




**North East and North Cumbria  
Integrated Care Board**

# **LeDeR Annual Report 2023 Easy Read short summary**

**Learning from the lives and deaths of people  
with a learning disability and autistic people**



**In loving  
memory**

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# What this report is about



We are The North East and Cumbria Integrated Care Board.



The Integrated Care Board is part of the NHS that buys health and care services for people in the North East and Cumbria.



This report looks at the lives and deaths of people with a learning disability and autism who died in 2023.



Every area has to follow the government LeDeR plan.

LeDeR stands for learning from the lives and deaths of people with a learning disability and autistic people.



By looking at why people died we can learn what went well and what can be done better.



This plan is about improving the lives of people with a learning disability and autism by providing better care.



**Sam Allen** is the big boss of the Integrated Care Board.

Sam wants everybody with a learning disability or autism to have great health care.



**“We will work very hard to improve the lives of people with a learning disability and autism”**

# What Happened in 2023?



## People with a learning disability

This section is about people with a learning disability



We looked at the deaths of 208 people with a learning disability from across the North east and Cumbria.

## Men and Women

We looked at the deaths of:

- 122 men
- 86 women



## The age of people

- The people that died were aged between 31 and over 80 years old.
- Most people who died were aged between 50 and 70



## Ethnicity



Ethnicity is your race or background.  
For example black, white or asian.



- Nearly everyone we looked at who had a learning disability was White British



- Only 1 person said they were Asian

- A few people did not want to say what race they were

## Where People Died



- Most people died in a hospital



- Some people died in residential care



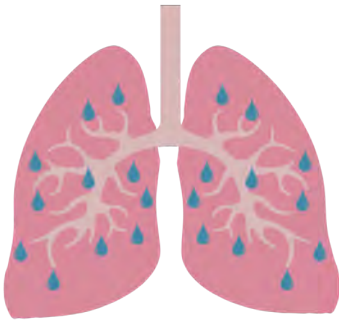
## The main things people died of

The biggest reason people died was illness to do with breathing:

Things like:

- Pneumonia

This is a disease where the lungs fill with water from the body. This makes it hard to breathe.



- Aspiration pneumonia

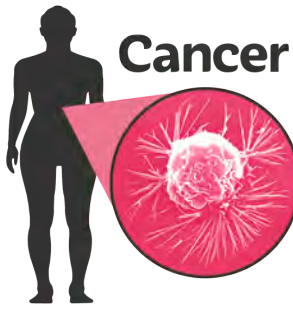
This is when something like food or drink gets stuck in the lungs. This can make people very ill.



- Respiratory disease

This means diseases to do with breathing. Asthma or colds are respiratory diseases.





The next biggest reasons were

- Cancer
- Heart problems



## People with autism



We looked at 8 deaths of autistic people from across North East and North Cumbria.

Autistic people are **neurodivergent**.

We say **neurodivergent** like this: new-roe-die-ver-jent.



**Neurodivergent** means your brain works in a different way to most people.





## Men and women

- 5 men
- 3 women



## The age of People

- The people that died were aged between 18 and over 60 years old.



- Most people who died were aged between 31 and 40



## Ethnicity

- 2 people were Asian
- 6 people were white British



## Where people died



- 5 people died in their own home
- 1 person died in their family home
- 1 person died in hospital
- 1 person died somewhere else

We cannot share the information about this person.

## The main things people with autism died of



Autistic people mostly died from problems related to drugs, suicide, and other health issues.

# Learning from how people died

## John's Story



John was 71 years old and lived in a care home.

He loved music and was very happy.



He passed away because of a heart problem.

John's death teaches us:



- People need regular health checks

- Their choices need be followed



## Thea's Story



Thea was 26 and loved playing computer games.

Thea had trouble with friends and was worried.



Thea passed away because of drugs.

Thea's death teaches us:



- People need help to be well when they are children so they grow into healthy adults



- We need to learn the best ways to talk to people and know when people are feeling anxious

# The things we found out for people with a learning disability and autistic people



People need more help to speak up about their care. We call this advocacy support.



There needs to be better ways of deciding if people can make their own decisions.

This is so staff don't make decisions for people if they don't have to.



Not everyone gets the health checks they need. Things like:

- Diabetes checks



- Asthma checks



Not everyone gets the screening they need for diseases. Health screening is like a check up for your body to make sure everything is working well.

Things like:



- Checking your breasts for cancer



- Checking you bowel, which is inside your stomach. This is where poo comes from



Not all areas were as good as others at looking into the deaths of people.

Not enough deaths of people with autism were looked at.

Not enough deaths from different ethnic groups were looked at.

# What we will do



Make sure that people and organisations know they need to report the deaths of:

- People with a learning disability
- Autistic people
- Ethnic minorities



This will help us understand how different groups are treated when they die.



We will make sure more staff get learning disability and autism awareness training.



We will make sure that everybody who's death we look at is looked at properly.

By looking at what happens when people die we will:



- Help more people have happier and longer lives
- Everyone will have the same chance to be healthy
- Health services will get better at helping all people



**North East and North Cumbria Integrated Care Board**  
[northeastnorthcumbria.nhs.uk](https://northeastnorthcumbria.nhs.uk)

✕ [@NEnc\\_NHS](https://twitter.com/NEnc_NHS)

**North East and Cumbria Learning Disability Network**  
[neclidnetwork.co.uk](https://neclidnetwork.co.uk)

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**NHS LeDeR - About LeDeR**

Report a death to LeDeR Report the death of someone with a learning disability

[leder.nhs.uk](https://leder.nhs.uk)

