

Manchester Learning Disabilities Mortality Review (LeDeR) programme

Report for 2020



Part 1: Background



Who we are

We are Manchester Health and Care Commissioning. This is the NHS and Council in Manchester working to make health and social care work well for everyone.

What this report is for

This report is about work we have done in Manchester in 2020 for a project called 'Leder'. This stands for the Learning Disability Death Review. We used some of the first letters of each word to make the name 'LeDeR'. Manchester Health and Care Commissioning have written this report for the Manchester LeDeR Steering Group. This group reports to NHS England, so we have to do what we say we will.

What LeDeR is for

Some people who have a learning disability die sooner than people who do not have a learning disability. This should not happen. **We want to find out why it does, and look at how we can stop it.**



Most people do not like thinking about death. But doing this work will help health and social care services give better treatment and care. This will help people with a learning disability live well and have good health.



What LeDeR does

LeDeR work is done all over England. It is based at Bristol University. But this report is just about what we have done in Manchester.

When someone with a learning disability dies in England, how and why they died is looked at to see if there were any problems, or if things could have been done differently.

This is called an Initial Review.



If there were problems, there is a meeting with everyone who supported the person who died. Family members and people who knew them well are asked about what they think.



The meeting will see if services need to change the way they do things. If they do need to change an Action Plan is made.



Then a report is written. This says what happened and what was done about it. It is sent to the LeDeR Team at Bristol University. They look at all the reports and come up with ways things can be done better.

Sometimes the same sort of thing happens in different places. By getting 'the big picture' we can learn from other's mistakes and share good ideas.

Local LeDeR groups such as the one in Manchester also do this.



This report is about what happened in Manchester.

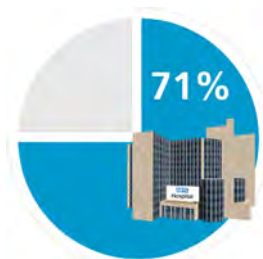


Part 2: What we found

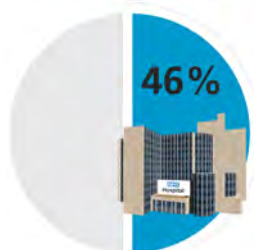


We looked at people in Manchester with a learning disability and who died between March 2017 and July 2019.

- 59 people died
- 46 were adults (people aged over 18)
- 13 were children (people aged under 18)



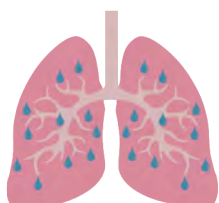
In Manchester most of the people with a learning disability who died (about 3/4) died in hospital



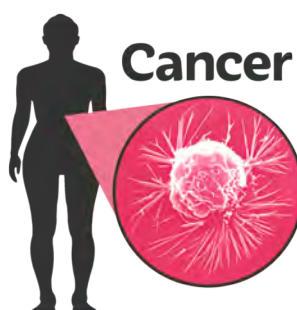
About half of people who did not have a learning disability died in hospital

What people died of

In Manchester, these were the main things the adults with a learning disability died of:



- Pneumonia – this is an infection in the lungs
- Aspiration pneumonia – this is an infection in the lungs caused by food or drink going down ‘the wrong way’.



- Cancer
- Sepsis – this is an infection that affects all of the body

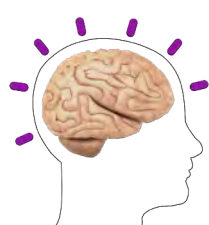


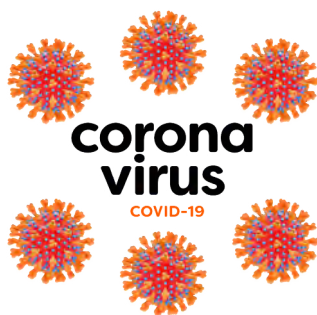
- Coronary heart disease – this is caused by the arteries that take blood around the body becoming blocked.

In the rest of England, people with a learning disability died of the same sorts of illnesses. But other big causes of death were:



- Dementia – these are diseases that make it harder for somebody to think and remember
- Epilepsy – this gives people ‘seizures’, these are like flashes in the brain, which stop it working properly for a while.





- COVID 6 people who died up to September 2020 had tested positive for COVID. This does not mean that COVID was the main cause of death.

People can have other conditions that can make another illness worse, Sometimes, this could mean they die, but they would have got better if they did not have the other condition.

We look at the 'whole picture' to see if other things might be a reason for people with a learning disability dying sooner than people without a learning disability.



We found a lot of the people who died had:

- Constipation and were taking medication for it



- Diabetes



- High BMI – this stands for 'Body Mass Index' and is a way of measuring if someone is an unhealthy weight.



- Dysphagia – this is when someone finds it hard to swallow it can be caused by disorders such as Parkinson’s Disease, or Multiple Sclerosis.



We found nearly 3 out of 10 (14 out of 46) were prescribed psychotropic medications. These are medications that affect the brain and are for for psychosis, depression, anxiety, sleep problems and epilepsy.

But sometimes they are wrongly prescribed to change the way someone behaves.



Stopping over medication of people with a learning disability, autism or both

So, a campaign has been started called STOMP to ‘STop Over Medication of People with a learning disability, autism or both.

Children with a learning disability who die

There is always a review if a child dies. If the child had a learning disability LeDeR is also told.

Some children who die may have had a learning disability, but it had not been diagnosed by the time they died.

This happens because sometimes a learning disability is not noticed until a child is at school and there are issues with the way they are learning.

In Manchester, we were told about 8 children with a learning disability who had died.

- All had severe learning disabilities
- All had life limiting diseases. These are diseases that are so serious people will not live as long as they should do.
- The youngest child who died was 6 years old, the oldest child was 15 years old.

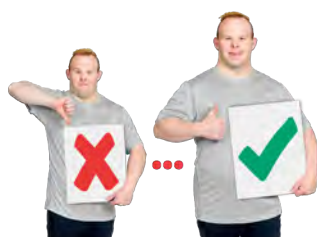
Part 3: What we will do

There are lots of groups and plans that are about helping people with a learning disability to have as good health as people who do not have a learning disability.

In Manchester, some of the main ones are the Manchester Learning Disabilities Good Health Group and the Manchester Learning Disability Strategy.



We looked at the information we got about the deaths of people who had a learning disability and the work that is being done by different groups, the health service and social care providers.



We saw what was good and what was not good and came up with a list of the main things we could do to make things better.



This is our Action Plan for the next year.

Part 4: Action plan



- Make sure staff know about the Mental Capacity Act and Best Interest Decisions



- Come up with a good communication guide
- Help staff know about Reasonable Adjustments



- All GP practices have a member of staff who is a **Learning Disability Champion** who makes sure Reasonable Adjustments are made



- Hospitals in the Manchester Foundation Trust will have more staff trained to understand the needs of people with a learning disability



- Get more people with a learning disability to have Annual Health Checks and be given a Health Action Plan



- Start a health promotion programme for people with a learning disability about early signs of cancer and cancer screening

- Help health and social care providers spot early signs of someone becoming more ill



- Get more people to have the flu vaccine



- Training about infection control in places where people with a learning disability live to keep people safe from the Coronavirus.

If you want to know more about the things in this report, or the work the Manchester LeDeR group does, please email the Head of Nursing:

mhcc.nursingteam@nhs.net

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