



# **LeDeR Annual Report Oxfordshire**

## **Easy Read**

From 1<sup>st</sup> April 2021 – 31<sup>st</sup> March 2022



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## Introduction

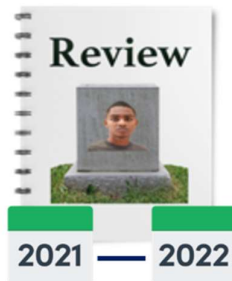


This report has been written by the Oxfordshire Clinical Commissioning Group (OCCG).



In July 2022, OCCG became part of the Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB).

The BOB ICB has joined up health and care services to make sure everyone gets the best care and support possible.



This report will only look at the information collected by the Oxfordshire Clinical Commissioning Group in 2021 – 2022.



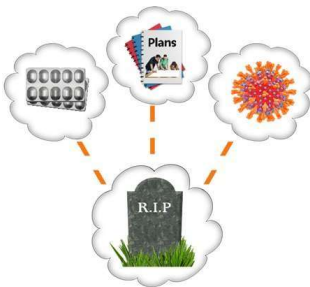
NHS England have asked for a report to look at the deaths of people with a learning disability in Oxfordshire.



They wanted to know about those who have died between April 2021 and March 2022.



This is the fifth year that this report has been done in Oxfordshire.



This report uses the Learning Disability Death Review (LeDeR) framework.

A LeDeR review looks at all of the different things that have led to the death of a person with a learning disability.



This might include looking at their health care records, the place they lived and speaking with their families.



The researchers can suggest things that can be changed to make sure those with a learning disability get the best care and support in the future.



In 2021-2022, OCCG got 52 reports of deaths of people with a learning disability in Oxfordshire.



They have looked into 27 of these deaths.

Some of these cases were from the year 2020-2021.

## Why this report is important



There are around 3,025 people in Oxfordshire who are known to have a learning disability.



This means that they are registered with a GP and have been diagnosed with a learning disability.



The adults with a learning disability who died in 2021-2022 had an average age of 61.

The youngest was 22 and the oldest was 88.



On average this is much earlier than those without a learning disability.

Most people without a learning disability died at an average age of 79.



People with a learning disability are also less likely to have access to good health care and support.



It is important to understand what causes people with a learning disability to die.



If we know what causes it, we will be able to make sure that people get the best care, support and treatment that they need.

## What we did



The OCCG is an organisation that plans, buys and looks at the health services for Oxfordshire.



They work with members of the public, the local authority, hospitals, doctors and local charities to make sure that the care provided meets the needs of the people who use it.



The team got 52 reports of people with a learning disability that had died in 2021 – 2022.

They have looked at 27 of these cases to understand what caused them to die.



The reviewers then looked at what had gone well to support people with a learning disability to have a good life.



They also thought about what needed to change and be improved.



You can read more about specific cases by looking at the 'Pen Portrait' documents on our website.



## What we found out



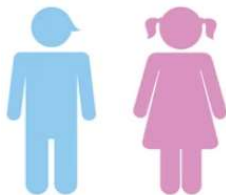
47 adults with a learning disability had died between 1<sup>st</sup> April 2021 and 31<sup>st</sup> March 2022.



20 of them were women.



27 of them were men.



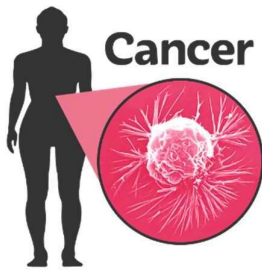
5 children with a learning disability also died in the last year.



We found that cancer was the biggest cause of deaths for people with a learning disability in the last year.

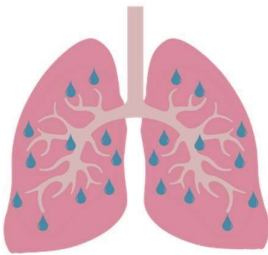
9 people died from cancer.





There are lots of different types of cancer and they can be caused by different things.

A cancer is a disease in the body caused by abnormal cells.



Other things that people died from were:

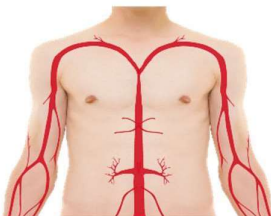
- Pneumonia

Pneumonia is an infection in your lungs where they can fill with liquid.



- Aspiration Pneumonia

Aspiration Pneumonia is an infection in your lungs which happens when food or liquids are breathed into your lungs rather than swallowing them.



- Sepsis

Sepsis is when your body reacts to an infection but starts to damage your organs, skin and muscles.

- Sudden Unexplained Death in Epilepsy (SUDEP)



SUDEP is when someone with epilepsy dies suddenly and without a reason.

The best way to lower the risk of SUDEP is to make sure your seizures are under control.

## Types of learning disability



It is important to know that a learning disability is different for everyone.



A person with a mild learning disability may need some support but is usually independent and able to do daily tasks without support.



A person with a moderate learning disability might find it more difficult to speak and move around.

They may need more support than someone with a mild learning disability.



A person with a severe learning disability will have little or no speech and find it hard to learn new skills.

They will need support to eat, get washed and dressed and keep safe.



When someone is known to have a profound and multiple learning disability (PMLD), it means they have a severe learning disability and other disabilities.

They might not be able to see, hear or speak on their own and will need support with all tasks.



Out of the 27 cases that the Oxfordshire Clinical Commissioning Group looked at in the last year;



- 7 people who had a mild learning disability had died



- 6 people who had a moderate learning disability had died



- 6 people who had a severe learning disability had died



- 1 person who had profound and multiple learning disabilities had died



- 7 people died where we did not know what level of learning disability they had



The research found that 14 people were in a hospital when they died.



12 people died in their homes which included:

- Their family home
- A residential care home
- A supported living service
- A nursing home



1 person died in a hospice.



It was seen that this year, more people were given a choice about where they wanted to be for the end of their life.

## Annual Health Checks and Screening



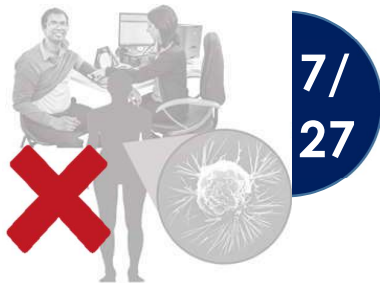
A learning disability annual health check is an appointment every year with your GP to check all areas of your health and wellbeing.

Everyone with a learning disability over the age of 14 has the right to have one.



2021 - 2022

17 people had a full health check in the last year.



Out of the 27 cases only 7 people had a health screening for a medical problem.

A health screening is a test to find out if you are more likely to have a health problem.

## Do not attempt cardio-pulmonary resuscitation



During the Covid-19 pandemic, some people with a learning disability had a do not attempt cardio-pulmonary resuscitation order on them without them knowing.

### DNACPR



A do not attempt cardio-pulmonary resuscitation order, also known as a DNACPR is a decision about what happens to a person when they are very ill or near the end of their life.



These decisions should be made with the person, their families and their doctors, about what they want to happen to them.

### CPR



People need to decide if they would like a doctor to try cardio-pulmonary treatment on them.

It is called CPR for short.





CPR is used to restart someone's heart if it stops beating or if they stop breathing.

## DNACPR



If a person has decided to have a DNACPR, it means that a doctor is not allowed to try CPR on them if their heart stops.



Out of all 27 reviews, 18 people had a DNACPR.

## DNACPR



9 people had all of the correct treatment to try and save their lives.



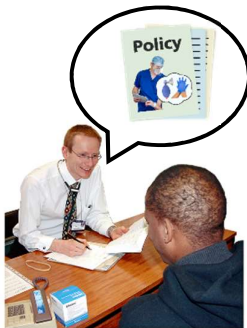
## What we have we learnt from this review



There are many things that we have learnt from the case reviews in 2021-2022.



One of the most important things that we learnt is that taking the time to get to know someone can lead to better health and support for them.



When professionals have more conversations with people about their treatments and DNACPRs they are more involved in their care.



This is called person centred care planning.



These conversations can help people to plan their end of the life care and to die at home if they wish.



Keeping really good records can help professionals to understand the person and their wishes.

It can make a big difference to people when reasonable adjustments are made for the people we support.



A reasonable adjustment is changing the way you do something so the person with a disability can get the best support for them.



Making information in Easy Read can help people to make decisions about their own health care.



Adjustments can help to build relationships with people and keep them calm.

For example, when you meet at a café rather than at someone's home or you turn the lights off if they don't like the room too bright.



People get better care when they, their families and their carers are included in the decisions about their health.

## Areas we need to improve on

More reasonable adjustments need to be made to make sure people can access good health and care support.



These might be:

- Easy Read Information
- Changing the environment where appointments take place
- Including family and carers in decisions



These reasonable adjustments need to be made clear to all staff and included in people's notes.

People's wishes about their treatment should be clear in their medical notes.



We need to make sure everyone with a learning disability has an up-to-date Hospital Passport.

A Hospital Passport helps hospital staff understand the person they are caring for and how best to communicate with them.

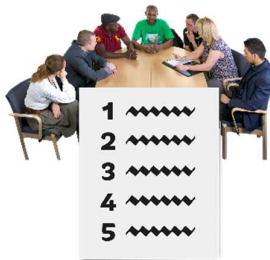


They also share information about their illnesses and health.



Discharge planning is also an area to improve on.

Discharge planning is a plan for when someone comes out of hospital to make sure they get the right care and support that they need.



Discharge plans need to be made with everyone involved in the care and support of the person.



They need to think about what the person wants, what the family want and what skills the staff will need.



They need to be agreed by everyone involved.

## What we will do moving forward



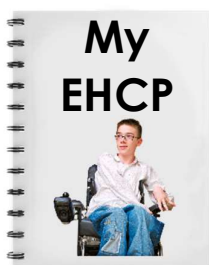
Moving forward, we will make sure that learning disability health checks are done for all people with a learning disability over the age of 14.



Health checks must be included in people's Health Action Plans and Education and Health Care Plans.



A Health Action Plan lets others know what services and support you need to live a healthy life.



An Education and Health Care Plan is for children and young people up to the age of 25 who need additional care and support.



We will also continue to promote living a healthy life and teaching people about making choices for their health.



We will make sure information is in Easy Read to help people to understand more about health screenings.

We will make sure they are understood by family and supporters to make sure they get the treatments that they need.



Providers need to make sure everyone has the chance to build good relationships with the people they work with and support.



We will work together with people, their families and their supporters to make sure they get the best care and support for them when they come out of hospital.



We will work across all teams to make sure we keep better records of people and their health.



## LeDeR Health Resources Project



Funding from NHS England was given to OCCG in March 2022.



We wanted to make a home for information about learning disabilities and autism that is in Easy Read, easy to use and all in one place.

It is for people with a learning disability, their families, carers, support staff and medical professionals.

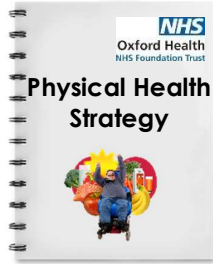


We have worked with Oxfordshire Family Support Network, My Life My Choice and health and social care teams to co-produce this piece of work.



This project was originally just for Oxfordshire but in May 2022, this project got bigger and included Berkshire West.





This project is also linked to the Physical Health Strategy and has worked with experts to include as much information about health as possible.



The Physical Health Strategy looks at your health, your wellbeing and care so you can have the best life possible.

This Easy Read report was created by My Life My Choice.

