Learning Disablities Mortality Review (LeDeR) Programme

Hertfordshire LeDeR Update 2017/18

(LeDeR – Learning Disability Review of Mortality)

Easy-read version

In Hertfordshire we want to make sure people with a learning disability stay healthy and well

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But not everyone shares the same chances of having good health. We call this ‘inequalities in health’

People with learning disabilities tend to have poorer health than other people.

This is an inequality, and it is unfair.

Often, people with learning disabilities also die at an earlier age than other people.

NHS East and North Hertfordshire Clinical Commissioning Group

NHS Herts Valleys Clinical Commissioning Group

Hertfordshire

Some of the people with learning disabilities who died could have had better healthcare.

The LeDeR Programme helps local areas like Hertfordshire to look at information about the deaths of people with learning disabilities

Someone who did not know the person called a ‘Reviewer’. They look at what happened before the person died

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The LeDeR reviews also involve speaking with the families and friends of the person who died.

This is very important to us.

We want people with learning disabilities to live longer. We can do this by finding out what can be done better.

In May 2018 NHS England wrote a report about how they set up the LeDeR programme and what has happened over the last year.

https://www.hqip.org.uk/wp-content/uploads/2018/05/LeDeR-annual-report_Easy_read.pdf

This report also tells people about what we are doing in Hertfordshire.

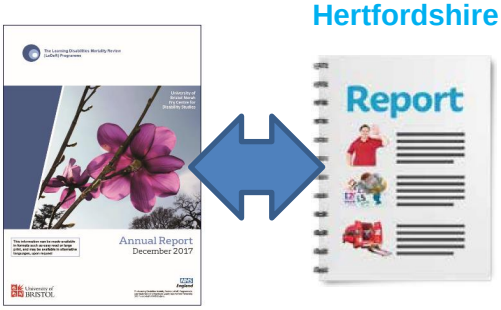
In Hertfordshire we have trained 25 reviewers.

The biggest challenge of LeDeR over the last year is getting reviews done.

Some have found it difficult to have the time to do

Learning Disablities Mortality Review (LeDeR) Programme

What have we found so far?



Hertfordshire

In Hertfordshire our findings from the cases we have looked at are similar to what is written in the annual report about the whole of England

Who were the people who died during this period?

In 2017 - 2018, 47 people from Hertfordshire were reported to the LeDeR Programme as having died. This is less than was expected.

10 cases had a full review. There are lots of cases where the review isn't finished yet.

Over half were men.

Most were white.

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Where did they die?

More people with learning disabilities died in hospital than we would expect.

How old were they when they died?

In Hertfordshire we found of those who died more people were around the age of 59 years.

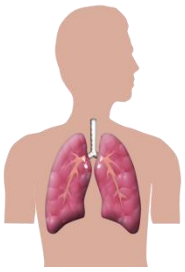
Across England this was 58 years.

Cause of death

In Hertfordshire there have been lots of reasons why people have died.

The 2 main causes of death are the same in Hertfordshire as across all of England.

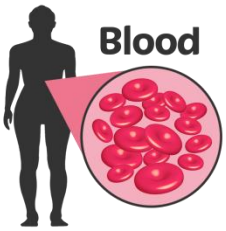
Of the 47 cases we knew the cause of death of 34 people.



1) Diseases of the respiratory system. These are to do with breathing and the lungs.

They were mentioned in 18 out of the 34 deaths.

Lots of these problems were caused by infections or by people having food or drink ‘going down the wrong way’. There were more deaths caused by



2) Sepsis is an infection that spreads through the body. It was mentioned in about 7 of the 34 deaths.

Learning from the reviews

Of the reviews looked at so far, many have , said we need to change how we do things to improve services.

1) There needs to be better communication and coordination of care.

This is to make sure important information is known by the right people.

Good communication is needed for people when they come out of hospital too

2) More training for staff. This is to raise awareness of the needs of people with learning disabilities.

Training is also needed so that health and care workers know about each other.

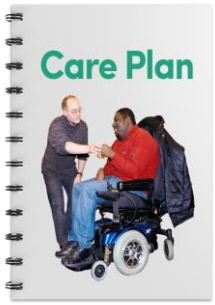
3) Lots of staff need to have a better understanding of the Mental Capacity Act.

This is important because the law says that someone who is able to understand the information can then make their own decisions.

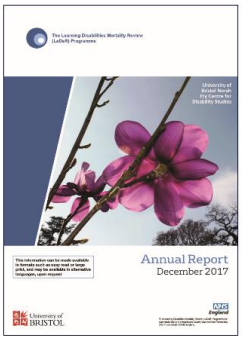
If someone cannot understand their choices about treatment, then staff need to make decisions in their best interests.

In Hertfordshire we did also see that there was good care

1) Carers were looked after well when they visited their family member was in hospital



2) There were examples of good ‘End of Life Planning’



The National Report talked about the changes that need to be made across the whole country. We will be working on making changes in Hertfordshire.

1. There should be a senior person in each health and social care service to make sure that communication between services is good.

2. Health and social care records should be improved so that important information can be shared between services.

3. Health Action Plans should be shared between services, if the person says this is OK.

4) People with learning disabilities with health problems that will last a long time need a named person to help different professionals work well together with them.

5) Services must know if people need changes to the way things are usually done.

They need to write this in people's notes, and check that people with learning disabilities can use services as easily as everybody else.

6) Those providing support to people with learning disabilities must have training about the needs of people with learning disabilities.

The training should be given by people with learning disabilities and their families.

7) People need to understand more about the problems with infections in people with learning disabilities

8) Professionals need to follow the Mental Capacity Act.

Someone in each service needs to help make sure this happens.

So what are we doing in Hertfordshire?

We have a LeDeR Action Plan. This tells us what we need to work on locally

We also have an ‘Improving Health Outcome Group’. The members of this group are people who work in health and social care.

They will be looking at how we can make sure the actions in the plan happen

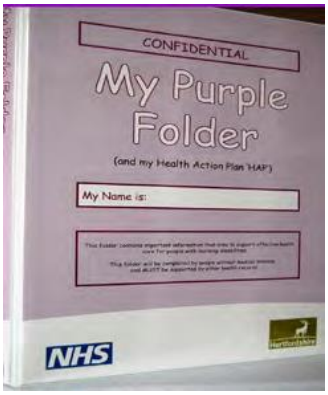
We will check how Hertfordshire is doing against all the areas of learning written in the National Report.

Over the next year we will be working specifically on:

1) Making sure everyone understands the Mental Capacity Act.

This will help people who can make their own decisions plan their future and how they are supported.

2) Reducing the number of people who die because of respiratory conditions.



We will also still work on helping people get a:

- Purple folder (if they want one)
- Annual Health Check
- Flu jab
- Support when in hospital

We will let people know in 6 months' time how we are getting on.

If you would like more information about LeDeR in Hertfordshire or a copy of the full report, please contact:

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Local Area Contact for Hertfordshire LeDeR

Email: tracey.brennan@hertfordshre.gov.uk

Or visit the LeDeR website at
www.bristol.ac.uk/sps/leder

To tell LeDeR when someone has died:

Phone number: 0300 777 4774