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Norfolk and Waveney Integrated Care System

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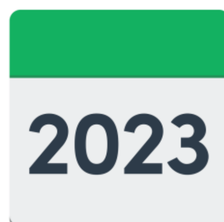
Norfolk and Waveney Annual Report



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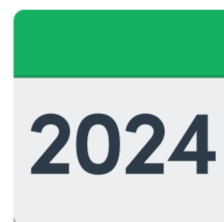

Learning from Lives and Deaths – People with a Learning Disability and Autistic People (LeDeR)

What is the LeDeR Annual Report?

It is a document that looks into why people with a learning disability and autism have died in Norfolk and Waveney.

It helps us to understand what we can do to support people to be healthier and live longer.

The full LeDeR Annual Report is available on our website.

If you have a learning disability and/or autism, we want you to tell us what your own lived experience is like.

We want you to tell us if what we are doing is making any difference to your life.

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How our reviews were done.

The LeDeR programme is led by the Integrated Care Board and supported by the Integrated Care System. It is a team effort.

An Integrated Care Board plans and buys healthcare services for where you live.

An Integrated Care System joins up all health and care organisations where you live to work.

We have looked into the deaths of people with a learning disability and/or autism over the age of eighteen.

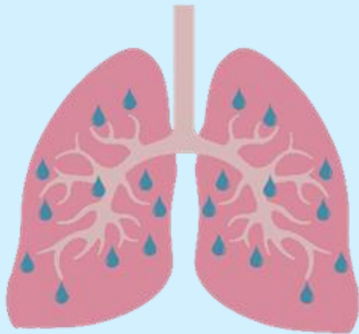
Anyone can make a referral to LeDeR. This is done online at https://leder.nhs.uk.

What does our annual report tell us?

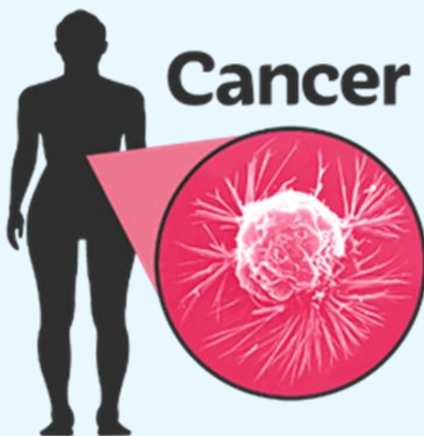
We completed 56 reviews for people with a learning disability and/or autism who died. This is less than last year.

We have had 22 more notifications this year, because we are better at telling people about LeDeR.

People with a learning disability and/or autism have shorter lives and die younger than people without a learning disability and/or autism.



The most common cause of death was a type of infection in a person's lungs.



The next most common cause of death was cancer. The most common cancer we saw was bladder cancer.

Over half of all the deaths could have been avoided or treated. This is more than last year.

The overall experience of care and service availability was not good, but we have seen things get better since last year.

There are some great examples of services supporting people to get the right care, services, and equipment they need. Such as…

Professionals are good at making sure they offer face to face appointments.

Hospitals are providing suitable rooms to make sure people are comfortable and have privacy.

We are involving familiar carers in a person's support where this is needed.

Services are preparing people better for appointments such as blood tests.

We see better person-centred care planning.

Admissions plans include ways to avoid overly restrictive care or restraint practices.

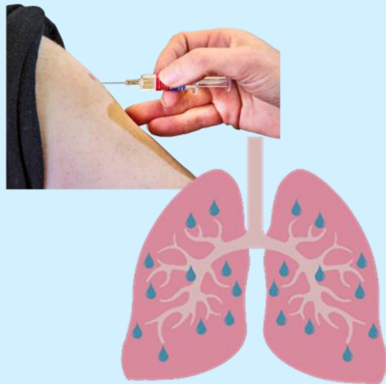
Carers are spotting when someone becomes unwell earlier.

Here are some other things we have learned from our reviews.

More people are having their annual health check which is good. This year 5,525 people had an annual health check.

More people need to have a health action plan as part of their annual health check. This year 5,176 people had a health action plan.

More people have had their COVID-19, flu and pneumonia vaccines.



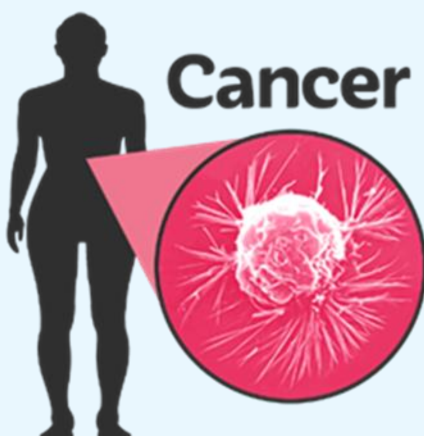
We still need to help more people have their pneumonia vaccination. This vaccine helps a certain type of lung infection.

We see more hospital staff making better DNACPR decisions. This means people are more involved in decisions about what health staff should do if their heart stops

Sometimes people having treatment or care might not be able to do all the things they want to do. Deprivation of Liberty Safeguards make sure this is done legally and that any restrictions are in the person's best interest. All services need to be better at getting Deprivation of Liberty Safeguards.

The Mental Capacity Act is a law about making decisions, and what to do when people cannot make some decisions for themselves. The Mental Capacity Act needs to be used better, to make sure appropriate decisions about patient care are made.

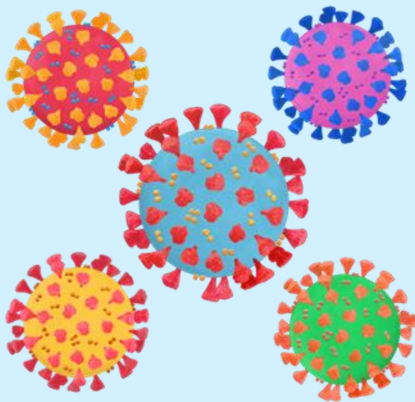
The Learning Disability and Autism Teams in hospitals are very important. They work very hard to train staff and help patients who are ill.



More people are having bowel screening, but we still need to do better at breast and cervical cancer screening.

We are seeing less people prescribed medicine for behaviour and services are better at making sure people have the right medication for the right reason.

The average age that people died has gone up, so people died slightly older this year than last year.



For the first time since 2020, we didn’t have any reviews where the person died because of COVID-19.

All health and social care professionals need to find ways of working better together, to help people with learning disabilities and/or autism.

More people have care plans in place in case they need an emergency hospital admission.

What are we going to do next to improve things?

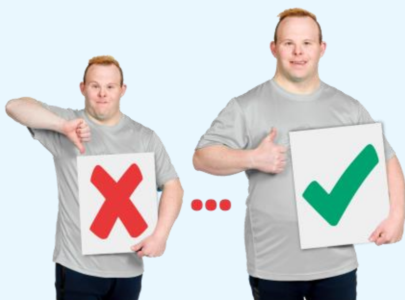
We will continue to complete really good quality reviews as quickly as we can.

We will continue to work together with health and social care staff, people with learning disabilities and autism and families and carers.

We will teach more people about LeDeR and how we can work better to support people with learning disabilities and autism.

We need to find more information about how people with autism have died.

We will continue our Learning into Action work.



Learning into Action is how we work to make care better and support people to live longer. Some examples of our work include:

Working to help moving from children's services to adult services for young people with complex needs.

Celebrating where we see good work and sharing this so it can be repeated.

Helping people to attend their annual health check and helping GPs to offer better annual health checks.

Making sure we use learning disability specific mental health assessments when this is needed.

Working to improve the ways to help people get an assessment to find out if they have dementia and the best way to support them.