



Action from learning report 2022 to 2023

Learning from lives and deaths (**LeDeR**) of people
with a learning disability and autistic people



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What is LeDeR?



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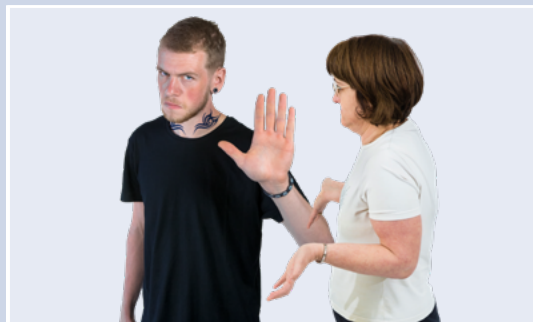
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LeDeR is the name given to the work that reviews the lives and deaths of people with a learning disability and autistic people.



The reviewer finds out about their care and why they died.



LeDeR has found that people with a learning disability and autistic people do not always get good healthcare.



What is LeDeR?



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They sometimes die younger than other people.



People with a learning disability and autistic people sometimes die younger than other people from illnesses that they could have got better from.



Good healthcare might have stopped them from becoming very unwell or dying.



KING'S
College
LONDON

NHS
England

Every year NHS England writes a report with King's College London about the LeDeR programme.

This is called the "action from learning report"



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This easy read report explains the work that the NHS is doing to make services better for people with a learning disability and autistic people.



This report is to help health and care staff learn more about how to:



- support people with a learning disability and autistic people to be healthy and well



- stop people with a learning disability and autistic people from dying too young.



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The 2022/3 LeDeR report is introduced by:



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Co-production:



People with a learning disability and autistic people worked with the NHS to:



- write this easy read report



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- [make two videos](#) to tell everyone about LeDeR and the important work we are doing to make services better.



The NHS LeDeR team has different people working with them. They have:



- people with a learning disability and autistic people

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- family carers



- family carers who had someone in their family with a learning disability who died



There is also a group of people who help the LeDeR team in their work to make services better. This is called the LeDeR 'independent advisory group'.



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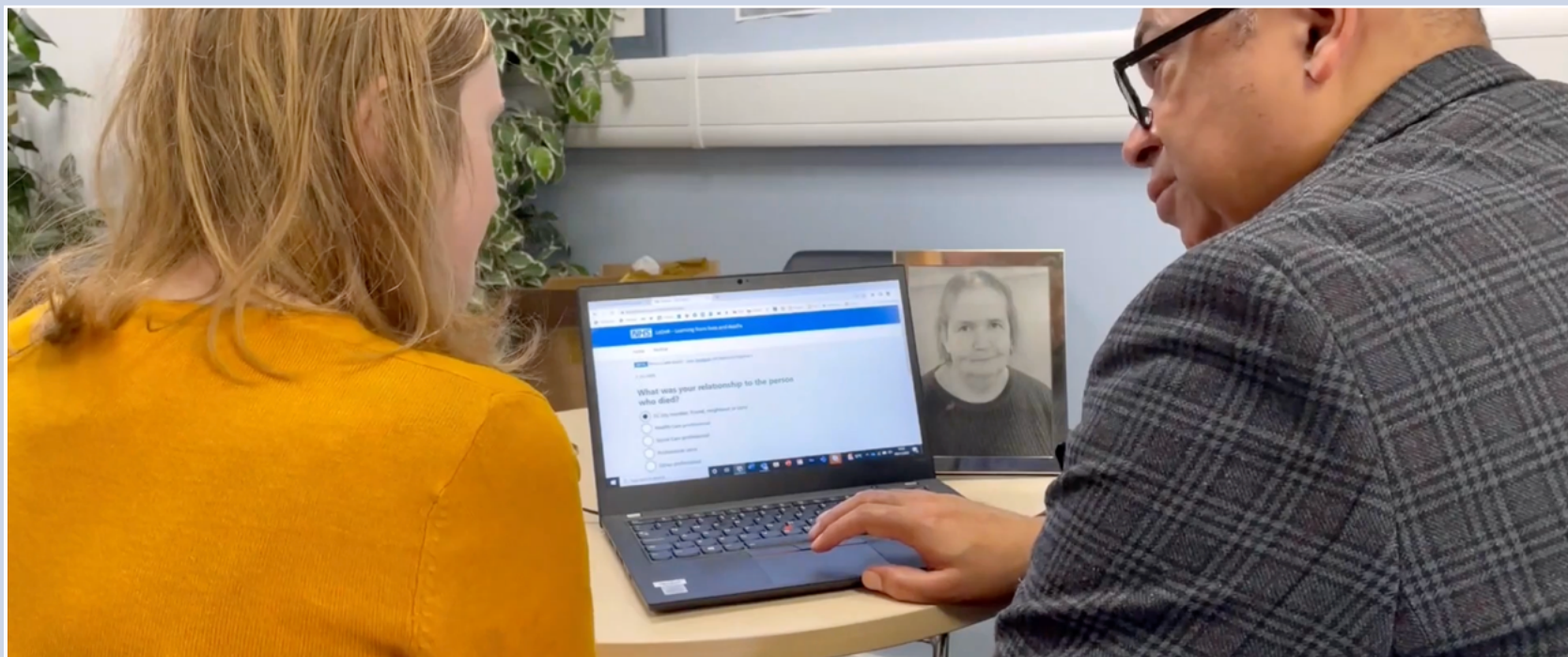
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Click on these links to watch two videos about the 2022 LeDeR report.

Video 1:

[What is LeDeR?](#)

Video 2:

[LeDeR - good work being done to support people with a learning disability and autistic people across England](#)



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Race, religion, ethnicity and culture



LeDeR reports show that people with a learning disability from a minority ethnic group have more problems with their healthcare than other people with a learning disability.



The NHS has started doing lots of work to make healthcare better for people with a learning disability from minority ethnic groups



The NHS has done research and trained staff on the issues that people from a minority ethnic group with a learning disability face.



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Different areas of England are called NHS regions and there are seven regions in total.



This report tells you about some of the work being done in those regions.



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Case study: Midlands region



Health and care teams in Leicester, Leicestershire and Rutland worked together to make sure people with a learning disability were looked after well and given good care.



Health and care staff worked hard to make sure that:



- more people with a learning disability had annual health checks



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- less people with a learning disability and autistic people stayed in hospital for a long time.



- Health and care staff also made sure LeDeR reviews are done quickly.



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Case study: North East and Yorkshire region



Reasonable adjustments in West Yorkshire



Because of what happened with coronavirus, there were lots of people waiting a long time for treatments and operations.



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The NHS in West Yorkshire decided to give people with a learning disability and autistic people their operations or treatment first.



This helped to keep people healthy and well and lowered their risk of becoming very unwell or dying too young.



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Type 2 diabetes



The North East and Cumbria Learning Disability Network made a six week course with and for people with a learning disability and autistic people who have type 2 diabetes.



Watch this video about the Skills for Living Diabetes Type 2 course.



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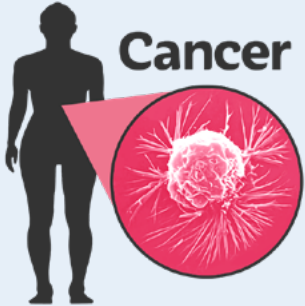
Find out more



Case study:
South West region



Cancer screenings



Cancer

Cancer screenings are tests to spot the signs of cancer as soon as possible, a lot of people with a learning disability do not go for cancer screening.



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In Cornwall NHS staff are helping people to go to their screening appointments, providing easy read leaflets and supporting people who are worried about cancer screening.



Dysphagia or swallowing problems



Dysphagia is when you find it hard to swallow.

It is more common in people with a learning disability.



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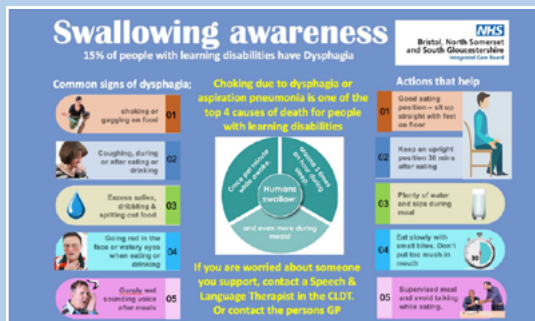
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Dysphagia is a serious problem in the South West region so they are doing three projects to help.



A **training course** was made by speech therapists in Devon.



A **swallowing awareness flyer** was made by health and care teams in Bristol, North Somerset and South Gloucestershire.



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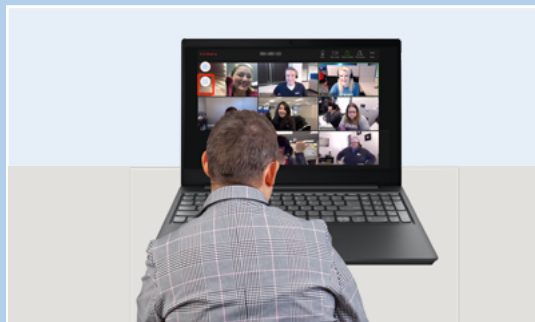
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In **December 2022**, the Learning Disability and Autism Programme Team of the NHS in the South West held an online dysphagia management event.



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Case study:
Midlands



Health and care teams in Birmingham and Solihull

2022



Birmingham and Solihull
Integrated Care System
Caring about healthier lives

The teams in Birmingham and Solihull wrote a three-year plan for LeDeR in 2022.



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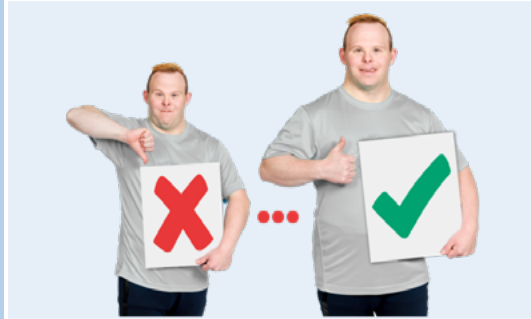
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The plan says how the teams are going to make health services better for people with a learning disability and autistic people.



Three projects in Birmingham and Solihull are making sure people with a learning disability and autistic people are one of the first groups of patients to get treatment for health problems.



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Case study: East of England



Talking therapies in Cambridgeshire and Peterborough



Health and care teams in Cambridgeshire and Peterborough are making it easier for people with a learning disability to access talking therapies.



Talking therapies help people who have problems with their feelings.



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Case study:
North West region



**Advance care planning and
end of life care**



Advance care planning and end of life care can help to make sure that people have good care at the end of their life.



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Planning ahead can help people choose how they would like to be cared for, in case they become unable to make choices.



Three self advocacy groups helped us make sure people with a learning disability get good end of life care.



Self advocacy groups are run by people with a learning disability and autistic people, who work together to speak up about the things people need.



The three groups doing this work are People First - Merseyside, Inclusion North and Speak Up.



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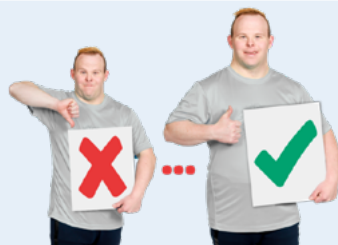
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They will be making easy read guides and videos, workshop plans and training plans.



These will help people to get better at:



- talking to people with a learning disability about death and dying



- giving people good support when they are too unwell to get better.



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Case study:
London region



A new app for health and care staff



**South London
and Maudsley**
NHS Foundation Trust

Health and care staff in South London are making
a new app.



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The app helps to check if the medication they give to someone with a learning disability, could:



- make them have constipation



- lead to other problems called side effects



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The new app will help healthcare staff to:



- choose the right medication to give to someone



- know when to change their medication to a different one.



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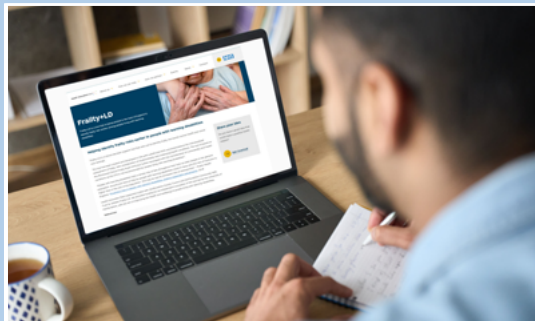
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Case study:
East of England



**A new app for health and care staff
in Hertfordshire**



The **Frailty+LD** tool by Hertfordshire Council helps to work out the risk of a person with a learning disability becoming frail by:



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- checking their health and what they need help with, to find out what extra support they need



- setting up the right care to manage their health and support needs.



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Case study: South East



All about Health – new website



There is a new accessible website in Oxfordshire to put health information in one place for:



- people with a learning disability and autistic people



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- their families



- people who support them.



The website is available at:

<https://allabouthealth.oxfsn.org.uk/>

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Managing health problems



Reviews have shown us some health problems are more common in people with a learning disability and autistic people.



In this part of the report we share examples of work being done in the NHS across England.



to make sure better care and treatment is given to people to spot these health problems sooner and manage them well.

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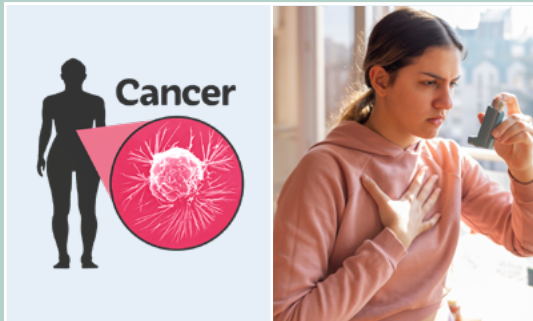
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Annual health checks



An annual health check can help make sure any signs of illnesses like cancer and diabetes, or breathing and heart issues are spotted early.



It is important for people with a learning disability and autistic people who are older than 14 years old to have an annual health check.



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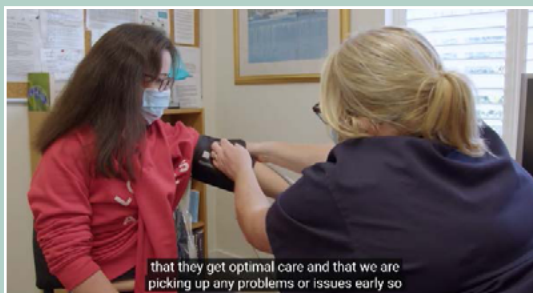
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If you have a learning disability make sure your name is on the learning disability register at your GP surgery (doctors) so that you get your annual health check.



Watch a video of Charlotte's annual health check.

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Breathing problems



Flu and pneumonia were one of the biggest causes of deaths between **2018 and 2021**.



Breathing problems like pneumonia can lead to deaths that would not have happened if the person had good healthcare.



A guide for health staff about pneumonia was co-produced in 2023. It should make pneumonia care better for people with a learning disability.



National work



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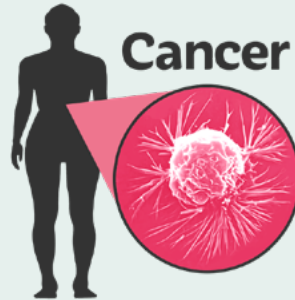
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Cancer



One of the main problems in 2021 was not many people were having cancer screenings.



Cancer screening means tests to help spot the signs of cancer as soon as possible.



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The NHS has done a lot of work in 2022 and 2023 to help more people to get their cancer screening. Here are some videos about cancer screening:



A video about cervical cancer screening showing Jodie talking about her first cervical cancer screening test.



A video on how to use the bowel cancer screening FIT kit.



A video telling people about cancer screening called Check It Out.

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A photograph of a man in a grey hoodie and white trousers sitting on a white toilet, looking down with a concerned expression.

Constipation

A photograph of a man in a striped shirt sitting on a toilet, leaning forward with his head buried in his hands, appearing to be in discomfort.

Constipation is when you find it hard to poo or do not poo as much as you need to.

A close-up photograph of a hand with the thumb pointing downwards, a common gesture for disapproval or a negative sign.

Constipation can be a big problem for people with a learning disability.

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We have made videos, leaflets and posters for people with a learning disability and carers to:



- help them spot the signs of constipation



- make sure they get help quickly if someone has problems with their poo.



We have also shared information about constipation with pharmacies and GP surgeries.



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We want to make sure that healthcare staff help people with a learning disability who have constipation quickly.



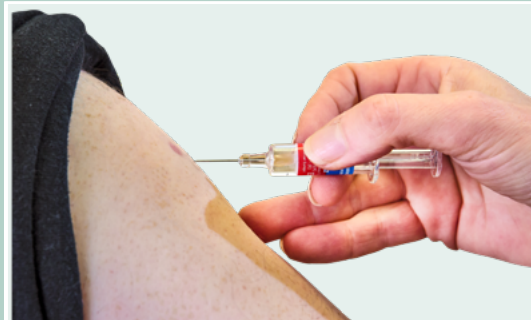
If you have any problems with your poo, make sure you tell someone straight away to get the help you need.



Look at [our leaflets](#) and watch [our constipation video](#) to find out more.



COVID and flu



A lot of work has been done to make sure people with a learning disability get their COVID booster.



Flu can be very serious for people with a learning disability.

Flu vaccines can make the illness much less serious.

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The NHS supported a short video of Rachel and her mum Carol having their combined COVID booster and flu vaccination together.



The NHS made a new Easy Read leaflet called ['Protect yourself from Flu'](#)



We also made a video guide for parents and carers of people with a learning disability and autistic people about flu vaccines.

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Epilepsy



Nearly one in three people with a mild to moderate learning disability has epilepsy.



People with a severe learning disability or autistic people are even more likely to have epilepsy.

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The NHS made [a video about how epilepsy care nurses support people with a learning disability.](#)



Work on epilepsy



SUDEP is the name used when someone with epilepsy dies suddenly and there is no other reason for their death.

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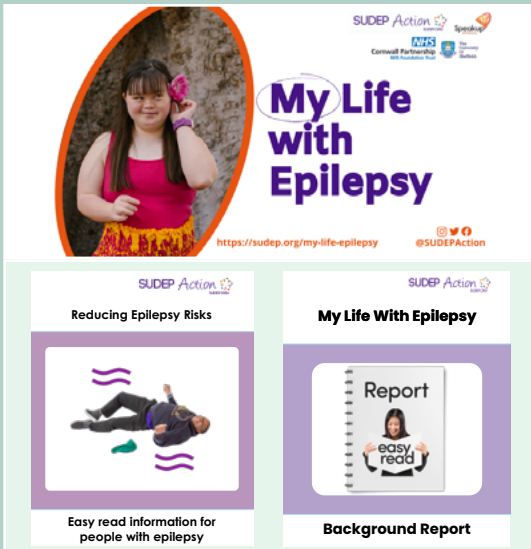
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SUDEP Action 
Making every epilepsy death count

A charity called SUDEP Action worked with the NHS to make videos and Easy Read leaflets for people with a learning disability and autistic people who have epilepsy.



They tell people about the dangers of epilepsy and the things people can do to stay safe and well.



SUDEP Action also made videos and leaflets for carers.

This work is called “my life with epilepsy” and you can find it on the SUDEP Action website.

You can download the leaflets or watch the videos by visiting:

sudep.org/my-life-epilepsy-resources



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LeDeR Resource Bank



Health and care staff are using a new website called the LeDer Resource Bank.



The website has lots of information, videos and guidance for health and care staff about:

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- different health problems that affect people with a learning disabilities and autistic people



- spotting the signs that someone is getting poorly

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Spotting when someone is feeling unwell



It may be difficult for some people with a learning disability and some autistic people to say they feel unwell.



This means their health could get a lot worse very quickly.

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We made a short training course for care homes and carers and families of people with a learning disability and autistic people.



The course **RESTORE2Mini** was made with the charity Skills for Care to support carers to:



- spot when people with a learning disability are getting unwell



- get help from healthcare staff quickly to help stop people dying too young.



Reasonable adjustments



Reasonable adjustments are changes to the way that care is given so that it meets your support needs and is right for you.



[A new short video](#) has been made for healthcare staff about supporting people with sensory difficulties.



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STOMP

STOMP

STOMP

Pledge for Social Care

Stopping Over-Medication of People with a Learning Disability, Autism or Both

Supported by NHS England



'STOMP' stands for stopping overmedication of people with a learning disability and autistic people.



People with a learning disability are still **16 times more likely** to be given antipsychotic medication than other people.

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Autistic people are **seven times more likely** to be given anti-psychotics than other people.



Anti-psychotic medication is used to treat mental health conditions.



Sometimes they are also given to people because their behaviour is seen as challenging.



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The NHS has made **new** online training for health and care staff to:

STOMP

- help them understand STOMP



- make sure people are only given medication that they need.



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Oliver McGowan mandatory training



The law now says that health and care services have to make sure their staff have training on how to look after people with a learning disability and autistic people.



The Oliver McGowan mandatory training can be used to train health and care staff



Watch this video with Tom Cahill, National Director for Learning Disability for NHS England.



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Remember if you feel unwell or notice any changes in your health, make sure you:



- tell someone you trust



- speak to healthcare staff as soon as you can



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You can find out more about:
the **NHS England** LeDeR programme at
leder.nhs.uk/



The **NHS England** learning disability and autism
programme at
england.nhs.uk/learning-disabilities