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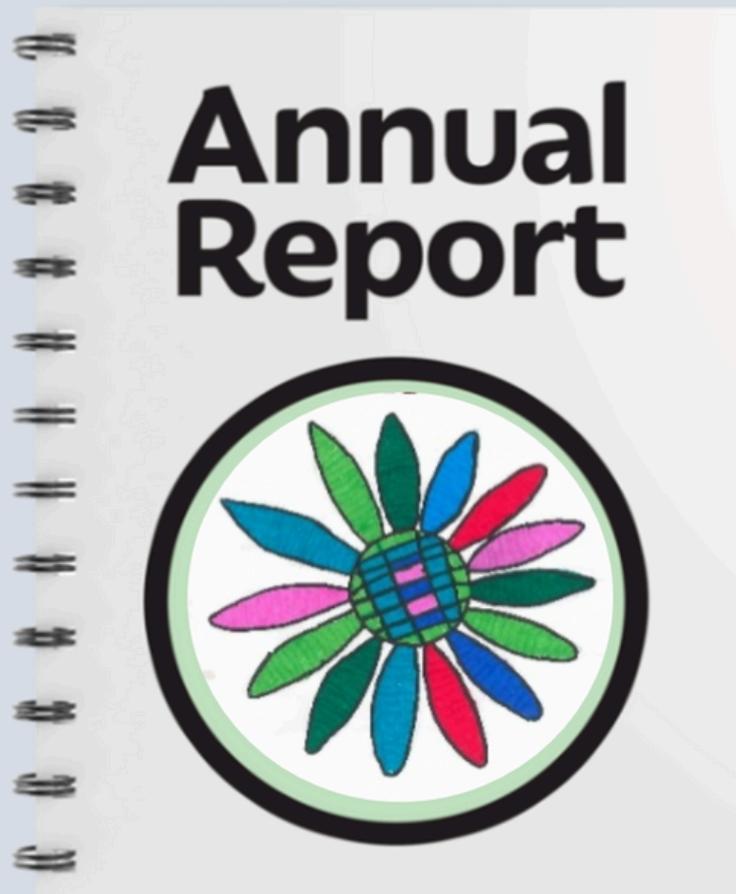
Learning from lives and deaths:
People with a learning disability
and autistic people

2023

UPDATED

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JANUARY
2026



Made with
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Presented by
the **STAYING ALIVE AND WELL GROUP.**



We are people with a learning disability and autism.

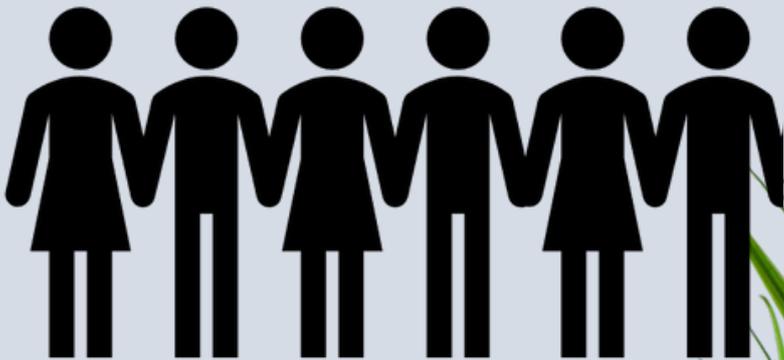
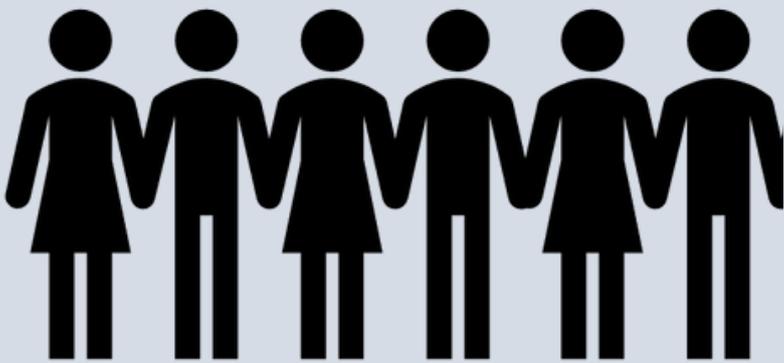
It was very difficult to make this report.

But we hope it is helpful.

There is also a video
on the @AliveLeDeR YouTube channel



We heard about **3,556 people**
with a learning disability
who died in 2023.



How old were people with a learning disability when they died?

2023



Died age
63

In 2023,
the average age of death was **63**

It is the general age.
Some people die much younger
and some people die much older.



Frankie and
Andrew

2022



Died age
62

In 2022,
the average age of death was **62**

I know it is
one year difference,
but it needs to be better



Sunny



Amanda

It is unfair that we do not live as long
as people who do not have a learning
disability. We want to live longer and
enjoy our lives



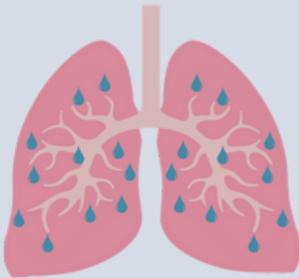
How do **YOU** feel
about the age at which
people die?

What did people with a learning disability die of in 2023?

Most common:



Cancer



Lung infections (pneumonia)



Heart problems.

Lots of people can easily miss the symptoms. It could turn a **treatable disease** into a **terminal disease** in the blink of an eye



You can get treatment for a **treatable disease** and you can get better.

You cannot get treatment for a **terminal disease** to get better and you will die.



Do **YOU** know anyone with a learning disability who has died of cancer, lung problems or heart problems?

Avoidable deaths



Some people died before their time.

They died of something that nowadays, you shouldn't have died of.



This is called **avoidable death.**

Bowel cancer is possibly avoidable because there are tests for bowel cancer.



Mark

Of each,
10 people with a learning disability
who died in 2023.



4 people should probably still be alive today.

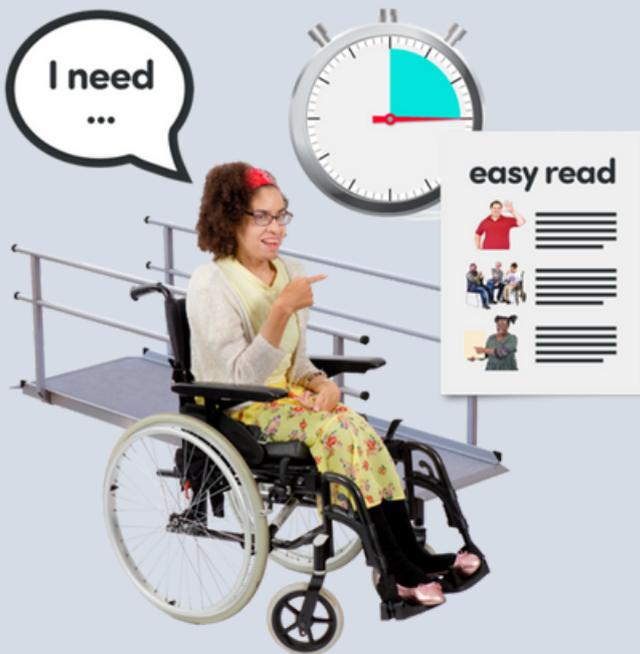


Can **YOU** think of ways
to stop people dying
too young?

Quality of care



**Most people got good care,
but a lot of people did not.**



**There were not enough
reasonable adjustments.**

**We felt scared at hospital
because they are so big.
People used too much jargon
when we were at hospital**



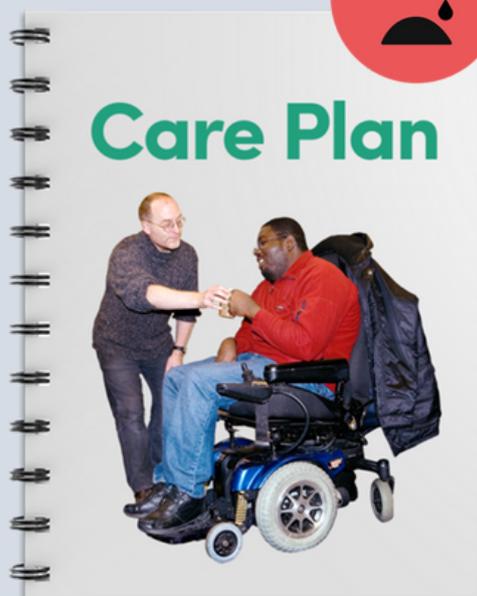
Maggie and Richard



People were **waiting too long** for tests and treatments.



Some people had a **care package** that **did not meet their needs**.



They should understand more about us



How was **YOUR** experience of doctors and hospitals?

Ethnicity

People from
black, Asian or mixed backgrounds
died even younger.



Their voices
are not heard



Why do **YOU** think
people from some backgrounds
die even younger?

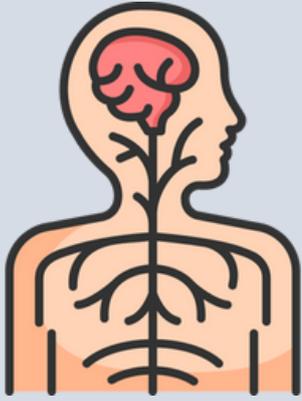
Severe and profound learning disabilities

People with severe and profound learning disabilities **died even younger.**

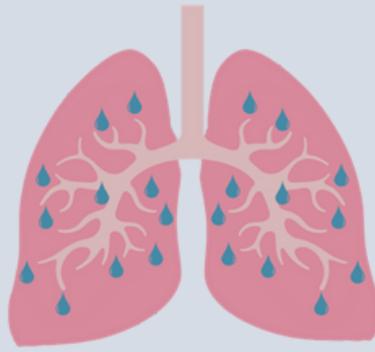


They were **even more likely** to die of something that **could have been treated.**

What they died of:



Diseases of the nervous system



Lung infections
Pneumonia



Conditions they were born with, from when they were babies

What are diseases of the nervous system?



It is conditions like **cerebral palsy** or **epilepsy**.

People don't actually die of cerebral palsy, but they sometimes have other illnesses that they then die of.



What do people with severe and profound learning disabilities need to stay as well as possible?

Diabetes

People with a learning disability
are **more likely**
to get diabetes.



They get diabetes
10-15 years earlier.

Bowel cancer

People with a learning disability
are **more likely**
to get bowel cancer **earlier**.



They are **more likely to die** from it.

Learning disability nurses

Learning disability nurses
help people
get **reasonable adjustments**.



**We need more
learning disability nurses in hospital.**

Constipation

People with a learning disability
**take lots of medication
that causes constipation.**



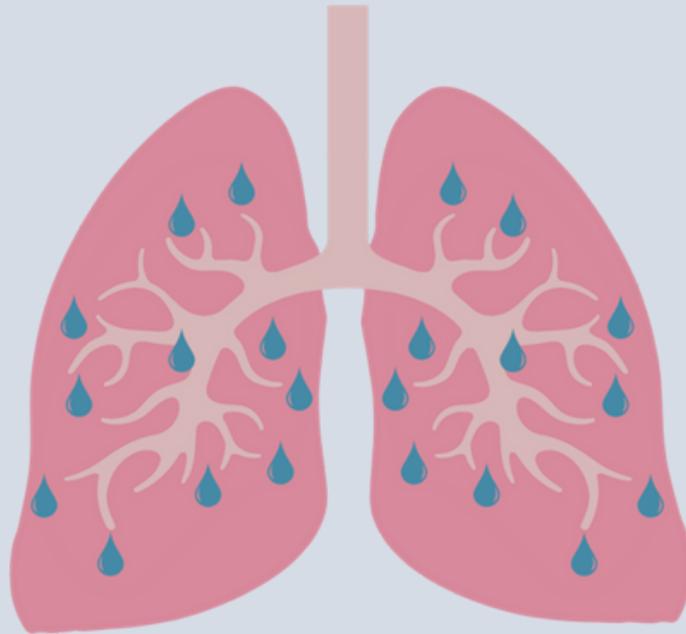
Why are people still dying of that?
What is going on? That is not on.



Frankie

Lung infections

People should get training to spot pneumonia.



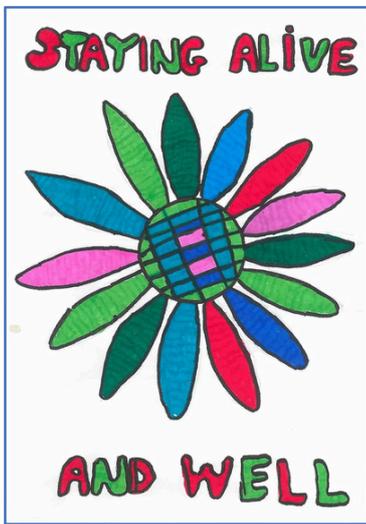
People should spot the signs



Sunny



What health problems are **YOU** worried about?



This report was produced by the Staying Alive and Well Group.

We are a group of people who have a learning disability or who are autistic, meeting at Kingston University London..

We are part of a research team led by King's College London, supporting the NHS England.



Our names are:

Richard Keagan-Bull, Maggie Brennan, Amanda Cresswell, Frankie Cutri, Joanne Kennedy, Andrew Meyer, Lee Scott, Mark Shackleton, Sonia Reed, Wayne McGregor, Caroline Ogundeji, Sunny Sokhal.



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This report is an accessible version of the full 2023 Annual Report for LeDeR: Learning from Lives and Deaths – People with a Learning Disability and Autistic People.



There are two other types of report:
The full 2023 Annual Report
An accessible video



Follow this link to see them:
www.kcl.ac.uk/research/leder



The report can be used by anyone but it must not be changed.

