NHS
North Central London
Clinical Commissioning Group

LeDeR annual report 2019-2020

EasyRead version

This report is in memory of Stuart Hasler who died in 2020

What is in this report

Page

About this report

This is the first LeDeR report from the North Central London Clinical Commissioning Group or NCL for short.

LeDeR stands for Learning Disabilities **Mortality Review.**

Mortality is when people die.

A **review** is looking back on what has happened.

This report is about:

- all of the LeDeR reviews in NCL in 2019 to 2020
- what we learned from the reviews
- what we did to try to make health and social care better for people with a learning disability.

We know lots of people with learning disabilities die younger than other people.

This can be because of some health problem they have.

Or because their social or health care was not good enough.

LeDeR was set up to:

- look at the health and social care people had before they died
- use what we find out about to try and make services better

- work to make health and social care better so people with a learning disability don't die younger than other people.

LeDeR looks at all the deaths of people with learning disabilities.

About Learning Disability Mortality Review

Bristol University runs LeDeR for NHS England.

LeDeR is one way the NHS is finding out how to help people with a learning disability to:

- live longer
- be healthier.

NCL makes sure LeDeR works properly:

- we check if the plans we make are done
- we check all the jobs we need to do are done

- each borough has local LeDeR workers who are called Local Area Contacts or LACs for short
- there is a central LeDeR worker who helps the LACs

LAC's:

- know their area and services
- are told when someone with a learning disability dies
- help the staff who do the reviews
- work with other staff in their local area to tell health and social care providers what they learnt

Our LAC's are:

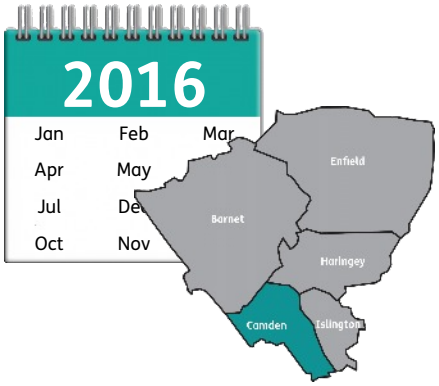
- **Islington**: David Pennington Designated Professional Safeguarding Adults
- **Haringey:** Beverly Mukandi, Head of Quality Improvement
- **Camden:** Sarah Phillip, Designated Professional Safeguarding Adult
- **Barnet:** Sue Tomlin, Head of Joint Commissioning Learning Disabilities and Physical & Sensory Impairment
- **Enfield:** Chris O'Donnell, Person Centred Planning Coordinator. Christina Keating, Designated Professional Safeguarding Children, NCL Child Death Overview Panel Lead

NCL has helped people learn about LeDeR, they:

- told more GP's about LeDeR
- told GP's about the details needed to tell us when someone with a learning disability dies
- told Community learning teams about the details they need to tell us when someone with a learning disability dies
- told families and carers about LeDeR and how it can help
- made a newsletter about what we have learned and what we have done
- talked to many different staff about how to be a LeDeR reviewer.

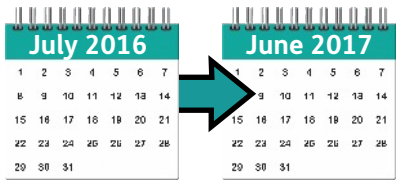
The deaths LeDeR has been told about

LeDeR needs to be told about the deaths of people with a learning disability.



It started in Camden in 2016.

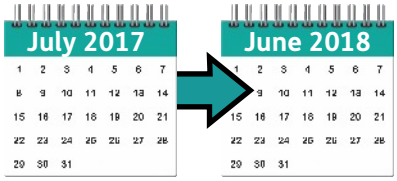
Each year other boroughs have learnt about LeDeR and then more staff tell LeDeR about people who have died each year.



In July 2016 to June 2017 LeDeR was told about:

- 6 people with a learning disability who died
- 2 people were female
- 4 people were male.

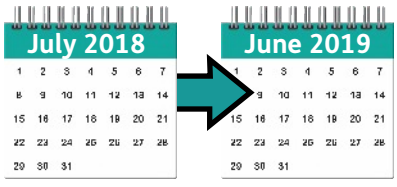
All of these reviews were finished.



In July 2017 to June 2018 LeDeR was told about:

- 43 people with a learning disability who died
- 19 people were female
- 24 people were male.

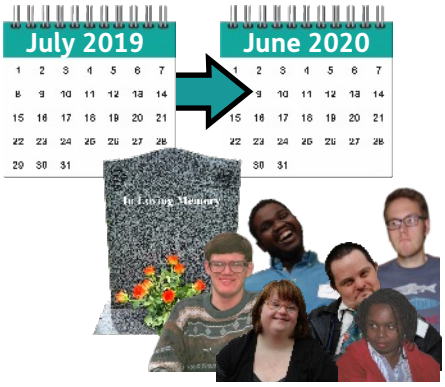
36 out of 43 of these reviews have been finished.



In July 2018 to June 2019 LeDeR was told about:

- 51 people with a learning disability died
- 24 people were female
- 28 people were male.

34 out of 51 have been finished.



Deaths and reviews between July 2019 and June 2020

LeDeR was told about 71 people with a learning disability who died.

23 out of 71 of these reviews have been finished. The rest are still being done.

NHS England gave some more money to get more of these LeDeR reviews finished. We know:

- Barnet and Enfield have many people living in supported living services and residential care homes. There were more people who died from these boroughs

- there are many LeDeR reviews to finish
- there are some problems getting LeDeR reviews done on time.

Where people lived

- 29 people lived in Barnet
- 5 people lived in Camden
- 20 people lived in Enfield
- 7 people lived in Haringey
- 10 people lived in Islington

If people were men or women

- 33 were women
- 38 were men
- this is about the same for other parts of England.

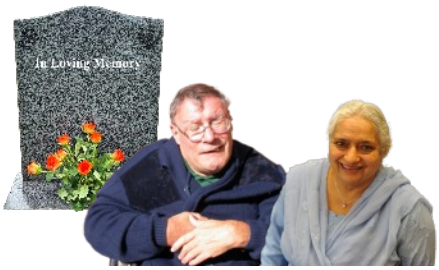
Peoples ages

- 1 child was between 4 and 9 years old
- 6 people were between 10 and 19 years old

- 4 people were between 20 and 29 years old
- 6 people were between 30 and 39 years old

- 4 people were between 40 and 49 years old
- 8 people were between 50 and 59 years old
- 15 people were between 60 and 69 years old

- 17 people were between 70 and 79 years old
- 10 people were 80 years old or older.



42 people who died were over 60 years old.

For all of England in 2019 LeDeR found that:

- women were on average about 59 years old when they died
- men were on average 61 years old when they died.

Locally we found that on average:

- in Camden men were 59, women 55 when they died
- in Islington men were 67, women 71½ when they died
- in Haringey men were 70, women 50 when they died
- in Barnet men were 58, women 57 when they died
- in Enfield men were 68, women 71 when they died.

People's ethnicity

LeDeR was told about the ethnicity of most people who died.

48 were White British.

Of the other people who died:

- 4 were from a Caribbean background
- 1 African
- 3 Indian
- 2 other Asian
- 2 other white
- 5 from other groups
- and 6 we don’t know.

In Barnet they had most reviews and found just over half of the people who died were White British and the rest were from Black, Asian and Minority Ethnic groups. This is the same as the rest of the people who live there.

Where people died

For all of NCL:

- 53 out of every 100 people who died were in hospital
- 42 out of every 100 people who died were at the place they lived
- just 5 out of every 100 people who died were at:
  - a place where people who are at the end of their life are looked after, like a hospice or palliative care unit
  - the home of a relative
  - the home of a friend.

62 out of 100 people across England died in hospital. This is more than for people without learning disabilities usual where only 46 out of 100 die in hospital.

LeDeR found that many people died soon after they left hospital:

- some of these people had good care and plans for the end of their life

- sometimes when people left hospital there were problems with the details about their care

- the learning disability nurses network has helped NCL to make accessible information about leaving hospital and care at home to try and fix these problems

29 out of 71 people died in winter.

Why deaths happened

In 2018 we found that:

- 40 out of 100 people die of breathing problems like aspiration pneumonia, when people get fluid on their lungs

- these breathing problems can make it hard for people to eat and drink. They can more easily choke on food

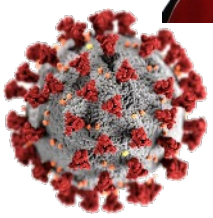
- 7 out of 100 people died of sepsis. This is a very urgent and serious illness
- 6 out of 10 died having a fit called epilepsy.

We did reviews for 50 people who died:

- some of the reviews are from 2018 to 2019
- others from 2019 to 2020.

We found out that:

- 21 out of 50 died from breathing problems
- 7 out of 50 died from heart problems
- 6 out of 50 died from cancer
- 5 out of 50 died of sepsis



- 3 out of 50 died of brain injury
- 2 out of 50 died from COVID-19
- 6 people died of other reasons.

Enfield have made changes to try and fix the problems of people dying from breathing problems:

- they have helped people with difficulty swallowing
- there has been a few less people in Enfield who have died of breathing problems this year

- some people in Enfield who have breathing problems have lived a little longer

- we think things may have got better because of what Enfield are doing but we are not sure yet.

What we have learned

Local LeDeR groups have learned that we need to:

- keep telling people about annual health checks

- give people help to go to annual health checks
- make sure services make accessible health care information and give care that is right for them

- teach people how to tell when someone is ill
- include different staff in teams to help people best with their physical and mental health

- teach staff how to help people who make unwise decisions and don't look after themselves properly sometimes

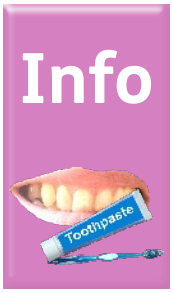
- keep clear information about assessments about people making their own decisions and decisions made for them in GP and hospital records

- talk to people about end of life planning early and talk about having a good end of life.

What NCL services did well

All NCL Services:

- told people about ‘STOP and Watch’. STOP and Watch helps people to see when a person with a learning disability might be ill, see Extra Part 1



- all of the Learning disability teams got information about looking after your mouth. Looking after your mouth helps with breathing problems

- made sure learning disability nurses have got to know other staff and helped them learn new skills

- Helped Barnet and Enfield to make Easy read information about going home from hospital. We are going to do more work sharing this next year.

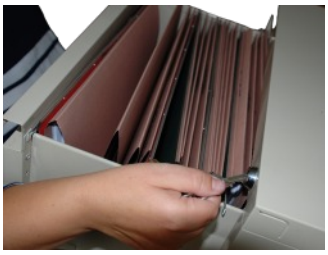
Lots of groups of people in NCL helped to make things better.

In Camden services:

- keep information and think about how to solve problems for different groups of people. It is called HealtheIntent. The Camden staff will think about how they can help people with learning disabilities

- worked with care homes to help care staff learn how to tell when to take someone to hospital. This was called the Significant 7. They will keep helping people learn the new skills

- made films to help hospital staff learn more skills about helping patients with learning disabilities



- is keeping information about patients care plans in one place. They are helping other boroughs do the same

- made a kit to help staff when people make unwise decisions or show self-neglect about their health. Lots of different staff worked on this together.

In Enfield services:

- have people with learning disabilities in a Steering Group at the local hospital about LeDeR. They listen and have a say when the things we learn in reviews are talked about

- had workshops about End of Life Care Plans for people with learning disabilities to help think about what a good death is

- shared what they learnt about the LeDeR reviews with three groups of people. People said this was helpful.

In Islington services:

- had places in the community where people with a learning disability under 65 years old could get the flu jab

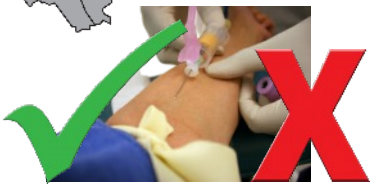
- helped GP's when people with a learning disability had annual health checks

- made Easy read information for people with learning disabilities to learn about sepsis, see Extra Part 2

- made films to tell families how LeDeR works and who can help them
- made an Easy read booklet about End of Life. People can put their details in the booklet and make a plan.

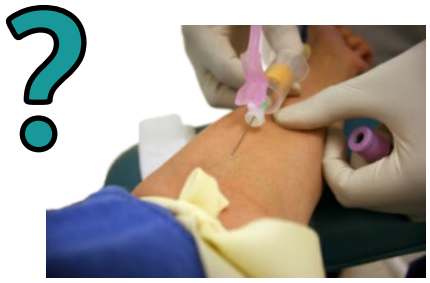
In Haringey services:

- made a plan with the steps needed to help people with learning disabilities who have lots of health problems to:
  - have a healthy life
  - have a good quality of life
  - stay well in the community and not need to go to hospital.



Haringey and Barnet services worked together to:

- learn about what worked and didn't work for people when they had blood tests



- They made a plan with the steps about:
  - what was needed to help people have blood tests
  - what to do when there were problems.

In Barnet services:

- helped GP's to work with a new staff member who knows a lot about LeDeR

- My Health Matters Folder is Barnet's health action plan. They have a health event every year, this years looked at mental health

- made End of Life information packs for families and carers about how to talk about death and dying with people with learning disabilities

- hospital staff meet each week to review all patients with physical health care needs and plan when patients will go home

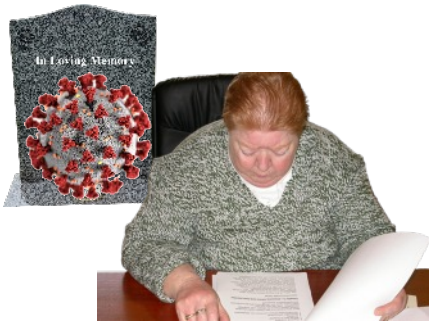
- made Easy read letters to ask people to come in for early checks about Cancer.

What we will do in 2021

LeDeR is very important in NCL.

LeDeR reviews have looked at all of the details when people die.

COVID-19 made it hard to do all of the reviews. There are still some reviews to do.



We will finish the reviews.

We will do any new reviews for people who have died of COVID-19.

We will help more staff learn how to do reviews.

When these reviews are done we will make a plan for how to make LeDeR better.

We will work on making these things better:

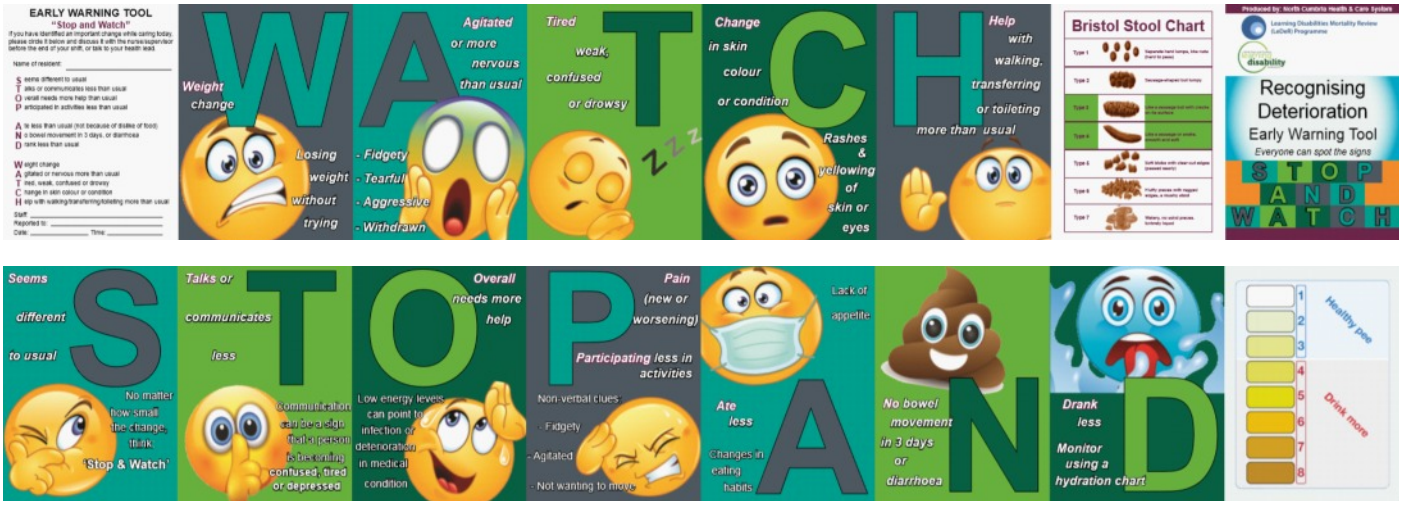
- helping people to learn about and have a good End of life care
- helping people to have and get help to go to Annual health checks
- knowing about the decisions people can make
- sharing health information.

We would like to thank all of the LeDeR reviewers for:

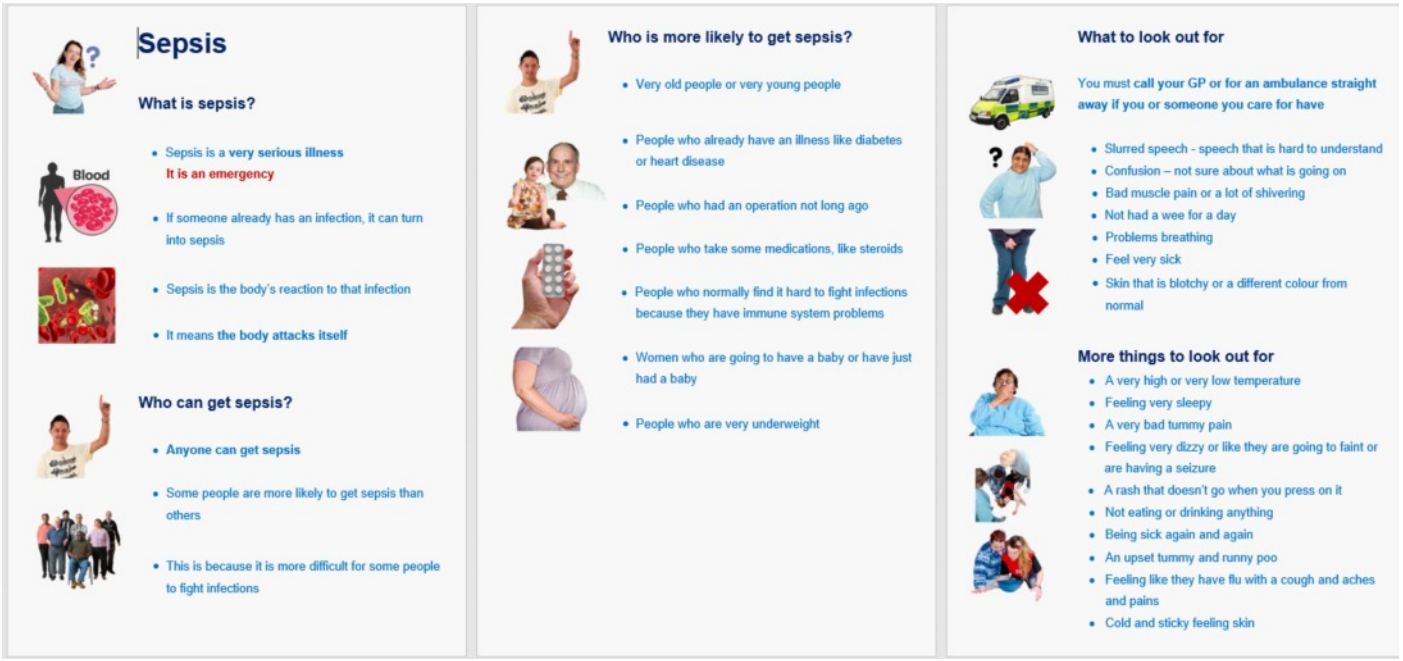
- doing an important job
- doing extra work to help people

- doing good work to learn about the reasons people died
- telling about the reasons people who died in a helpful way.

Extra part 1 Stop and Watch early warning signs tool

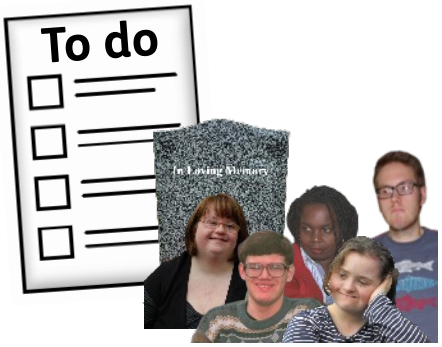


Extra part 2



Extra part 3

The NHS tells NCL and other CCG's the jobs that need to be done.



The NHS tells NCL the jobs that need to be done for LeDeR.

About the LeDeR in NCL:

There need to be people who lead LeDeR:

- in NCL there is a central LeDeR worker
- in NCL each borough has local LeDeR workers they are called Local Area Contacts (LAC).

Reviews should be done in 6 months after LeDeR is told about a death:

- this was hard to do during COVID-19
- boroughs will try to have all reviews done by 30 November 2020 if LeDeR is told about the death before June 2020.

LeDeR must have ways to find out from reviews:

- what the problems are for many people
- make plans to try and fix the problems.

NCL and boroughs:

- find out what the problems are
- make plans and do things to try to fix the problems
- check if the plans to fix the problems are done.

A report about LeDeR needs to be written every year:

- all boroughs wrote a report in 2018/2019
- NCL wrote the first report in 2019/2020 (this the Easy Read version).

Credits

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