

South West: helping people with learning disabilities

Summary

Collaborative approach to keep people with learning disabilities as healthy as possible with the promotion of prevention and training and education for carers and families. For people with multiple conditions there is a focus on ensuring opportunities for prevention – like health checks – are taken up and that the signs of deteriorating health are spotted early.



Main points

- Two clinicians championed the needs of people with learning disabilities, helping to set up a collaborative group of local partners across Bristol, North Somerset, South Gloucestershire, Swindon, Wiltshire and Gloucestershire
- Conference held and priority areas established, including helping to spot signs of deterioration and keeping people well
- Steering group established to drive forward the work
- Partners now making progress, training families in how to monitor deterioration and encourage people with learning disabilities to come forward for flu jabs and health checks



Context

There are around 1.5m people with learning disabilities across the UK. They face significant health inequalities.

Around one in three people with a learning disability die from potentially avoidable causes, compared to one in 11 of the general population.

Major factors behind this include not acting early enough when patients deteriorate and failing to diagnose and therefore manage long-term conditions – rates of obesity, diabetes, coronary heart disease and epilepsy are all higher.



The average age of death of someone with a learning disability is 60 for men and 59 for women – that is more than 20 years earlier than the average.



What has been done?

Improving care for people with a learning disability is one of the key priorities of NHS England's long-term plan published in early 2019.

Some key personnel in the south west region had started to think about what more could be done to help this vulnerable population.

The West of England Academic Health Science Network (AHSN) had already helped to roll out the National Early Warning Scores (NEWS) tool across the health system including to acute hospitals, primary care, mental health, community and ambulances services. The tool is traditionally used by hospital doctors and nurses to help spot the early signs of deterioration by monitoring breathing, oxygen levels, blood pressure, heart rate and temperature.

It had improved outcomes for patients across the region so the network wanted to see if this could be used to improve care for people with learning disabilities specifically.

West of England AHSN primary care clinical lead Dr Alison Tavare had had personal experience of the challenges people with learning disabilities face. Her nephew, Toby, has profound learning disabilities. A few years ago he was admitted to hospital with abdominal pain. It was very challenging as he was unable to say what was happening. Eventually he had an operation for a ruptured appendix.

After that Dr Tavare was involved in raising awareness of NEWS so she decided to teach Toby's parents how to use the system. In 2016 Toby became very unwell again and after using NEWS his mother took him into hospital saying she thought he had sepsis. She was right and potentially saved his life.

Meanwhile, Kevin Elliott, NHS England's lead nurse for learning disabilities for the south west, with others in his team had been championing improvements in local services for some time. When Dr Tavare contacted him to see if they could work together, he immediately agreed.

They decided to set up a collaborative group, incorporating people with lived experience, local social care teams, hospitals, GPs, families and carers. A host event was held in Bristol and more than 130 people attended from Bristol, Gloucestershire, Wiltshire and North Somerset.

The conference identified three key priorities:

- Increasing uptake of flu vaccinations
- Increasing uptake of health checks
- Improving the ability of social care and families to identify the signs of deterioration

A steering group, composed of key partners chaired by Dr Tavare and Mr Elliott, was established to drive forward the work and an online forum was set up to help partners share ideas and good practice.

Mr Elliott says: "People with learning disabilities face many barriers to achieving equal health outcomes compared to the rest of the population. They face greater disadvantages in terms of social determinants, such as housing, health literacy and social isolation."

"What is more, services are not always geared up in a way that makes them easy to access and often they rely on others to help them."

"It means they are not getting the preventative care they need to keep them well. Around half of people with long-term conditions fail to attend their annual health checks and even more do not get their flu vaccinations."



What has been achieved?

A number of different projects are now beginning to get off the ground. In Gloucestershire the Clinical Commissioning Group (CCG) has been working with local social care teams to introduce a telehealth project whereby carers take blood pressure, pulse and respiratory readings.

The local parents forum has been tasked with doing some communications around take up of the annual health check. This is likely to include some postcards spelling out the importance of the checks and how to make sure people with learning disabilities get them.

Organisations across the region which support people with learning disabilities have formed a focus group to find out what is being done well and what could be done better. They are sharing ideas and resources. Some are really simple such as ensuring that people with learning disability are sent letters about flu immunisation in Easy Read format. These ideas and resources are being collated into a series of toolkits and activities to be shared across the region.

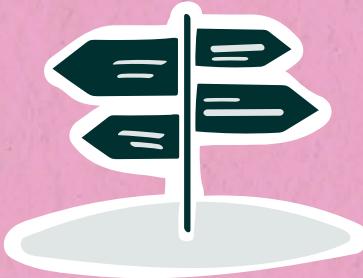
Meanwhile, a specialist community learning disability team has commenced training workshops for care staff, families and carers about spotting the signs of deterioration using NEWS.

Dr Tavare said: "Using NEWS as a common language across the NHS, from the GP surgery, to the ambulance service, to the emergency department and into the hospital has improved outcomes for the general population.

"We hope that by working together across the region we can similarly use NEWS as a common language to help quickly identify when people with learning disability are unwell and then use it to communicate with other teams to enable prompt treatment."

"WE HAVE BEEN OVERWHELMED WITH THE ENTHUSIASM AND SIGN UP OF SO MANY PARTNERS ACROSS THE HEALTH AND SOCIAL CARE SECTORS AS WELL AS FROM EXPERTS BY EXPERIENCE AND FAMILY CARERS"

- KEVIN ELLIOTT, NHS ENGLAND'S LEAD NURSE FOR LEARNING DISABILITIES FOR THE SOUTH WEST



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- DR ALISON TAVARE, GP

What challenges have been overcome?

Some concerns have been expressed that NEWS can be too complicated for non-clinical people to use, requiring knowledge and judgements to be made.

Therefore, the collaborative have been working with West Hampshire CCG and Wessex Academic Health Science Network as they have produced a package called RESTORE2.

RESTORE2 has been used in care homes by paid carers. It starts with the idea of "soft signs" such as someone becoming much more quiet than usual and worrying the carers who know them well.

After training the carers are then shown how to measure NEWS and use this to talk to others about why they think someone could be unwell. It is at the early stages, but staff say they feel empowered so the team want to see if it can be spread to other care homes and if outcomes can be improved.

The collaborative believe this could be a useful way of helping care staff, families and carers of people with learning disabilities alongside the use of NEWS and are aiming to trial its use with care staff.

What is happening now?

The project is due to run until the end of summer 2020. Then, at the end of the programme of work, the steering group will carry out a formal review of what has worked.

Mr Elliott said: "We have been overwhelmed with the enthusiasm and sign up of so many partners across the health and social care sectors as well as from experts by experience and family carers. It is presenting a challenge in finding the capacity and resources to support all of the innovations."

"NHS England and Improvement has committed funding from the regional learning disability programme budget, however, this is finite. The collaborative is looking to other funding streams to support the work. That said, much is being achieved without funding, simply in bringing partners together across the whole health and care system."

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