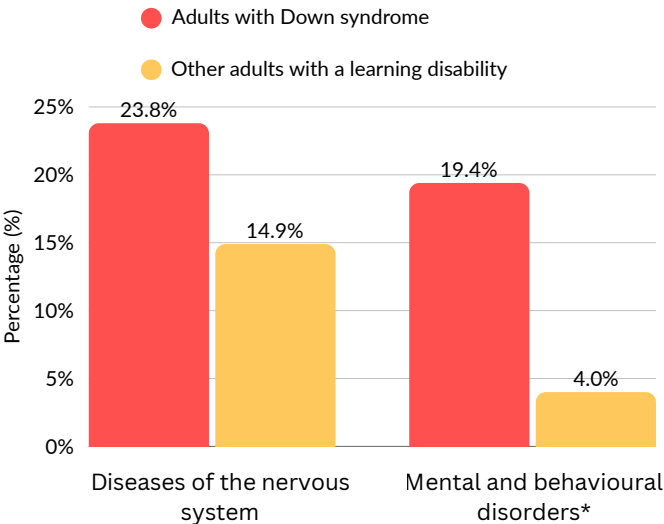
General adult population 2022
81.9 years



*note median age at death is not life expectancy

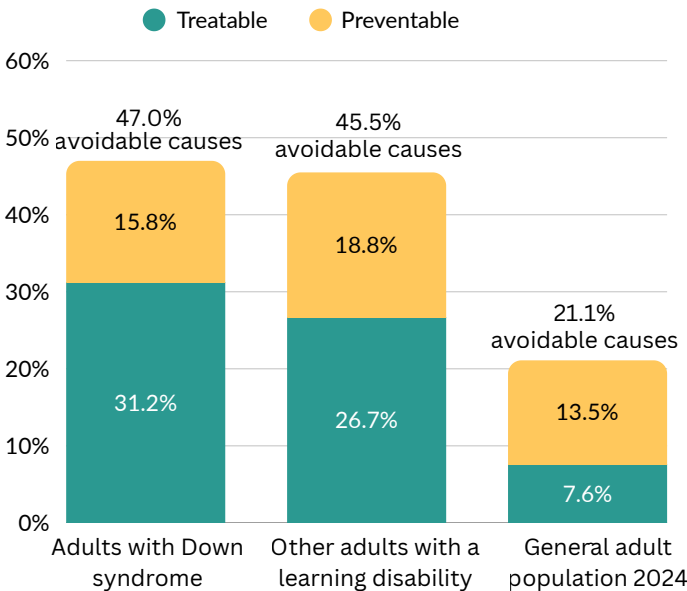
MOST COMMON ICD-10 CHAPTER CAUSES OF DEATH (2021-2024)

Compared with other adults with a learning disability, deaths due to nervous system diseases were more than 1.5 times higher, while deaths due to mental and behavioural disorders were almost 5 times higher.



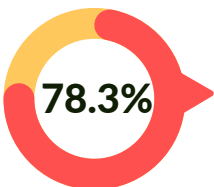
AVOIDABLE DEATHS (2021-2024)

Nearly one-third of deaths (31.2%) were due to treatable causes, significantly higher than in other adults with a learning disability (26.7%) and the general adult population (7.6%).

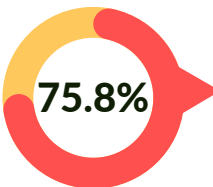


*Mental and behavioural disorders (ICD-10 Chapter V) include deaths due to diagnosed medical conditions such as dementia, severe mental illness, or alcohol/substance-related disorders recorded on death certificates.

QUALITY OF CARE (2021-2024)



Over three quarters of adults with Down syndrome had a care package that met their needs.



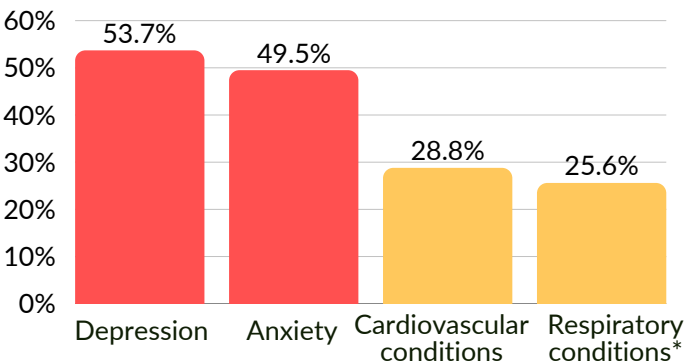
Three quarters of adults with Down syndrome had all their reasonable adjustments provided.

CHAPTER 4 - AUTISTIC ADULTS WITHOUT A LEARNING DISABILITY WHO DIED BETWEEN 2021 AND 2024 WHO WERE REPORTED TO LEDER BY NOVEMBER 2025

Small numbers and the type of deaths notified to LeDeR, mean that these data may not be representative of the whole population of autistic adults without a learning disability.

MOST COMMON CO-OCCURRING PHYSICAL AND MENTAL HEALTH CONDITIONS (2021-2024)

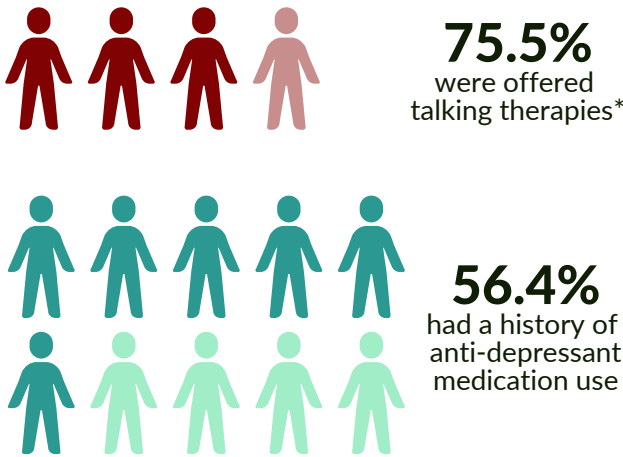
Over half (53.7%) of all autistic adults reviewed had depression, and almost half (49.5%) were recorded as having anxiety. More than a quarter were affected by cardiovascular (28.8%) and respiratory (25.6%) conditions.



*Including COVID-19.

MENTAL HEALTH SUPPORT (2021-2024)

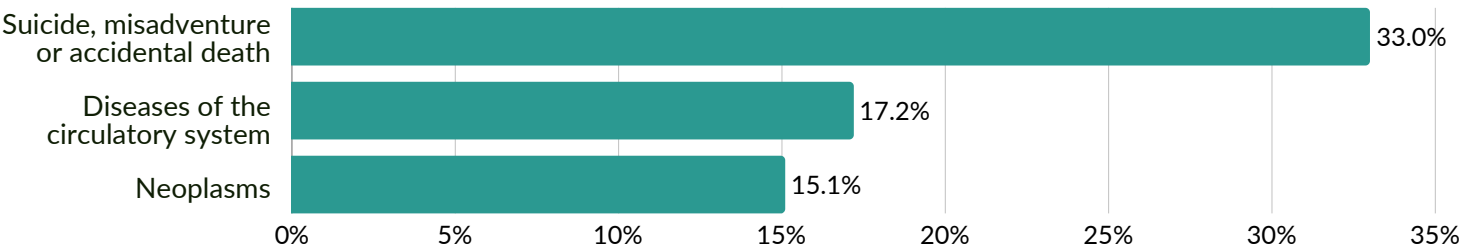
Among autistic adults without a learning disability who died by suicide, misadventure or accidental death:



*Remaining proportion includes both "No" and "not known" responses.

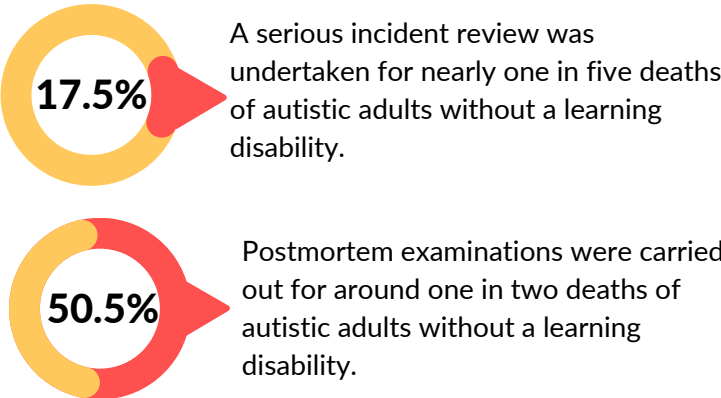
MOST COMMON GROUPED CAUSES OF DEATH (2021-2024)

Among autistic adults without a learning disability, suicide, misadventure, or accidental death accounted for around a third (33.0%) of all deaths, making it the most common cause of death.



CIRCUMSTANCES OF DEATH (2021-2024)

Issues with care



- Delays in recognising needs and escalating concerns.
- Inconsistent care and continuity of support.
- Fragmented and poorly coordinated care across services.
- Care and treatment not consistently adapted to autistic adults' needs.