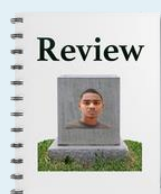




LeDeR 2024 - 2025 NHS Sussex Report



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 the programme that Learns 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. It does this to make improvements for future.



This report is about people with learning disabilities and autistic people who died in Sussex from April 2024 until April 2025.

Why is this important?



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



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

Working together



People with learning disabilities, autistic people, families and carers know most about the care they need. We listen and learn from them carefully.



The LeDeR programme also works with other organisations in the health service - GP surgeries, NHS trusts, the Council, care home managers, and experts by experience.

How we work



The LeDeR programme in Sussex reports to the NHS Sussex Integrated Care Board. We follow the national LeDeR policy on how we should work.



One person on our board is an expert by experience who knows a lot about LeDeR. They left this year, so we wanted to say a big thank you to them in this report.



We work with health services in Sussex to share the learning from our reviews, so that they can learn and make improvements.

An example of really good healthcare



We did a focused review of a man called David.

David loved music and watching airplanes.

He didn't like medical procedures.



David had lived at home with his parents until he was 42. He had phobias that stopped him going out, but when he moved into his new home he built good relationships with the staff that helped him to start to go out more.

Sadly, David had a large stroke that he could not recover from at the age of 52. But his care staff wanted him to come home and die in a familiar place with loved ones. Everyone worked together to make this happen.



An example of unequal healthcare

We did a focused review of a woman called Janet. She was described as being happy and full of life. In 2021 Janet's carers noticed her breast looked strange, but it then returned back to normal again.



In 2022 they found a lump and found out Janet had breast cancer. She had surgery and treatment. But a little later on in 2022, the breast cancer returned and spread throughout her body.



Janet later collapsed at her home and died at age 66.

Janet had been seen as not suitable for a mamogram to screen for breast cancer in 2010 because she did not cooperate. We found that Janet had been removed from breast screening programme in the wrong way.



Are we working well and meeting our targets?



We have national targets for how quickly we review the death of someone, and what things we should look at in each review.



We are meant to complete all reviews within 6 months of the person dying. This year, we completed nearly 7 out of 10 of our reviews within that 6 month deadline.



Of all of our reviews, at least 3 out of every 10 should be 'focused reviews', meaning they look at more detail than the other reviews. This year, 4 out of every 10 of our reviews were 'focused' reviews.

The facts for 2024 - 2025

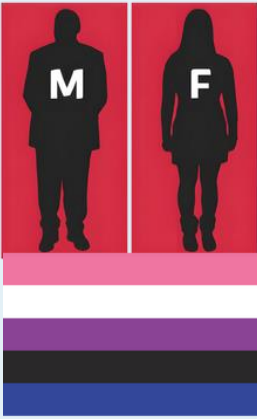


We were told about **158 deaths**. This is 20 more deaths than we were told about last year. This doesn't have to mean more people are dying, just that more people are learning to tell us about deaths so we can review them.



Age

- Age of death ranged between 19 - 91.
- Many people died in their early 60s.



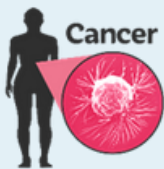
Gender

- 77 females died
- 79 males died
- 2 autistic people who were 'non-binary' died. Non-binary means they don't see themselves as male or female.

Main causes of death



Respiratory diseases - Diseases of the lungs and breathing systems.



Cancer - this is when the cells in your body go wrong and start to make you sick.



Diseases of the heart and blood systems



Sepsis - Sepsis is when your body fights too hard against an infection and damages itself.



Dementia - a disease of the brain that stops it from working properly.

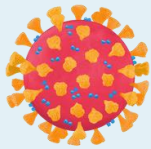
Most common health issues



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



Respiratory conditions - Issues with the lungs and breathing systems.



Infection - any type, like a UTI or a virus.



Incontinence - Incontinence is when you cannot control your bladder, so that pee can leak out when you don't want it to.



Sensory impairment - This means that one of your senses does not work well or at all. For example, trouble seeing or hearing.

What we have been doing



Our LeDeR programme works hard to learn from the reviews and make changes to health services as a result. We do this by working with others, including charities and people with learning disabilities.



We tell people about our learning and service improvements through talks and newsletters.

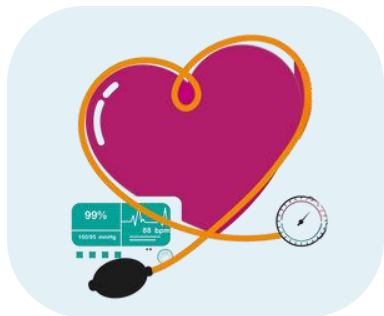
The 'Stop Look Care' tool and training



We worked with our Health Facilitation colleagues to create a tool for staff in care homes to use to spot if anybody is getting really unwell.



595 people were trained this year on how to 'Stop Look Care'. There are 4 more trainings booked in for 2025 and 2026.



We have shown care staff other resources they can use, like the Cardiovascular (or Heart Health) films we helped to make last year, and epilepsy resources.

Support to stop smoking



Continuing a plan we started last year, we worked with a Stopping Smoking service to improve these services for people with learning disabilities and autistic people.



We helped to create easy read resources to help people stop smoking. We sent these out to other areas of the country so that they can use the resources too.



We helped to train 70 different healthcare staff about stop smoking resources and how they could improve their services for people with learning disabilities too.

Planning for the end of life

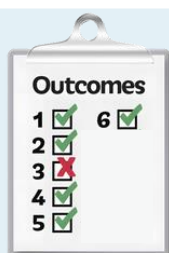


We have been working with the 'Sussex Palliative and End of Life Oversight' group and the 'Learning Disability Palliative Care Link Group'.



Palliative care is the care and treatment for people living with serious or longterm illness to make them more comfortable.

Did we achieve our goals for last year?



We had 6 goals, or priorities, from last year's report. In this section we will track what we have been doing to achieve each one.

Breast cancer



We wanted to learn more about women with a learning disability who died from breast cancer, especially if they could have had screening to catch the cancer earlier.



We did 'focused' reviews into these deaths to work out what the main issues are stopping women from using breast cancer screening.

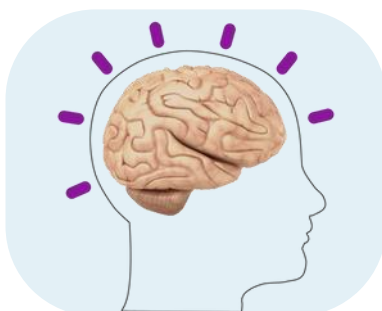


We have helped start a new group of healthcare professionals to work together to address the issue in Surrey and Sussex.



We met with a breast cancer screening service in Somerset that is for people with learning disabilities to learn from them. We have shared this with the services in Sussex.

Health inequalities for Autistic people



We wanted to focus on the health inequalities that autistic people face in Sussex around their physical and mental health, neurodivergence support and suicide prevention.



We are still waiting on a trial of doing annual health checks for autistic people.



We are focusing on helping people after a mental health diagnosis. This should reduce mental health hospital admissions or make stays shorter.



We are working with local suicide prevention and autism partnership boards. The local specialist mental health provider delivered a national presentation on Neurodivergence and Suicide Prevention.

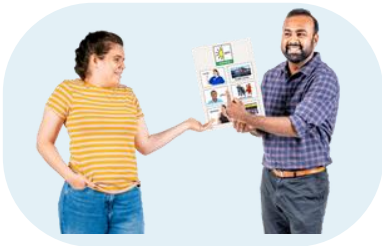
Obesity and diabetes



We are working with different healthcare staff to tell more people with learning disabilities learn about 'continuous glucose monitoring', which is a device that lets diabetics check their sugar levels without pricking their finger.



We have been working with a Sussex programme that is trying to understand why some people are getting Type 2 diabetes before they are 40, because we know getting it early makes the disease more deadly.



We helped them understand what happens for people with learning disabilities, and how to make their resources accessible for them.

Sepsis



Sepsis is when your body fights too hard against an infection and damages itself. It is one of the main causes of death for people.



We have helped to train over 100 people on how to prevent people with a learning disability from dying of sepsis. This was mainly adult social care staff.

Planning to die how you would like to



We have been sharing a toolkit that was developed to help people with learning disabilities plan for the end of life. It is called 'The Victoria and Stuart Project'.



We have also been working with healthcare staff in Palliative Care and End of Life Care to make sure they understand what people with learning disabilities need.

Supporting people from ethnic minorities



We know that we don't understand as much we would like to about people with learning disability for minority ethnic communities. We want to improve this.



We helped to make sure that a new resource called 'Respecting Faith and Culture in End-of-Life Care Handbook' included the needs of people with learning disabilities too.

What we are going to focus on over the next year



We will make sure that healthcare providers have a formal system to learn from LeDeR reviews to stop people from dying earlier.



We will work to hear from more autistic people who should be entitled to a proper review of their death.



We will look into the community and hospital mental health care for autistic people.



We will make sure LeDeR learning is used to help make the decisions about which NHS services are funded or not funded.



We will make accessible information about how to drink enough and stay hydrated.



We will work with dental care services to make sure there is accessible information about having healthy teeth and gums.

To finish



This report shows that people with learning disabilities and autistic people still face health inequalities. We need to do better.



One of the people who died was Julie. Julie had to die in hospital, even though she would have preferred to die in her home. Her sister wanted to share Julie's talent for poetry. Here is a piece of a poem she wrote.

The distant hills are calling.
They are far away.
I can't remember where they are.
Yes I do now.
Blue sky.
The rolling hills are soft and green and gentle.
I know where they are.....on the moors where I love to be.
They are calling me to come to the place where I belong.