

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

The LeDeR Programme 2021-2022





This is the third report of the Learning from Lives and Deaths of people with learning disabilities (LeDeR) programme in Derbyshire

The report was made available to the public in June 2022



It tells you about the deaths of people with learning disabilities. The deaths were checked in 2021 and 2022



This report is about people who have died

They were special to their families and friends

Thank you to those families who have shared their stories

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Some difficult words we use

Annual Health Check	An annual health check helps you to stay well by talking about your health You have chance to find problems early and get the right care
Aspiration Pneumonia	A lung infection that develops after you inhale food, liquid, or vomit into your lungs
Bacteria	Very small living things that can be found in all natural environments They are made of a single cell Most bacteria can be seen only with a microscope
Coroner	An official who looks into why somebody died
Covid-19	Covid-19 is also sometimes called coronavirus An infectious disease caused by a newly discovered coronavirus A coronavirus is a disease that can affect the health of the lungs
Dementia	An illness that is caused by damage to a person's brain
Epilepsy	Seizures, which are unusual flashes in the brain, which stop it working properly for a while
Initial review	A first check on a person's death
Focused review	A more detailed check on a person's death
LeDeR	Learning from lives and deaths – people with a learning disability or autistic people
Pneumonia	Swelling of the tissue in one or both lungs
Review	A check on a person's death
Reviewer	Someone who checks up on a person's death
Sepsis	An infection of the blood stream

Chapter 1: Introduction



The aims of the **LeDeR** programme are:

1. To help improve health and social care services for people with learning disabilities
2. To stop people with learning disabilities dying too soon



All deaths of people with learning disabilities (aged 18 years and over) have a **review**



Everyone in Derbyshire has their death looked at in the same way



Every death has a first check

We call this an '**initial review**'



If any problems are found, the **reviewer** does more checks

The **reviewer** will find out more information about the person who has died

This is called a **focused review**

Chapter 2: The deaths the LeDeR programme has been told about



In 2021 to 2022 we were told about **59** deaths of people with learning disabilities in Derbyshire

48

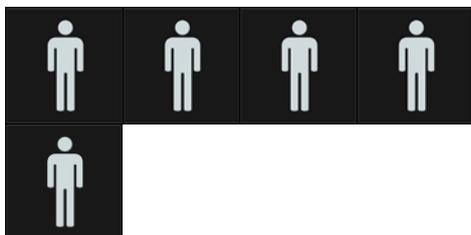
In the year we finished **48 reviews**



There are some deaths that are still being reviewed

Some deaths take longer to **review** as they are being investigated by police or by the **Coroner**

Chapter 3: The people who died



5 out of 10 people who died were male



5 out of 10 people who died were female



The age of people when they died

The average age at death was 65 years for female and 62 years for male

This is better than last year

In last year's report the average age at death was 62 years for female and 60 for male



1 in every 25 of the notifications were deaths from Black, Asian and Minority Ethnic groups

There were not as many adults from Black, Asian and Minority Ethnic groups as we think there should be

We will be doing work in Derbyshire to look at this

Chapter 4: The deaths of people with learning disabilities



Where did people die?

Nearly half of the people died in the place they usually lived (their home)

This was 23 out of the 48 people



23 of the people died in hospital

This was nearly half of the 48 people that were reviewed



The remaining 2 people died in a hospice

A hospice is a place that people with a serious illness can go to live in

The people who work in a hospice will look after the person who is ill



Was a coroner told about their death?

Some deaths were reviewed by the **Coroner**



Causes of death

The five most common causes of death were:



1. Dementia

Dementia is an illness that is caused by damage to a person's brain



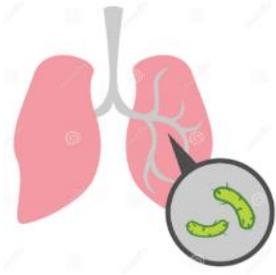
2. Aspiration Pneumonia

Aspiration pneumonia is a lung infection that develops after you inhale food, liquid, or vomit into your lungs

If you are not able to cough up the food or liquid, **bacteria** can grow in your lungs and cause an infection

3. Other Pneumonias

Pneumonia is swelling (inflammation) of the tissue in one or both lungs



Pneumonia is usually caused by a infection of **bacteria**

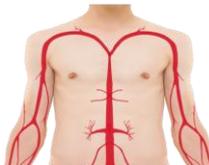


4. Covid-19

Coronavirus disease (**COVID-19**) is an infectious disease caused by a newly discovered coronavirus

A coronavirus is a disease that can affect the health of the lungs

Lungs help you to breathe



5. Sepsis/Sepsis shock

Sepsis is an infection of the blood stream

Sepsis needs to be treated urgently because it can quickly get worse and lead to septic shock.

Septic shock is very serious, as it can cause organ failure and death

Anyone with an infection can get sepsis

Chapter 5: Deaths because of Covid-19



4 reviews that were completed showed the person had died of Covid-19



3 of these people died in hospital



1 person died at home

Chapter 6: Autism Only reviews



From January 2022 we have started to include the **review** of deaths for people who have autism but no learning disability

1

This year there has only been one death we have been told about for a person with autism but no learning disability



The **review** of this death is not yet finished

Chapter 7: What have we done to improve services?



We have produced a video which tells people what to do when it is difficult to have a poo

The video is called Poobusters



We are telling more people about learning disability **annual health checks**

We want people with a learning disability to know what a health check is

My Health Action Plan

What I do that affects my health



We also want people to know what a health action plan is and that they can get one when they go for the health check

Workshops have been held to tell people with learning disabilities and their families about **annual health checks** and health action plans

We have also produced a video to tell people about **annual health checks**

Chapter 8: What else are we doing to improve services?



We must remind workers and families to tell **LeDeR** about the death of a person with a learning disability from Black, Asian and Minority Ethnic groups

This is important to learn and improve services and share good work

This is very important for people with learning disabilities from Black, Asian and minority ethnic communities

Nationally there are more worries about the deaths of people from ethnic minority groups



We want to make sure people who work with people with learning disabilities and autism understand **epilepsy**

We want to make sure people know how to refer to our **epilepsy** services



Osteoporosis is when bone strength weakens which means bones will break more easily

LeDeR showed us that a lot of people with learning disabilities have osteoporosis

Some work has already been done to help people with learning disabilities who have osteoporosis but we want to do more



Work with care homes to support them to look after a person when they are unwell or dying

Thank you



Thank you to the people who helped with our **reviews** and this annual report

Where you can get more information



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