

Action from learning: Deaths of people with a learning disability from coronavirus





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### About this report



On 12 November the University of Bristol published a **report** about the **deaths of 206 people** with a learning disability who died during the **coronavirus pandemic**.



The **report** talked about some of the **good things** which had happened to people with a learning disability who had **coronavirus**.



The **report** also talked about some things which were **not good**.



We will **tell you** about the things that were **not good** and tell you what we are going to do to **make them better**.

## Spotting when people are getting more unwell



The **report** said that sometimes **community health and care staff** didn't know how to spot when someone was **getting more unwell**.



Sometimes **community health and care staff** did not have the **right things** to help them. For **example** the **right machines**.



What we are doing about it



We are working with care homes so that staff get better at spotting when somebody with a learning disability is poorly, and getting more unwell. Spotting when people are getting more unwell



We are training 5,000 paid and unpaid carers so that they can spot when the person they support is poorly and getting more unwell.



We are writing some **documents to help hospital staff spot the signs** that somebody with a learning disability is **getting more unwell**.



The **documents** will say **how the signs might be different** to someone without a learning disability.

# DNACPR and learning disability as a cause of death

# DNACPR

DNACPR stands for Do Not Attempt Cardiopulmonary Resuscitation.



**Cardiopulmonary resuscitation or CPR** is when someone tries to make your heart start again if it stops.



If people **do not want CPR**, they can choose to have a **Do Not Attempt Cardiopulmonary Resuscitation recommendation or DNACPR**.



If you have a **DNACPR** a health professional **will not try** to start your heart if it stops.

#### DNACPR & learning disability as a cause of death



The **report** said that sometimes a **learning disability** was still being used as a reason not to try and resuscitate someone.



A learning disability is never a reason to not try and resuscitate someone.



The **report** also said that some people were still putting **learning disability** as the **reason someone died on their death certificate**.



A learning disability should never be put as the reason someone died on their death certificate.

#### DNACPR & learning disability as a cause of death



#### What we are doing about it



All the way through the **coronavirus pandemic** we have been reminding doctors that a **learning disability is not a reason not to try and resuscitate someone**.



We are making sure that **GPs look at all DNACPR decisions** and make sure they are right for each person.



We are making sure that **staff working in health and social care get good training in caring** for people with a learning disability and autistic people.

#### DNACPR & learning disability as a cause of death



We have worked with **Learning Disability England** and **Turning Point** to make some **good information** for families and carers about **DNACPRs**.



We are working with a **new type of doctor** called a medical examiner to make sure that doctors use the right words on death certificates for people with a learning disability.



The Care Quality Commission (CQC) checks services like GPs, hospitals and care homes to make sure they are giving good health and social care to people.



The CQC are doing a **report** about **DNACPR** and how they were used during the coronavirus pandemic and this will come out in **Spring 2021**.

# Looking at someone's learning disability instead of their health



We know that sometimes people decide what is wrong with somebody based on their learning disability instead of the symptoms which are making them poorly.



The **report** said that this meant some people **didn't get the treatment they needed at the right time**.



What we are doing about it



We are **working with NHS 111** to look at how they **look** at people with a learning disability. This is so we can make things **better** for people.

# Looking at someone's learning disability instead of their health



We are reminding **GPs to look at all of the health issues** a person on their **learning disability register** has.



This means that people who are more likely to get **very poorly or even die** from coronavirus can be asked to take **extra care to keep themselves safe**.



We are reminding **GPs** that the **signs that someone with a learning disability is getting more unwell** might be different to someone without a learning disability.



This will help people with a learning disability get the right care when they need it.



**Reasonable adjustments** make it **easier** for someone with a disability to **access** the **NHS services** they need to keep healthy.



The **report** said that some people **did not get the reasonable adjustments they needed.** 



What we are doing about it



We are working with doctors so that they can put a note on the computer about the kind of support a person with a learning disability needs.



We call this **note** a **flag**. The **flag** means that other **NHS** staff can read about the best way to look after you.



During the coronavirus pandemic we made lots of information to remind staff who support people with a learning disability to make reasonable adjustments.



We made the **Grab and Go Guide** for **doctors** and **nurses**.



The Grab and Go Guide has information doctors and nurses will need if a person with a learning disability goes in to hospital because of coronavirus.



We made some **information** to help support **health services** to keep doing what they needed to during the **coronavirus pandemic**.



We sent a letter to hospitals to tell them that a reasonable adjustment for someone with a learning disability might be having their family visit them.



We have done some work to get more people to have their **flu vaccination** and their **annual health check** this year.



We have done some work to make sure that **all NHS organisations** look at **how good the care they give** to people with a learning disability is.



Every year the NHS organisations need to look at how well they are doing with reasonable adjustments.



The NHS organisations need to ask people who use the services and their families and carers, as well as staff, what they think.



We are going to write to **NHS** organisations reminding them that they need to make reasonable adjustments for people with a learning disability.



We will tell **NHS organisations** that **learning disability nurses** are an **important way** of making sure that **doctors** and **nurses** make **reasonable adjustments**.

# Find out more about our work



The University of Bristol work with us on the LeDeR programme.



You can find out more about their work at www.bristol.ac.uk/sps/leder



You can find out more about the NHS England and NHS Improvement learning disability and autism programme at:



www.england.nhs.uk/learning-disabilities



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