

# LeDeR

## Learning from lives and deaths: People with a learning disability and autistic people 2023



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**

This year,  
the average age of death is **63**

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



Frankie and  
Andrew

2022



Died age  
**62**

Last year,  
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?

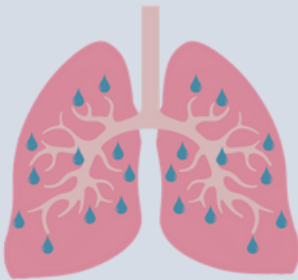


# What did people with a learning disability die of in 2023?

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



Andrew

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.





This year,  
compared with the year before  
**not as many** people with a learning disability  
died an avoidable death.



But it is still quite a lot.



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?

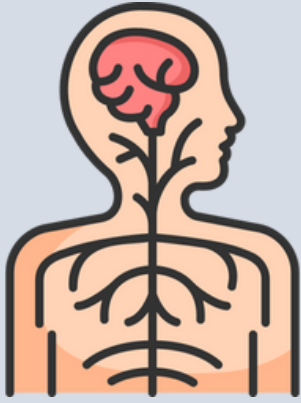
# Severe and profound learning disabilities

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

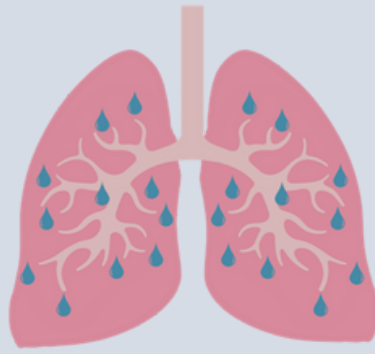


They were **even more likely**  
to die of something that  
**could have been treated.**

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.**

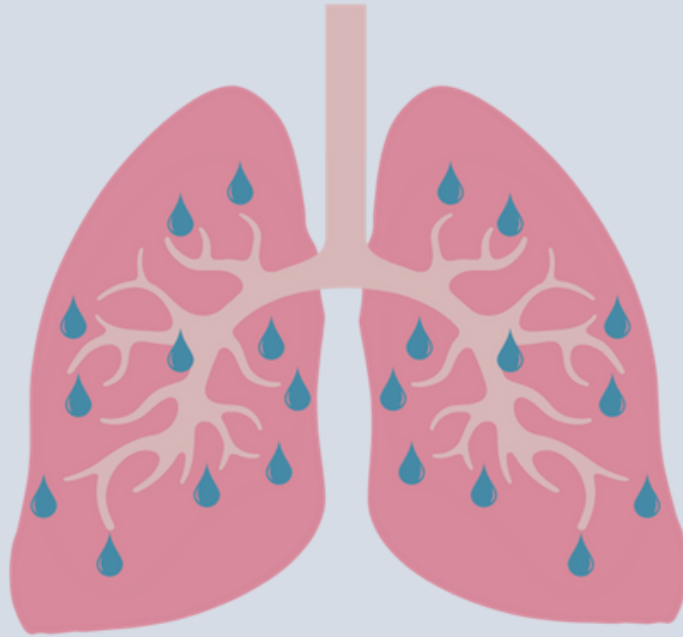


Why are people still dying of that?  
What is going on? That is not on.

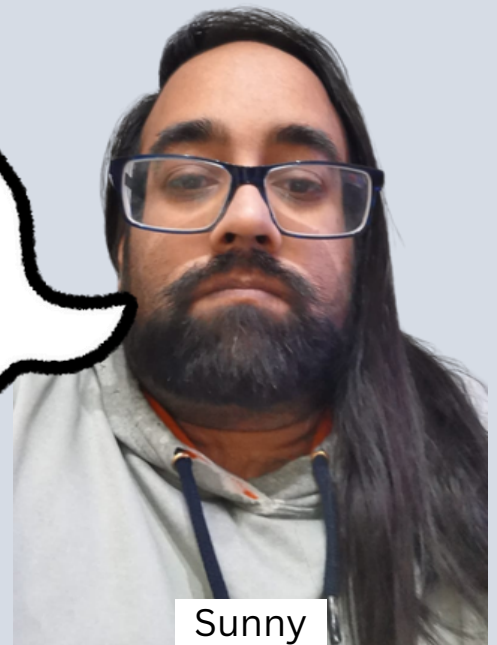


# Lung infections

People should get training to spot pneumonia.



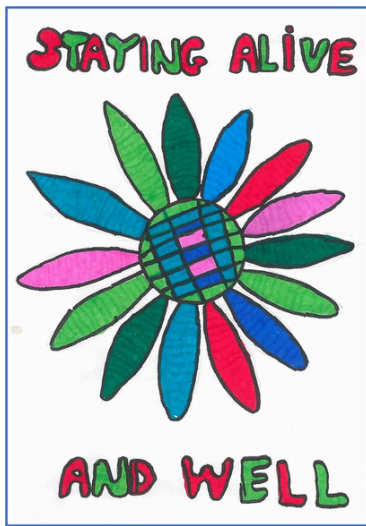
People should  
spot the signs



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](http://www.kcl.ac.uk/research/leder)

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

