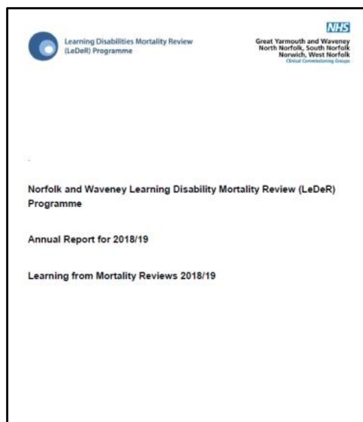
Learning Disabilities Mortality Review
(LeDeR) Programme

NHS
Norfolk and Waveney
Clinical Commissioning Group

Norfolk and Waveney Learning Disability Mortality Review Programme



Learning Disabilities Mortality Review
(LeDeR) Programme

NHS
Great Yarmouth and Waveney
North Norfolk, South Norfolk
Norwich, West Norfolk

Norfolk and Waveney Learning Disability Mortality Review (LeDeR) Programme

Annual Report for 2018/19

Learning from Mortality Reviews 2018/19

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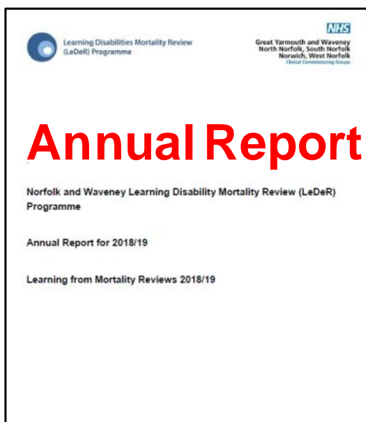
Easy Read Report

About this document

This document is a report that looks into when people with a learning disability die in Norfolk and Waveney.

The **average age of people with a learning disability in Norfolk and Waveney is 61 years old.** This is a lot younger than people who do not have learning disabilities.

The NHS have set up a review to look into why people with learning disabilities die, and what changes we can do to give people longer, healthier lives. This is called the **Learning Disability Mortality Review Programme, or LeDeR.**



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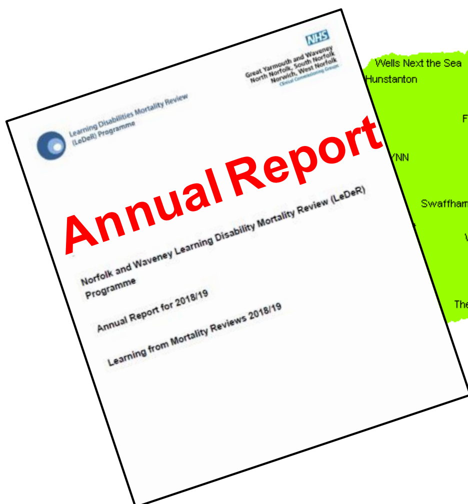
This report that has been written by the **Norfolk and Waveney Learning Disability Mortality Steering Group.**

The Learning Disability Mortality Steering Group is co-Chaired by **Sarah-Jane Ward**, Associate Director of Quality in Care NHS Norfolk and Waveney Clinical Commissioning Group, and **Andrew Borrett**, an Expert by Lived Experience. They work hard to include people with learning disabilities and autism in the work of the steering group

What is the process when someone with a learning disability dies?

The Learning Disabilities Mortality Review (LeDeR) programme **helps local areas to review the deaths of people with learning disabilities** aged over 4 years of age.



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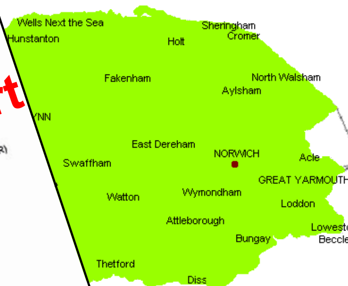


The local reviews of deaths looks into **what could have been done differently to avoid the person dying** and to develop a plan of action to help stop people with learning disabilities dying younger.

Anyone can inform the LeDeR team at Bristol of a death of someone with a learning disability by using an online form:
http://www.bristol.ac.uk/sps/leder/notify-a-death/

What we have done in 2019-20

This year, we have continued to improve how **communicate** with each other. This includes people with learning disabilities, carers, and professionals.

Experts by Lived Experience have told us to **think about people,** and to listen to people with learning disabilities about their health issues and life experiences

We have continued our way of being able to review any deaths of people with learning disabilities that happen, so we can **quickly learn what happened and make changes**.

In 2020, many people that work in health and care have been working to care for people, and prevent the spread, of the coronavirus.

We run the **'Learning into Action'** Group, co-chaired by Andrew Borrett, to make sure that we understand how people have died, and try to make changes so less people go through this experience

What have we learned locally?

In 2019 to 2020, we received **72 notifications of people with learning disabilities that had died**. Over half of these people died in a hospital.

We know that **constipation** affects people with learning disabilities. We have trained **over 70 people in care and residential homes** to make them aware of this important issue.

We need to make sure more people are aware of the importance of getting a **Health Check** every year, and working **on Health Action Plans** where they are needed.

We need to help people with learning disabilities look after any other long term health conditions they may have. Where possible, a person should have a **health care coordinator** to help them look after their conditions.

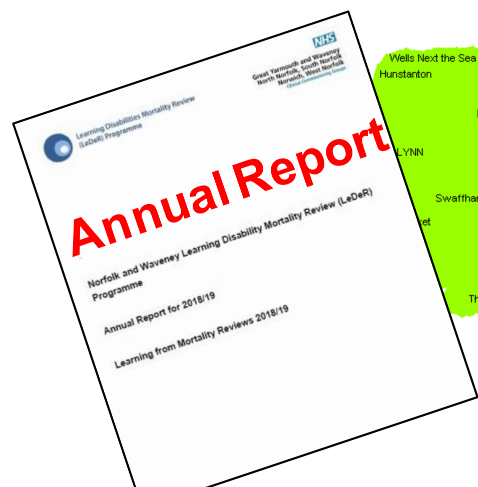
What have we learned locally? Continued…

We need to make sure all people with learning disabilities, their carers and professionals know how to make **reasonable adjustments** so everyone can get the care they need.

A reasonable adjustment is a change to the way things are normally done to help people – like information in Easy Read, longer health appointments or wheelchair access

We need to make sure everyone knows about **pneumonia**, and make sure people get their flu jab this winter.

We need to make sure everyone knows about the **Mental Capacity Act (MCA)** and it is used in their jobs.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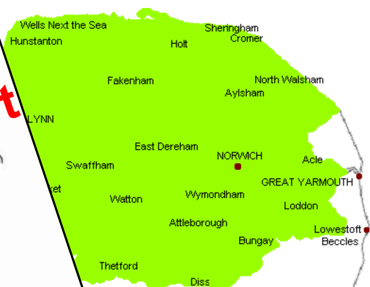

We need to make sure that the things we have learned from peoples deaths are shared with everyone so it doesn't happen again.

What happens next?

We must take what we have learned and **put it into practice**. We will work hard to complete all the outstanding reviews in time for March 2021.

We need to do further work to make sure that more people with learning disabilities do not die from **pneumonia**, **constipation and swallowing difficulties.**

We will write a **Quality Improvement Plan** to make things better in the areas where we have learned that improvements are needed.

The **NHS Long Term Plan** says that continuing to review the deaths of people with learning disabilities is important. We will work closely with Experts by Lived Experience locally to form plans for Norfolk and Waveney