NHS
Derby and Derbyshire
Clinical Commissioning Group

Derbyshire Learning from Deaths of those with a Learning Disability

The LeDeR Programme

2020-2021

This information can be made available in formats such as large print, and may be available in alternative languages, upon request

The Learning Disabilities Mortality Review (LeDeR) Programme is commissioned by the Healthcare Quality Improvement Partnership (HQIP), on behalf of NHS England.

This is the second report of the Learning Disabilities Death Review (LeDeR) programme in Derbyshire.

The report was made available to the public in June 2021.

It tells you about the deaths of people with learning disabilities. The deaths were checked in 2020 and 2021.

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.

Contents

Some difficult words we use

Annual Health Check	An annual health check helps you stay well by talking about your health and finding any problems early, so you get the right care
Cancers	This is a condition that can affect some parts or the whole of your body
Coroner	An official who looks into why somebody died
Constipation	This is a condition that causes your bowels to have difficulty having a poo
Do Not Resuscitate	If the doctors think that a person's heart would not be able to be re- started, they fill in a Do Not Resuscitate form
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
Heart failure	A condition that occurs when your heart is unable to function
Kidney Failure	A condition that occurs when your kidneys are unable to function
LeDeR	Learning Disabilities Mortality Review Programme
Liver Failure	A condition that occurs when your liver is unable to function
Police investigation	Sometimes a death has to be looked at in more detail because of the way in which the person died
Respiratory	The bodily process that helps you to breath
Review	A check on a person's death
Reviewer	Someone who checks up on a person's death

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**.

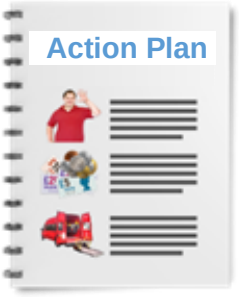
Everyone in Derbyshire has their death looked at in the same way.

Every death has a first check. We call this an '**initial review**'.

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

They talk with other people at a meeting. Everyone who supported the person is invited to the meeting.

They talk about what happened and decide if they need to make any changes to services.



If changes are needed, an action plan is set up.

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

In 2020 to 2021 we were told about **74** deaths of people with learning disabilities.

In the year we finished 7 reviews each month

There are some deaths that are still being reviewed.

We have got better this year at starting to review deaths quicker.

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

Chapter 3- The people who died

4 out of 10 people who died were male.

6 out of 10 people who died were female.

The age of people when they died

The average age at death was 62 years for female and 60 years for male.

1 in every 20 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.

3 out of every 10 people had mild learning disabilities.

3 out of every 10 had moderate learning disabilities.

3 out of every 10 had severe learning disabilities.

One out of every 10 had profound or multiple learning disabilities.

Chapter 4 - The deaths of people with learning disabilities

Where did people die?

4 out of 10 people died in their usual place of residence.

6 out of 10 people died in hospital

Was a coroner told about their death?

Some deaths were reviewed by the Coroner.

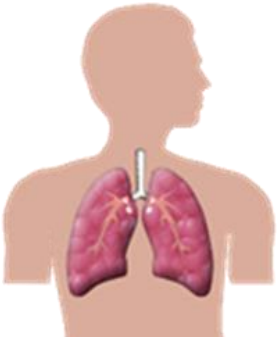
Causes of death

The five most common causes of death were:

1. Covid-19

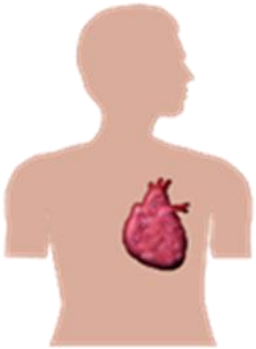
Coronavirus disease (COVID-19) is an infectious disease caused by a newly discovered coronavirus.

A coronavirus is a disease that can affect the health of the lungs. Lungs help you to breathe.



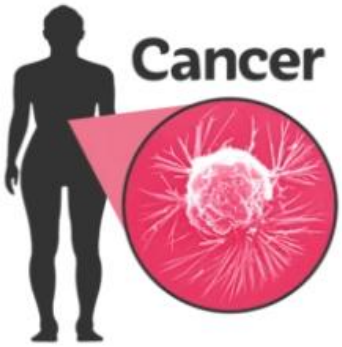
2. Respiratory

Many conditions can affect the health of the lungs. Lungs help you to breathe.



3. Heart Failure

This is a condition where the heart stops working. The heart pumps blood around your body. When the heart stops working people die.



4. Cancer

This is a disease that can affect some parts or the whole of your body. Not all people with cancer die. Most cancers can be treated by doctors.

5. Dementia

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

Chapter 5 – Deaths because of Covid-19

21 people we were told about died of Covid-19

8 out of **10** of these people died in hospital

Chapter 6 - The quality of care given to people who have died

What was good?

- 1 out of 10 people received excellent care
- 5 out of 10 people received good care
- 3 out of 10 people received satisfactory care

This was because:

- Everyone supporting the person worked well together.

- The care was what the person needed.

- When the person was at the end of their life their care was good.

- The person was supported to die in their home.

What was not so good?

- 1 out of 10 people received unsatisfactory or poor care

  The poor quality care may have made them ill or made them die sooner than they should have done.

This is because:
Some people said that they were worried or concerned about what had happened before the person died.

- Some people did not have their illness explained in a way they understood.
- Some people did not have regular health screening and check ups.
- Sometimes people did not receive the services they needed.
- Some people had delays in their care or treatment.

- Sometimes the illness was not noticed, such as understanding when people have constipation.

- Sometimes there were problems with how services supported people.
- For example, different services didn't work together and share information as well as they could.

Chapter 7 - What we think needs to change

Reviewers had lots of ideas about things that could change.

They wanted information about good services to be shared with other services.

Some of the other things they thought should change were:

- Training staff about how to support people with learning disabilities.

- Making sure that services work together when supporting people with learning disabilities.

- Helping people to notice when a person is ill, and treating them early.

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.

People who check up on deaths should agree a way for families to speak up if they have any concerns about their relatives' death.

We must get better at:

- Noticing when a person is becoming unwell or their health is getting worse.

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

- Promote people working together and sharing information.

- Make sure people know about constipation which is when it's hard or painful to poo.

  Make sure people know about other bowel problems and how to help.

  Sometimes these can contribute to a person's death.

- We need to support people to know about and attend the Learning Disability Annual Health Checks.

- Share information to support people looking after a person who is dying

Thank you

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

Including our colleagues at NHS England for use of this template.

Thank you to the LeDeR team at Derby and Derbyshire Clinical Commissioning Group

Who pays for our work?

NHS
Derby and Derbyshire
Clinical Commissioning Group

The LeDeR programme is paid for by NHS England and Derby and Derbyshire Clinical Commissioning Group

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