



LeDeR 2023 - 2024 NHS Sussex Report



Learning from the Lives and Deaths of People with a Learning Disability and Autistic People



An easy read guide

What is LeDeR?



LeDeR is the name for Learning from the Lives and Deaths of People with a Learning Disability and Autistic People.



It finds out why people with a learning disability or autistic people have died. To make improvements in care.



This report is about people with learning disabilities and autistic people who died in Sussex from April 2023 until April 2024.

What is LeDeR?



We believe everyone has the right to good health. Getting the care you need is very important.



People with learning disabilities and autistic people are more likely to have health problems. They die at a younger age than other people.



Sometimes they die from things that are easy to cure with early treatment.



The review finds out why this is and what we can do about it. It helps us plan how to make healthcare better for people with learning disabilities and autistic people.

Working together



People with learning disabilities, autistic people, families and carers know most about the care they need.



We think it is important to work together with them to plan services.



We involve local groups, Learning Disability Partnership Boards, Autism Partnership Boards, and the Sussex Learning Disability board.

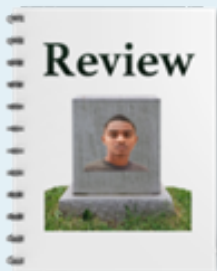


If you want to have your say, please contact the team:

sxib.leder@nhs.net

What we found out

Life stories



We found out about each person with a learning disability that died in Sussex from April 2023 until April 2024.



We learned about their lives and the things that mattered to them.



We want to thank the families of the people who died for sharing their memories with us.

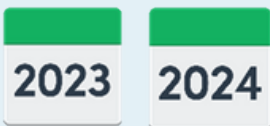


This helped us understand what support and care people need.



We also want to thank other people that helped. GP surgeries, NHS, social care, carers, residential home managers and staff.

The facts



138

65

55

77

2

From April 2023 until April 2024:

- 138 people with learning disabilities and autistic people in Sussex died.
- The average age people died was 65 years old.
- 55 women died.
- 77 men died.
- 2 transgender people died.



Transgender is when the gender you are born with does not feel right. If you are transgender, you might start living your life as a different gender than what you were born as.

What people died of



We found out about the illnesses people died from. The most common causes of death were:



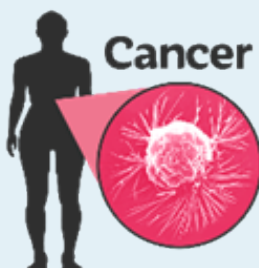
1. Pneumonia: Pneumonia is an infection in one or both lungs.



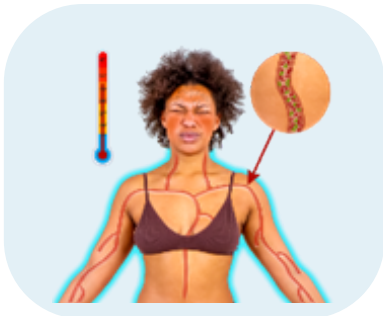
2. Frailty: Frailty is when your body becomes weak due to age or health condition. It makes it harder to recover when you become ill.



3. Diseases of the circulatory system: Cardiovascular Disease is when your heart does not work well. It can cause high blood pressure, heart attacks, and strokes.



4. Cancer: Cancer is when cells in your body grow in an uncontrolled way. These cells develop into tumors.



5. Sepsis: Sepsis is when your body fights too hard against a serious infection. It can damage your organs and stop them working. For example, your kidneys might stop working.

What we learned



The Equality Act is law. It is about making sure people have the support they need to access services, like reasonable adjustments.



Reasonable adjustments are things like:

- Extra time
- Special equipment
- Easy read information
- Quiet spaces



Not using reasonable adjustments puts people's lives at risk.



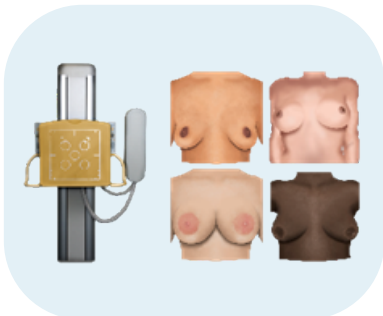
People with learning disabilities from ethnic minorities die at a much younger age than white British people. A national report in 2023 found the average age people from an ethnic minority died was 34 years old.



We need more information about the health needs of people from ethnic minorities. So they can get the right care.



People who have diabetes or who are overweight need to get the right information and support.



Screening helps spot some cancers early on. We need more women with a learning disability to have their breast screening.



The Mental Capacity Act is law. It is about making sure that people have the support they need to make decisions and protects people who need others to make decisions for them.



Staff need to understand how to use The Mental Capacity Act when a person is making an important decision about their health.



Services should understand the needs of autistic people so they can get the right care.



Care for a person at the end of their life should be co-ordinated. This means that different people should work together to make things as easy as possible.



Keeping information about a person in one place is important. It helps them get better care at the end of their life.



People should get support from learning disability nurses when they are in hospital.

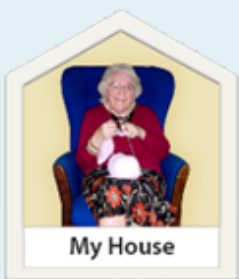


People are being given some medications they don't need. More doctors should use STOMP to make sure people are taking medication that is right for them.



STOMP stands for STopping Over-Medication for People with a learning Disability and/or autism.

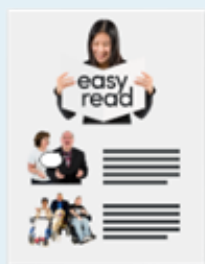
The good things we heard about



People with learning disabilities are living for longer in Sussex. A lady called Ruth lived to 98 years old.



Advanced care planning helps make sure people have a good death in their own home.



Care providers supporting people when they are in hospital for free.



Doctors doing medication reviews as part of the annual health check. So people are not given medication they do not need.



Learning disability nurses working together with care providers to give people better care.



Care homes using a new tool to spot when a person is at risk of becoming seriously ill.



Better use of easy read information so that people with a learning disability and/or autism can understand what is happening.

What are we doing

Chest infections



We have put an easy read check-list on our website to help people understand how to prevent chest infections.



We are helping people understand and get help for those who are at risk of chest infections.



We have set up a clinic to help people who are at risk of getting chest infections.

Sepsis



It is important that everyone understands more about sepsis. We will give training to staff about sepsis.

Cardiovascular disease heart health



We made some easy read information and films. We trained 78 people to support people to make healthy changes.



2 people with a learning disability gave the training.

Constipation



Constipation is when it is hard or painful to go for a poo. This can be very serious and make people ill.

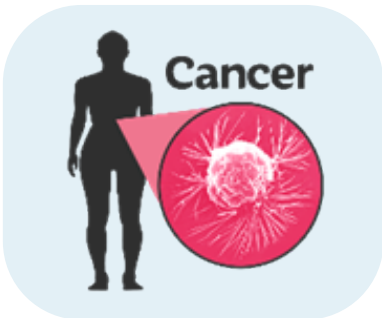


You can learn some fun things about constipation by watching this film:
<https://www.youtube.com/watch?v=R16WY6MLBBU>



We gave training to more staff about preventing people dying from constipation. You can watch this on our website (below).

Cancer



Cancer screenings are tests to see if a person has cancer. We want more people with a learning disability and autistic people to have their cancer screening.



We put better information about cancer screenings on our website. The information helps people know what to expect and understand what is happening.



We made 2 films for NHS staff so that they use the Mental Capacity Act properly.



We are training staff about reasonable adjustments to make screenings easier for people with a learning disability and autistic people.



Reasonable adjustments are things like:

- Extra time
- Special equipment
- Easy read information
- Quiet spaces

Support to stop smoking



Smoking is very dangerous for your body.



We have started a project to help make it easier for people with learning disabilities and autistic people to get help to stop smoking.



We are working to help services that help people stop smoking make reasonable adjustments for people with learning disabilities and autistic people.

Planning for a good death



We gave training in ReSPECT to show people why it is important and how to complete one.

ReSPECT means **R**ecommended **S**ummary **P**lan for **E**mergency Care and Treatment.



We are helping the Community Learning Disability Team understand about frailty and how to help people have a good death.

Stop Look Care



We trained 218 people in Stop Look Care. This is a booklet that helps you spot if a person is starting to become ill.



People who work with anyone with a learning disability can do the training on-line.



We created a new learning disability and autism version of the Stop Look Care booklet.

This includes epilepsy care, preventing chest infections, annual health checks, and STOMP.

Annual health checks



People with learning disabilities should get an annual health check if they are on their GPs learning disability register.



We reached our target of 75% of people getting their annual health check and a health action plan.



We know autistic people also need annual health checks.



We are working to make sure every annual health check means a person has a health action plan.

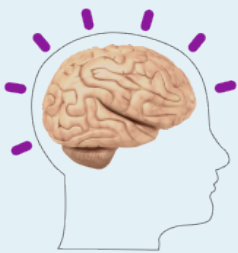


We use a checklist and gave the Thumbs up award to six surgeries that are doing good annual health checks and health action planning.

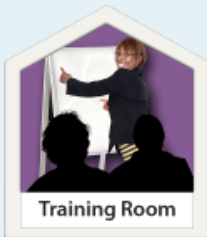


Here is a video about having an annual health check here [Support for people with a learning disability - Sussex Health & Care](#)

What we are going to do over the next year



We will work with others to find better epilepsy treatments for people with learning disabilities and autistic people.



We will train NHS staff to make it easier for women with learning disabilities to have their breast screening.



We will make services better for people with learning disabilities and autistic people who have diabetes and who are overweight.



We will teach people who support people with learning disabilities and autistic people how to spot if somebody has sepsis.



We want to hear more about the lives of people from ethnic communities who have died. To make improvements in care.

For more information



For more information about LeDeR in England:

<https://www.england.nhs.uk/learning-disabilities/improving-health/mortality-review/>



You can find the easy read resources we have made on this website

<https://www.sussex.ics.nhs.uk/your-care/support-for-people-with-a-learning-disability/>



If you have any questions or feedback please email:

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Easy Read by Brighton and Hove Speak Out, made with Photosymbols.