

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

The LeDeR Programme 2022-2023





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

The report was made available to the public in June 2023



When people die they are either cremated or buried

The LeDeR review tells you about the deaths of people with learning disabilities

This report is about deaths that were checked in 2022 and 2023



This report is about people who have died


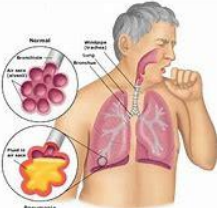

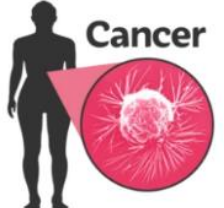

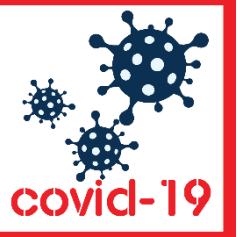
They were special to their families and friends







Thank you to those families who have shared their stories






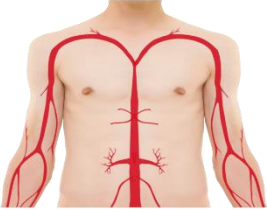
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Some difficult words we use

<p>Annual Health Check</p>	<p>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</p>	
<p>Aspiration Pneumonia</p>	<p>A lung infection that develops after you inhale food, liquid, or vomit into your lungs</p>	
<p>Bacteria</p>	<p>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</p>	
<p>Cancers</p>	<p>Disease in which some of the body's cells grow uncontrollably and spread to other parts of the body</p>	
<p>Coroner</p>	<p>An official who looks into why somebody died</p>	
<p>Covid-19</p>	<p>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</p>	

<p>Dementia</p>	<p>An illness that is caused by damage to a person's brain</p>	
<p>DNACPR</p>	<p>This stands for Do Not Attempt Resuscitation</p> <p>Where a decision has been made that if the person's heart stops beating then no attempt will be made to re-start it</p>	<p>DNACPR</p> 
<p>Epilepsy</p>	<p>Seizures, which are unusual flashes in the brain, which stop it working properly for a while</p>	
<p>Frailty</p>	<p>When a person has other health conditions they have an increased risk to becoming weak</p>	
<p>Initial review</p>	<p>A first check on a person's death</p>	
<p>Focused review</p>	<p>A more detailed check on a person's death</p>	

<p>Heart Disease</p>	<p>When blood flow becomes limited or stopped, the body shuts down and without can lead to death</p>	
<p>LeDeR</p>	<p>Learning from lives and deaths – people with a learning disability or autistic people</p>	
<p>Pneumonia</p>	<p>Swelling of the tissue in one or both lungs</p>	
<p>Review</p>	<p>A check on a person's death</p>	
<p>Reviewer</p>	<p>Someone who checks up on a person's death</p>	
<p>Sepsis</p>	<p>An infection of the blood stream</p>	

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 2022 to 2023 we were told about **62** deaths of people with learning disabilities in Derbyshire



In the year we finished **58 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



52%

30 of the people who died were male



48%

28 of the people who died were female



The age of people when they died

The average age at death was 58 years for female and 58 years for male

This is a younger average age than last year

In last year's report the average age at death was 65 years for female and 62 for male



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

This is higher than last year

In last year's report this was only 1 in every 25 notifications

We will continue to do work in Derbyshire to make sure we continue to get notifications

Chapter 4: The deaths of people with learning disabilities



Where did people die?

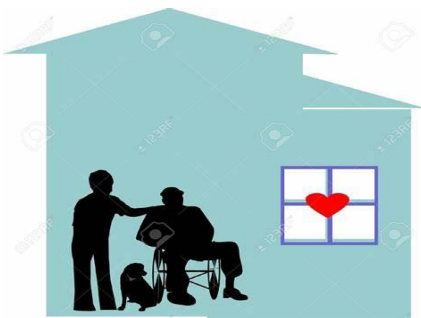
Less than half of the people died in the place they usually lived (their home)

This was 25 out of the 58 people



31 of the people died in hospital

This was over half of the 58 people that were reviewed



One person 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

One person died when they were away from home

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. Pneumonias

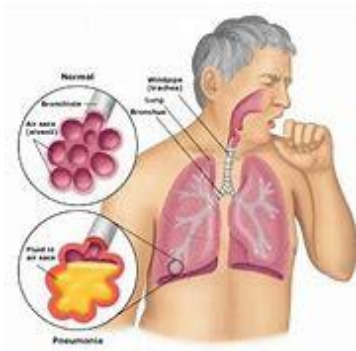
Pneumonia is swelling (inflammation) of the tissue in one or both lungs

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

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





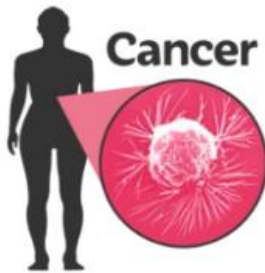
3. Heart Disease

When blood flow becomes limited or stopped, the body shuts down and - without help - can lead to death



4. Frailty

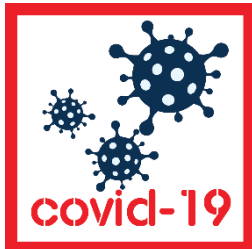
When a person has other health conditions they have an increased risk to becoming weak



5. Cancers

Disease in which some of the body's cells grow uncontrollably and spread to other parts of the body

Chapter 5: Deaths because of Covid-19



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

3 extra reviews showed the person had Covid-19 when they died but this was not their main reason for death



The 2 people who died of Covid-19 died in hospital

Chapter 6: Autism Only reviews



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

1

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

2

In total we have only been told about 2 people who have died who have autism but no learning disability



The **reviews** of these deaths are not yet finished

The Coroner is still looking at why they died

Chapter 7: What have we done to improve services?



We have been checking how good the annual health checks are

We want to make sure people get a good health check

We want to make sure people get information about their health to help them keep fit and healthy

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

We have been checking how good the health action plan is

We want to make sure people understand the information they are given



One of our hospitals have a new team who will support people with a learning disability or autistic people when they are in hospital



A lot of work has been done to make sure **reasonable adjustments** are being used to help people with learning disabilities and autism

We are working with our GP practices to check they are using reasonable adjustments to help people when they go to see their doctor

One of our hospitals now has people who work there called Reasonable Adjustment Coordinators

They help people with learning disabilities and autism when they go to hospital

A person is now working in our community to make sure reasonable adjustments are being used in the services we provide

We want to make sure that people working in the community know about **epilepsy**



Epilepsy training has been given to people working in the learning disability community teams

We want to make sure that people who care for people with learning disabilities understand epilepsy

We would like there to be a person who could make sure that the right care and services are there for people with epilepsy and learning disabilities

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 will continue to promote LeDeR to ask people to refer deaths of autistic people with no learning disability

DNACPR



We want to make sure that **DNACPR** documents are completed and followed correctly

This stands for Do Not Attempt Resuscitation

DNACPR is where a decision has been made that if the person's heart stops beating then no attempt will be made to re-start it

We want to make sure the information is explained to people so they know what **DNACPR** means

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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