



Norfolk and Waveney Annual Report



Learning from Lives and Deaths – People
with a Learning Disability and People with
Autism (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.



A nurse called Andy O'Connell has written this report with help from colleagues and experts by experience.



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.



Tell us what you think

1. Do you think the idea is a good one?

☐ Yes

☒ No

☐ Not sure

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

Get in touch

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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's 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 together.



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



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

What does our annual report tell us?



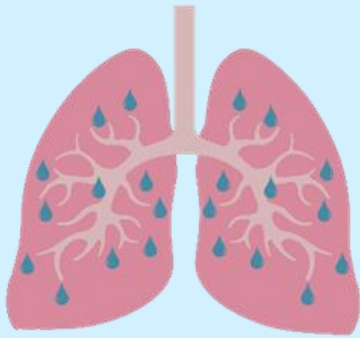
We completed 72 reviews for people with a learning disability and/or autism who died. This is less than last year.



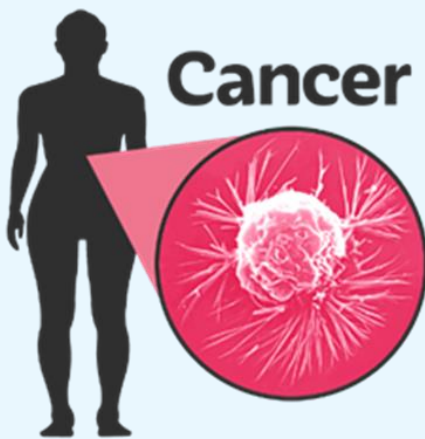
People with a learning disability and/or autism have shorter lives and die younger than people without a learning disability and/or autism.



More than half of adults died in hospital.



Most people died of pneumonia.
This is an infection in a person's lungs.



The second most common cause of death was cancer. These included breast, bowel and lung cancer.



Nearly half of all the deaths could have been avoided or treated.



Most people did not receive satisfactory or good care. Most people had a bad experience of health and care services.



There are really good examples of services using reasonable adjustments to support people. For example:



We are making services more accessible to people's different needs, for example using hospital passports.



We are communicating better with people in a way they understand.



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



Community and residential care staff need to be better at helping people live healthier lives by exercising more and eating better.



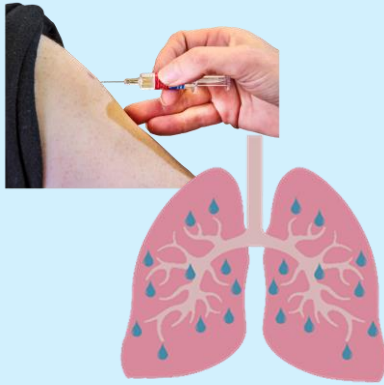
More people are having their annual health check which is good. This year 5012 people had an annual health check.



More people need to have a health action plan as part of their annual health check. This year 4671 people had a health action plan.



We are doing well to help people have their COVID-19 and flu vaccination.



We really need to help more people have their pneumonia vaccination.



Hospitals need to be better at using the Mental Capacity Act to make sure decisions about people are being made in the right way.



We need to try to give people a better choice about where they live.



More Care and Treatment Reviews and Wellbeing Reviews means we check people are being cared for properly in secure hospitals.



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



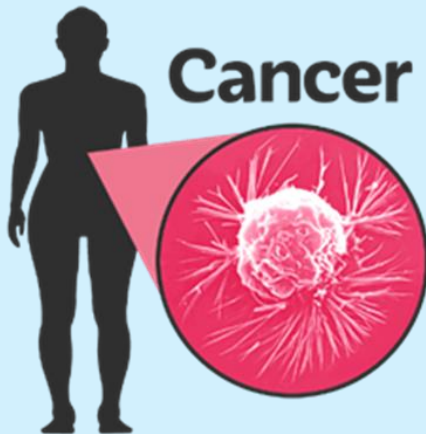
GP practices are doing their best to make more face-to-face appointments.



Services could be better at making sure people have the right medication for the right reason and make sure this is reviewed regularly.



We need to make sure the care people experience is good quality and with people they trust.



We need to support more people to attend their cancer screening appointments, especially breast and cervical cancer.



Better care co-ordination is needed for people with learning disabilities and/or autism.



Care staff need more training and support to know when someone is becoming unwell and how to help them.

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 colleagues, people with learning disabilities and autism and families and carers.



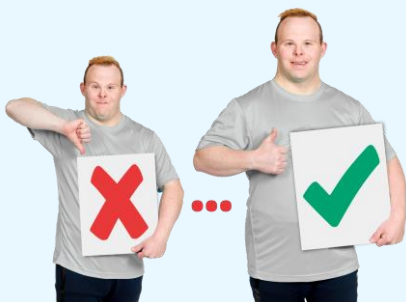
We will teach more people about LeDeR and how we can work better to support people with learning disabilities and autism.



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:



Finding a way for care homes and supporting living to help people lose weight and be more active.



Helping care homes and supporting living, so more people can die at home if they choose too.



Improving the quality of care for people who need a machine to help them breathe.



Making it easier for staff to help, when a person goes into hospital and goes home again.