



# Action from Learning report on working together



NHS England and  
NHS Improvement



Camden People  
First

2019

# In this report



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Messages from a person with a learning disability, from a family member of somebody with a learning disability who has died, and from NHS England and NHS Improvement.



## What this report is all about

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What you can find out about in this report about action from learning.



**STOMP**

Stopping the over medication of  
learning disability,  
or both



## Things NHS England and NHS Improvement are already doing

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Work that is going on including:

- Annual Health Checks
- stopping people getting too much medicine (STOMP)
- helping people with feedback, concerns and complaints (Ask Listen Do).

## New work

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What NHS England and NHS Improvement are doing , including work on:

- Sepsis
- Mental Capacity Act
- Constipation
- Dysphagia
- Cancer.



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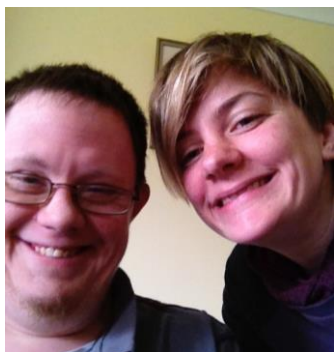
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# First thoughts



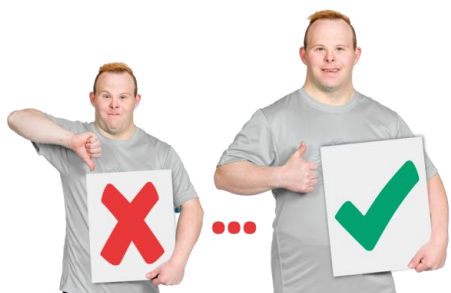
from a bereaved family member



When my happy, healthy and much-loved brother Richard died in 2012 with constipation, I was very sad and upset.



Richard's death made it clear to me that we need to make services better so that no other person with a learning disability dies, when it could be stopped.



There is still lots of work to do but I am hopeful that change is happening.

**NHS**



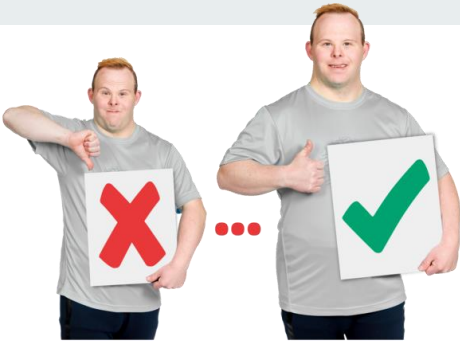
The NHS has promised to help people with a learning disability live happier, healthier lives, and to listen to families who have lost a loved one.

**Dr Emily Handley-Cole** is a learning disabilities clinical psychologist, currently working for NHS England and NHS Improvement as one of the leads for the LeDeR programme.

# First thoughts



from NHS England and NHS Improvement



The Learning Disability **Mortality** (death) Review programme is about making care better for people with a learning disability.



It is worrying to hear from the reviews that people with a learning disability die around 20 years younger than other people.



But it is good to see that there are many people living good lives with person-centred care and support.



It is important that we keep learning from the reviews to make sure people with a learning disability live longer, healthier lives.

**Ray James, CBE** - National Learning Disability Director

**Dr Jean O'Hara** - National Clinical Director for Learning Disabilities



# First thoughts



## Message from a person with a learning disability



I would like to say thank you to everyone who has been involved in the LeDeR programme.



The LeDeR programme is important work which should save the lives of people with a learning disability.



Listening to and working with people with a learning disability and our families should help to make sure that me and my friends have the chance to live long and healthy lives like everyone else.

**Aaron Oxford**

**Learning Disability and Autism Network Manager**

# What this report is all about



**Action from Learning** means taking what you learn, to make changes that are needed to make things better



In Spring 2018 NHS England set up a new group to look at what has been learned from **Learning from Deaths Reviews (LeDeR)**.



A Learning from Deaths Review is when someone with a learning disability dies and we try to find out why.



The group look at how we can share:

- what is helping people with a learning disability to live longer.



- what is helping people with a learning disability to live healthy lives.

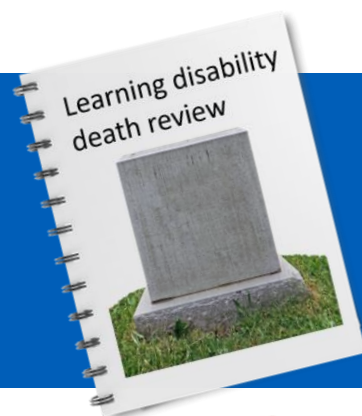


- how people die from something that could be stopped. The group wants to stop this happening.



The Action from Learning group has people from

- the NHS
- the government
- other groups.

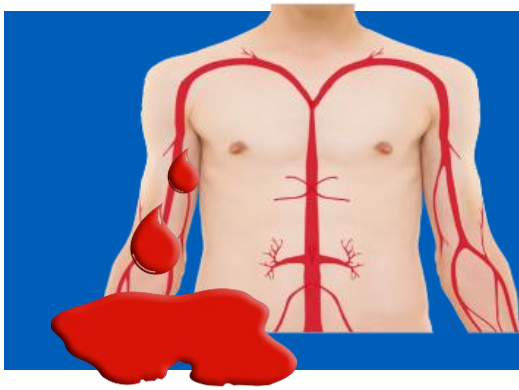


From the reviews which have been done, we know that people with a learning disability are dying from:



- **Pneumonia.** This is when you have a problem with your chest and breathing





- **Sepsis.** This is when you have an infection that can get into your blood and makes you very poorly



- **Constipation.** This is when you find it difficult to poo.

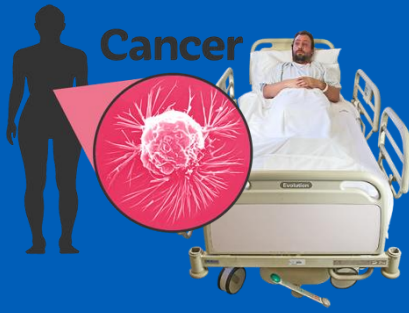


- There are sometimes problems with using the **Mental Capacity Act.**

This is a law that says everyone should be able to make decisions that affect their lives. It says there might be times when you do not have the capacity to make some decisions, for example if you're really poorly.



Professionals must work with the person and be able to show when they don't have capacity to make a decision.



- **Cancer.** This is a disease that makes your body change. It can cause lumps on your body and make you very poorly.



We want to make sure we know when new problems come out of the reviews.

# Things NHS England and NHS Improvement are already doing:



- **Annual Health Checks.** This is when you see the GP once a year

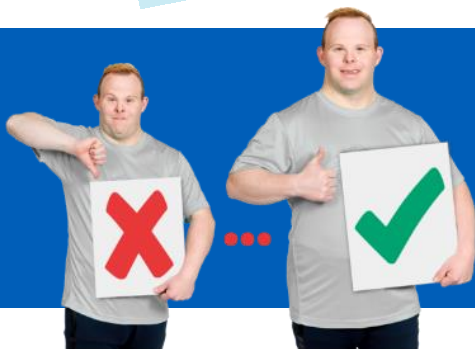
## STOMP

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

- Getting medication right (**STOMP**)



- **Ask Listen Do** makes it easier for people with a learning disability and autistic people and their families, to tell someone when something is wrong with their healthcare



- We want **Action from Learning** to make all this work better.



- **Digital flagging.** This is a reminder on a doctor's computer that tells them if a person has a learning disability, is autistic or both, so they can make things easier for them.

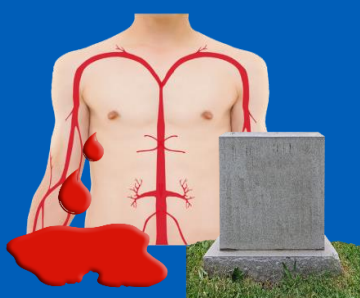
# New work that NHS England and NHS Improvement are doing to stop people dying younger



## Sepsis



**Sepsis** is when you have an infection that gets into your blood and makes you very poorly.



We know that too many people with a learning disability are dying from sepsis.



There is a **sepsis group** is looking at:

- how we can help people to spot the signs of sepsis early so that they can get help







- how health and care staff can get the right information



- how other organisations tell each other what works well.

## Mental Capacity Act



The **Mental Capacity Act** is a law that says everyone should be able to make decisions that affect their lives. It says there might be times when do not have the capacity to make some decisions, for example if you're really poorly.



Professionals must work with the person and be able to prove when they don't have capacity to make a decision.



The Mental Capacity Act group is looking at how to:



- tell more people about the Mental Capacity Act.



- help people understand the Mental Capacity Act better so they know when and how to use it



- help people understand the things people with a learning disability can find hard about the Mental Capacity Act



- help organisations tell each other what works well.

# Constipation



**Constipation** is when you find it difficult to poo.



We know that too many people with a learning disability are dying from constipation.



There is a constipation group which is:



- telling more people about constipation and that it can be a big problem if they do not get help straight away



- Giving people different ways to find out about constipation



- Making sure people have information about constipation and how having a healthy diet and being active can help to stop this
- Helping people to think and talk about constipation, because it can save lives.

## Dysphagia



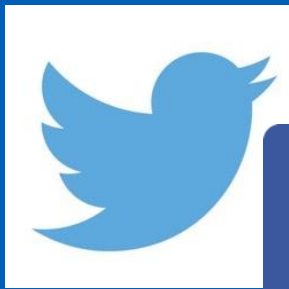
We know that lots of people with a learning disability have problems swallowing. This is called **dysphagia**.



There is a dysphagia group who are:

- giving people and professionals different ways to find out about dysphagia



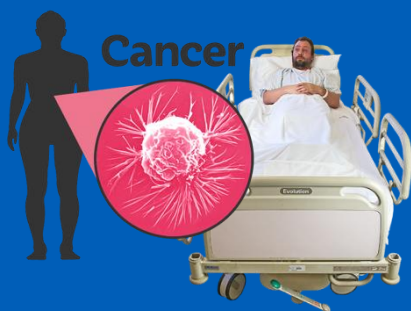


- Using **Twitter** and **Facebook** to tell people about the swallowing problems that people with a learning disability have



- Holding an event about people with a learning disability who have swallowing problems.

## Cancer



We know that some people with a learning disability are dying from **cancer**.



Sometimes this is because people do not have the right support





We want to make sure cancers are spotted earlier, so you are more likely to get better.



Things like

- making sure you know about cancer screenings

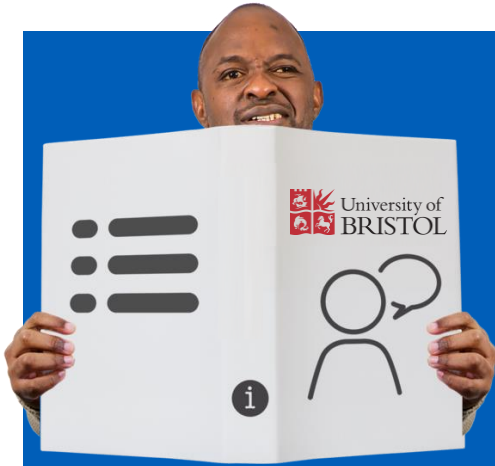


- that health staff are making it easier for you to get a screening.

# How we tell people about this work



## Newsletters



The **University of Bristol** work with us on the Learning from Death Review programme and they send out newsletters to more than **3 000** people.



So far, newsletters have been about:



- **Aspiration pneumonia.** This is a really serious chest infection you can get when food goes down the wrong way



- Knowing when a person is becoming more poorly



- **Constipation.** This is when you find it difficult to poo



- **Mental Capacity Act.** This is the law that says everyone should be able to make decisions that affect their lives.

It says there might be times when you do not have the capacity to make some decisions, for example if you're really poorly.

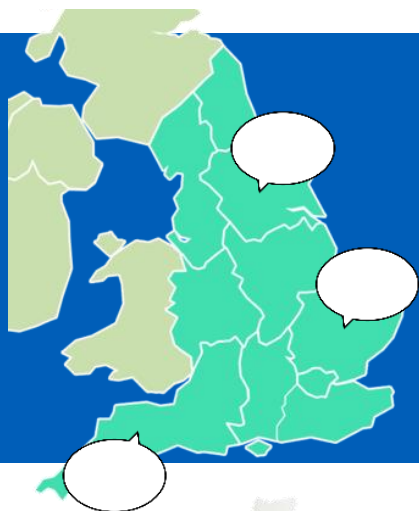


All the newsletters can be found at [tinyurl.com/BristolNewsletters](https://tinyurl.com/BristolNewsletters)

# Learning and sharing what we know



## Sharing information online



The Action from Learning programme set up a group on the internet to share information and talk to each other more easily across the country.

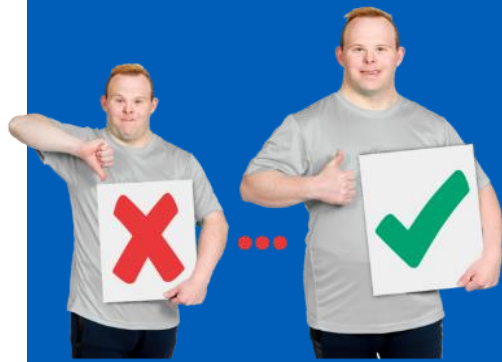


Anyone from a health or social care organisation or voluntary organisation can join the group.

## Local learning and sharing



Learning from Death Reviews are already giving us the information we need to make services better.



Now this information will be used in local areas to make a difference to the lives of people with a learning disability and their families.



We will hold local events about the reviews.



# Local planning



In each area of the country there is a steering group.

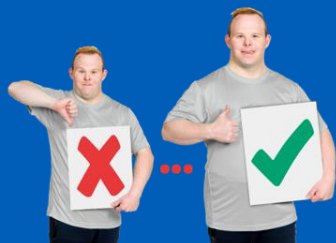
A steering group is a group of people with different experiences who lead the work locally.



In Autumn 2018 each local group wrote a report a plan for the next year.



The plans tell us there are big differences in the ways that local services are changing.



Some of the problems for local areas are:

- Not enough of the reviews have been finished
- It takes time to show that things are getting better

# Examples of local areas making a difference:



These are some ways areas have been working to improve things:



- Things are getting better in hospitals.

For example some hospitals have started making sure all staff know when a person who is staying in hospital has a hospital passport, so that they everything they need to about the person



- Things are getting better in **community learning disability teams.**

For example lots of teams have made accessible information for people with a learning disability and their families



- Things are getting better in **primary care**. This is things like when you go to see your **GP**.



- In **South West London** they are working towards having a **champion** in each GP surgery to support people with a learning disability and their families. This will give people someone to contact who knows their story and needs who can provide support and reasonable adjustments.



- Another example is in **Camden** where there are training sessions on the Mental Capacity Act to improve people's knowledge and confidence.



- There are things that are getting better in local areas for families and carers.

For example, the **Enfield** learning disability team have started using a dysphagia fridge magnet so that carers can spot the signs of breathing problems, and know how to report things that they are really worried about



- There are lots of other things getting better around the country.

For example, in **Derbyshire**, they have held sessions about trouble pooing for people involved in health and care. This was to explain

- why it is a problem
- how to look after yourself and stop having trouble pooing.





## Next steps



We know there is still work to do to make a difference to people's lives. This includes:



- Making sure that everyone who is looking at why someone has died is working together



- Working with people with a learning disability and families to find out whether people are seeing changes in services



- Getting and sharing information that is useful for all health and care professionals, not just learning disability professionals



- Making sure that we know if the Learning from Death Reviews programme is helping people to live longer, healthier, happier lives.



# Thank you



Thank you to **Camden People First** for helping us make this report into easy read.



NHS England and NHS Improvement would not have been able to do this work without the support from families who have lost a loved one.

They have shared their stories and have pushed the work to get better.



NHS England has paid for Respond, a learning disability charity, to work with a group of families who have lost someone. They are working to make things better for families who are part of LeDeR reviews.



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