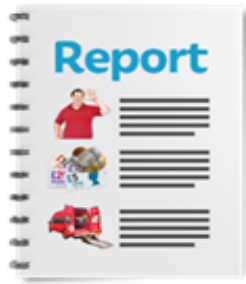


Learning from lives and deaths – People with a learning disability and autistic people

The LeDeR Programme 2023-2024





This is the fifth 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 September 2024



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 2023 and 2024



This report is about people who have died


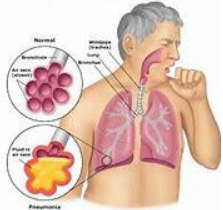

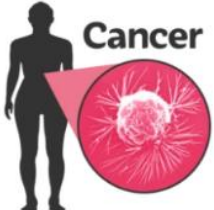


They were special to their families and friends





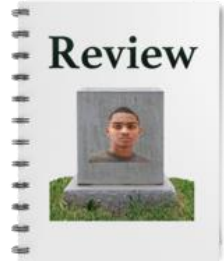

Thank you to those families who have shared their stories



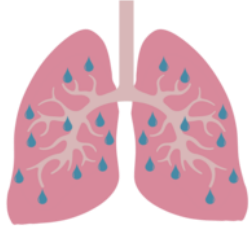
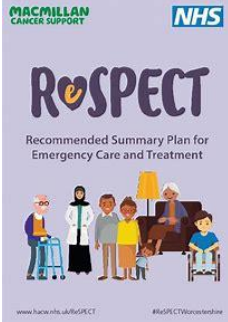

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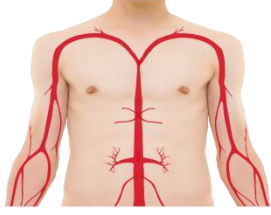
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Some difficult words we use

<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>ReSPECT</p>	<p>ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment</p> <p>The ReSPECT form is part of a process where your care in an emergency is agreed</p> <p>The form is filled out by you and a healthcare worker together</p> <p>The form asks about what is important to you and the kinds of treatments you would want to have in an emergency</p>	
<p>Review</p>	<p>A check on a person's death</p>	

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**



The **reviewer** might need to 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 2023 to 2024 we were told about **83** deaths of people with learning disabilities in Derbyshire

This is 21 more deaths than we were told about last year

This is good because it means more people know about LeDeR and to tell us about the deaths

65

In the year we finished 65 **reviews**

2 of the reviews were for autistic people who did not have a learning disability

63 of the reviews were for people with a learning disability



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 who were autistic but had no learning disability

2

2 of the reviews were for autistic people who did not have a learning disability



The 2 reviews were both male



They died at home



Both deaths were investigated by the Coroner

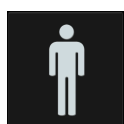
One of the deaths was suicide

Suicide is when someone has killed themselves

Chapter 4: The people who died who had a learning disability

63

63 of the reviews were for people with a learning disability



48%

30 of the people who died were male



52%

33 of the people who died were female



The age of people when they died

The average age at death was 61 years for female and 60 years for male

This is a better average age than last year

In last year's report the average age at death was 58 years for female and 58 for male



5 of the reviews were deaths from Black, Asian and Minority Ethnic groups

This is the same number as last year

8% of the reviews were people from Black, Asian and Minority Ethnic groups

92% of the reviews were people who are from White British ethnicity

Chapter 5: The deaths of people with learning disabilities



Where did people die?

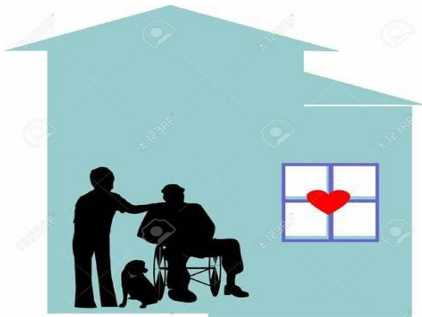
Less than half of the people died in the place they usually lived (their home)

This was 26 out of the 63 people



36 of the people died in hospital

This was over half of the 63 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



Was a coroner told about their death?

Some deaths were reviewed by the **Coroner**



Causes of death

The most common causes of death were:

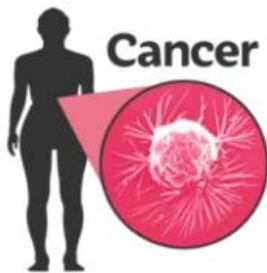


1. Respiratory infections

Respiratory infections include different types of Pneumonia

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

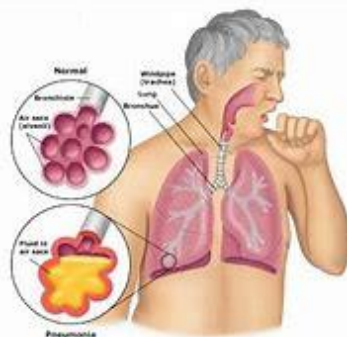
Pneumonia is usually caused by an infection of **bacteria**



2. Cancers

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

Aspiration Pneumonia and Heart conditions had the same number of people die so both were the third top reason for death



3. Aspiration Pneumonia

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

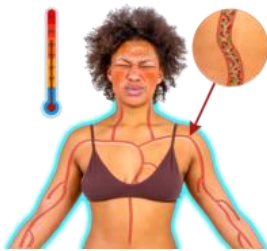
If you are not able to cough up the food or liquid, **bacteria** can grow in your lungs and cause an infection



3. Heart Conditions

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

Sepsis and Covid-19 had the same number of people die and so both were the fourth top reason for death



4. Sepsis/Septic shock

Happens when your body overreacts to an infection you already have and starts to damage your body's own tissues and organs



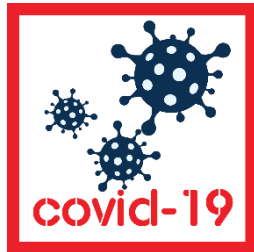
4. Covid-19

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

Chapter 6: Deaths because of Covid-19



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

This is one more death than last year

2 people died of Covid-19 last year

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



2 people who died of Covid-19 died in hospital



1 person who died of Covid-19 died in a care home

Chapter 7: What have we done to improve services?



A survey was produced to find out more from individuals and their carers as to why people have not been attending their annual health checks

The survey told us what stops people going for their annual health check

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



Support services have been introduced for autistic people

Education and training courses are being held for autistic people and professionals to tell them more about autism



A project has been set up through one of our hospitals to support people with learning disabilities when they are invited for bowel cancer screening

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



We must continue to 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

DNACPR

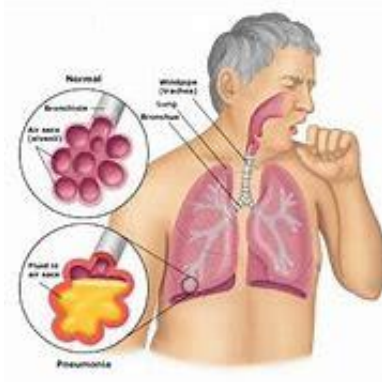


We want to make sure that DNACPR documents are completed and followed correctly

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 have been using the learning from LeDeR to help us understand what good things are happening and what needs to get better when the ReSPECT forms are completed



Aspiration pneumonia is when something other than air goes into your lungs from the stomach or the mouth and causes an infection

This could be food, liquid, saliva, stomach contents, toxins or even a small foreign object

We have had a lot of deaths caused by aspiration pneumonia

We are looking at the learning from LeDeR to help us understand if any changes can be made to care to help people who are more at risk of aspiration pneumonia

Thank you



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

Thanks to the Derbyshire Reps on Board and Denise and Daniel who helped with the easy read report

Where you can get more information



The **LeDeR** team
Derby and Derbyshire
Integrated Care Board
The Council House
First Floor
Corporation Street
Derby
DE1 2FS



ddicb.lederteam@nhs.net



www.leder.nhs.uk