



North East London
Clinical Commissioning Group

Learning from lives and deaths of people with learning disabilities



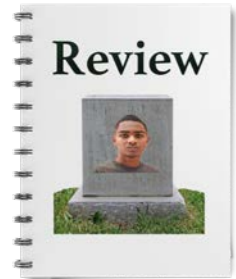
LeDeR Annual Report 2020-21



Learning from deaths



We are the NHS in North East London.



Every year we write a report about all the people with a learning disability who died.



We can learn from these deaths and help other people live longer and happier lives.



Some things in this report might upset you.



You could talk to someone you trust like a friend, family or support worker.



This easy-read report has the main points from our big report.

Deaths in England



Just over **12,000 people** with learning disabilities died in the whole of England between April 2017 and March 2021.



1434 people were in London.



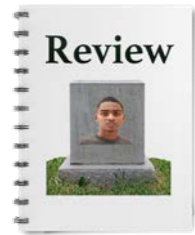
This report is about **333 people** in North East London who died since 2017.



Deaths in North East London



When a person with a learning disability dies in North East London, we look into what happened.



This is called a **review**.



We were told about **333 people** who died.



We have completed reviews for **290 people**.



We have started reviews for **38 people**.



We have not yet started reviews for **5 people**.

About the people who died



Male or female?

140 people were female.
193 people were male.



Ethnicity

216 people were White.
77 people were Asian.
97 people were Black African and Caribbean.
7 people were from other ethnic groups.



Kind of learning disability

84 people had a mild learning disability.
107 people had a moderate learning disability.
87 people had a severe learning disability.
56 people had profound or multiple disabilities.








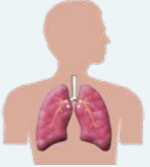



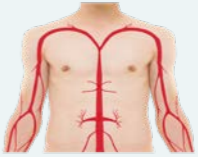
Health conditions

People who died had one or more of these health conditions

 Epilepsy or seizures	 Constipation
 Breathing problems	 Skin conditions
 High blood pressure	 Bad teeth or gums
 Diabetes	 Low vitamins
 Mental health conditions	 Heartburn
 Falling or unsteady on feet	 Incontinence
 Very overweight or obese	 Very little mobility

Top causes of death

These are the main causes of death

 COVID-19	 Multi-organ failure
 Breathing problems	 Diabetes
 Pneumonia	 Kidney failure
 Aspirational Pneumonia	 Lung failure
 Heart	 Cancers
 High blood pressure	 Sepsis

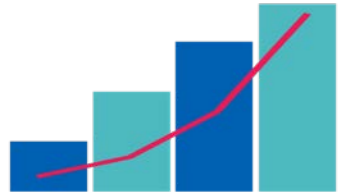
Sepsis is when your body has a really bad response to an infection.

Aspirational Pneumonia is when someone breaths food, drink, saliva or vomit into their lungs.

Annual Health Checks



We looked at how many people who died had **Annual Health Checks**.



In the last few years, more and more people were getting Annual Health Checks.



Some people did not have their Annual Health Check because of Covid-19.



265 people who died could have had an Annual Health Check.



192 people had an Annual Health Check.



73 people did not have an Annual Health Check.



Some Annual Health Checks were done better than others.

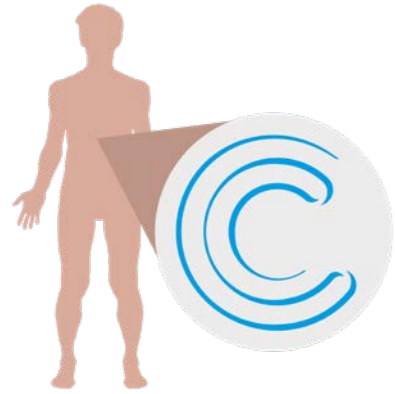


Most people also had a **Health Action Plan**.



Ask your GP/ family doctor if you have not had your Annual Health Check.

Health screening



We wanted to know if people who died had checkups (called **screening**) to look for illnesses.



Smear tests

This is where we look for a kind of cancer that affects women called **cervical cancer**.

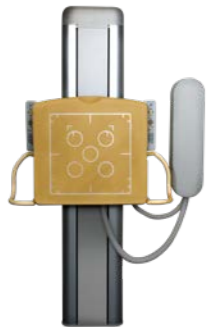


Not enough women were checked, only **56 people**.



Breast screening

All women over 50 years old should get the chance to have breast screening for cancer.



But only **83 people** who died had a checkup for breast screening.



Bowel screening

Men and women over the age of 60 should be screened for **bowel cancer**. But only half the people over 60 who died were.



More people need to be encouraged and supported to have health-screening appointments.



Flu jabs



Less than half of people with learning disabilities who died had their flu jab – **150 people**.

This is about the same as the year before.

People with learning disabilities need better support to get their flu jabs in the future.



People's weight



Being overweight can make you less healthy. We looked at the weights of just over half of the people who died – **182 people**.

Just over half the people were overweight or **obese**, more men than women.

18 people were underweight, more women than men.

Just under half of the people who died were taking medicine that affects the brain or mental health called **psychotropic medicine**.

Some of these medicines make people put on weight.

More people need to be supported to lose weight through exercise clubs or gyms and healthy eating.

Teeth and gums



We looked at people's teeth and gums, and what **dental care** they had.



180 people – just over half – had been told to see the dentist more often because their teeth were bad.



One issue is that many people did not like cleaning their teeth or having it done for them.



Health services should do more to help support people to have healthy teeth and gums.



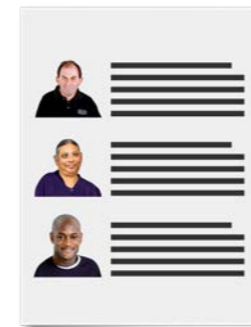
There are dentists who are trained to help people who get scared or have trouble cleaning their teeth. More people should get to see these dentists.

Medicine



99 people who died had epilepsy, behaviours that challenge or mental health conditions.

88 people were taking **psychotropic medicines**. Some people were given these medicines without a reason.



It is not clear why most people were men - **52 men** and **36 women**.

Most people had mild or moderate learning disabilities – **74 people**.



People living in residential care were more likely to be given these medicines – **79 people**.



People living with their families were less likely – only **19 people**.

15 people said they wanted to stop taking these medicines, but only 4 people were supported to stop.



More people should be reviewed and supported to stop medicines that they do not need.

Making your own decisions



Some people had **Mental Capacity Assessments** – this is to find out if someone can make their own decisions safely.



108 people had this assessment.



73 of these people needed extra support to make safe decisions. These were mostly people with more severe learning disabilities.



Carers and support workers can ask for an assessment for someone they support.

Family carers



Carers of people with learning disabilities should get their own assessment, but not many did.



Some families felt that care was their responsibility.



Others were worried an assessment might change benefits or even make someone move to residential care.



Health and social care workers can give family carers information and support, so they understand the benefits of carer assessments.

Reasonable adjustments



The law says health and social care services must make any **reasonable adjustments** you ask for.



This is extra help you might need to use health and social care services.



You could ask for a long appointment, or to come at a quiet time.



Or you may need help with **access** or a **home visit**.



206 people who died needed help getting around or moving.



283 people needed help with communication or accessible information.



We did find some really good examples of reasonable adjustments



A doctor visited a care home where the patient felt more comfortable.



One place got a special chair that leans back so a patient did not need to be hoisted to a bed.



One patient got money to pay for private foot care because they had been on the waiting list for a year.

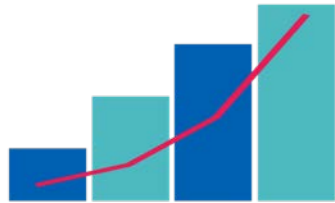


Speak to your GP or social worker about any help you think you need.

How good care is



We looked at the **quality** of care – how good it is.



Overall, care quality was much better last year, even with the pandemic happening.



However, people with milder learning disabilities did not get as good care.



People from **BAME groups** got worse care than White people.



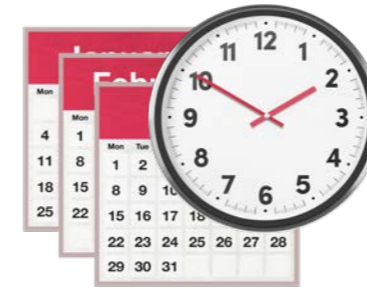
People with mental health issues did not always get the best care.

Care for the dying



When someone is about to die a plan should be made to help make them as comfortable as possible – this is called an **End of Life** plan.

For most people who died, the plan was made when they went to hospital for the last time. Many died in hospital.



For some people these plans lasted 2 weeks. For other people they were just a few hours.



32 people died where they usually live.



13 people died in a **hospice** – a place where people live when they are dying.

We encourage workers to support people with learning disabilities to be involved in making these plans.

When patients stop breathing



Sometimes a patient stops breathing. This is because they are very ill and they die.



But sometimes they can come back to life with **CPR** – this is when the doctors press on the chest or use electricity to shock the heart to bring them back to life.

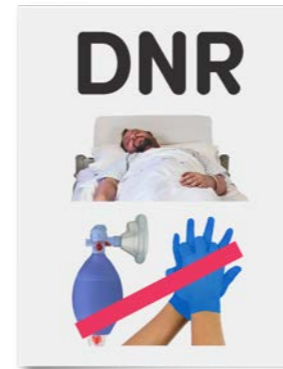


Sometimes a decision is made not to bring someone back to life.

This is called **Do Not Resuscitate** or **DNR** or **DNACPR**.



190 people who died had a DNR saying not to resuscitate.



Sometimes the **reason** was that the person had a learning disability.

This is wrong.



Some families thought doctors had made bad decisions about DNR.

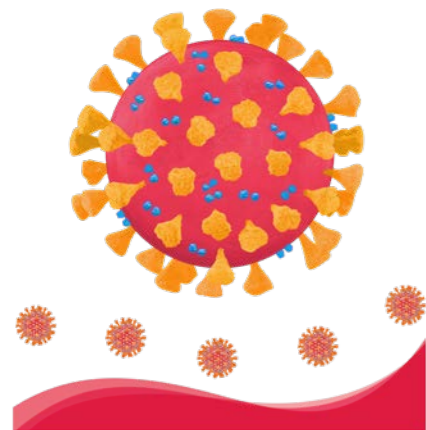


Some families got the doctors to change their minds and have the DNR taken away.



Doctors should speak with families about DNR and make sure they understand the reasons.

Coronavirus



A big part of last year was the **pandemic**.

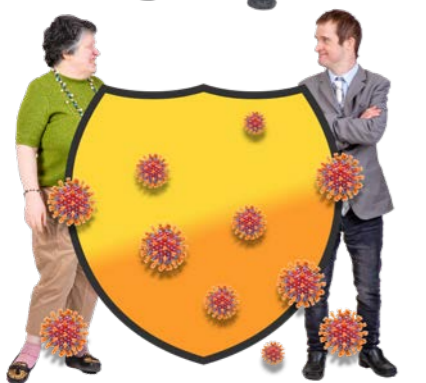
There were twice as many deaths as the year before.



84 people died from Coronavirus.



People with learning disabilities living in residential settings were more likely to catch Coronavirus because of care staff coming and going.



Also, many people had other health conditions that put them more at risk from Coronavirus.



We looked into 56 of the people who died from Coronavirus.



The youngest was 13 years old and the oldest was 85 years old.



Most of the deaths were men.



46 people died in hospital, **10 people** died in their own home.



Most of the people who died had **mild** and **moderate** learning disabilities.



Many people who caught Coronavirus lived in **supported living** and **residential care homes**.

Good things



These are some good things from the year



More people are now taking up Annual Health Checks.



Some people had really good reasonable adjustments.



Technology was used well – phone calls, video meetings and home visits.



Some people who were dying slowly got really good care.



Staff teams worked very well together.



Learning Disability Teams were great at communicating with families during the pandemic.

Bad things



Some things were not so good



Some people had appointments cancelled or were not told what was going on with their care plans.



Not everyone had good reasonable adjustments.

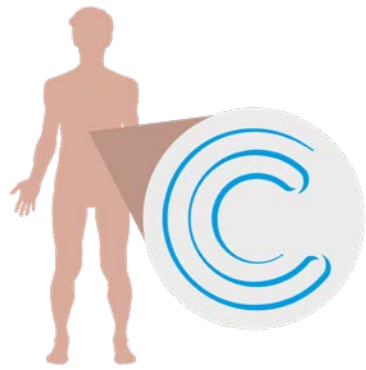


Not everyone who had an Annual Health Check had a Health Action Plan.



Young people (under 22) were not getting their Annual Health Checks.

Bad things



Not enough people had health screening appointments for cancer.



People and their carers missed out on important assessments.



Some people with higher needs were left out of services.



Some people were given medicines they didn't need.

How we are making things better



We will help more people get their Annual Health Checks, including teenagers from 14 years old.



We will help more people get a good Health Action Plan.



We will tell doctors to try and use **psychotropic medicines** only when they are needed because they can also do a lot of harm to someone.



We have plans to help people get regular check-ups and reviews.



We will train health and care staff to spot early signs someone is getting ill - so they can get help more quickly.

How we are making things better



We will work together better and share information more.



We will find better ways to communicate with people with learning disabilities and their families.



We will work with people and organisations to help people with learning disabilities get healthy and stay healthy.



This easy-read report was made with Photosymbols by Camden People First. October 2021.