

# LeDeR Newsletter

A newsletter brought to you by CWICB – August 2023

**Welcome** to our sixth issue of the Coventry & Warwickshire Integrated Care Board LeDeR newsletter.

## What is the LeDeR programme?

***Learning from lives and deaths – people with a learning disability and autistic people (LeDeR).***

**LeDeR** is a service improvement programme for people with a learning disability and autistic people.

Established in 2017 and funded by NHS England and NHS Improvement, LeDeR works to:

- improve care for people with a learning disability and autistic people
- reduce health inequalities for people with a learning disability and autistic people
- prevent people with a learning disability and autistic people from early deaths

## LeDeR Reviews:

A LeDeR review looks at key episodes of health and social care the person received that may have been relevant to their overall health outcomes. We look for areas that need improvement and areas of good practice. This helps reduce inequalities in care for people with a learning disability and autistic people. It reduces the number of people dying sooner than they should.

Anybody can make a referral to LeDeR if they believe that a person that has died had a learning disability (\*and was aged 18+) or was autistic (and was aged 18+).

This can be done via the following link:  
<https://leder.nhs.uk/report>

\* see '**Change to LeDeR Policy**' details in the 'Other News & Information' section in this newsletter.

## LeDeR Governance:

We have a dedicated LeDeR Governance Group which takes place on a monthly basis. Senior health and social care representatives from across Coventry and Warwickshire attend the meeting, consider findings of reviews, and oversee an action plan linked to the learning.

## LeDeR Subgroup:

It was recognised that a dedicated space was needed to work on the key themes coming from the LeDeR reviews, and so our LeDeR Subgroup was launched in May 2023.

The purpose of the LeDeR Subgroup is to ensure that the broader thematic findings and SMART actions from reviews are recognised by health and social care providers across the system, acted upon, and that meaningful changes are made to improve the quality of health for individuals with a learning disability and autistic people.

We are initially focusing on the topic of *constipation*. This will look at the training and resources currently available across health and social care and create an action plan with the goal of upskilling clinicians, carers, and people with a learning disability and autistic people, on the proactive care for constipation and the signs and symptoms to be aware of.

Between 1<sup>st</sup> April 2023 and 31<sup>st</sup> July 2023 the Coventry & Warwickshire LeDeR Programme has received:

18 Notifications.

14 reviews have been completed (nine Initial and five Focused) and one was out of scope.

There are currently 35 adult reviews and two child reviews on the system, with eight adult reviews on hold whilst we await the outcome of other investigations.

#### Key learning taken from reviews:

- Funding pathways for one-to-one carer support for people with a learning disability and/or autistic people in the acute hospital setting requires clarification
- Clarification of process is required, regarding acute hospitals contacting NOK and care providers, thus enabling those to be informed who need to be, without breaching confidentiality
- Need for awareness and recognition of 'cold' sepsis (10-20% of sepsis cases are hypothermic, meaning a diagnosis of such cases can be missed)
- Training and process to be enhanced for vaccinations, including declining, not attending and consent; also clarification is required regarding the administering of the pneumococcal vaccine

#### Examples of positive practice taken from reviews:

- ✓ The GP provided very good care, including good use of reasonable adjustments, which made appointments more accessible
- ✓ Three reviews highlighted care that was of a very high standard in each case; compassion and respect were shown and holistic multi-agency care planning took place, allowing each person to have a dignified death
- ✓ The person experienced a full and happy life at the care home, where he was treated as an individual. He was very happy there
- ✓ The Acute Liaison Nurse was actively involved during each hospital admission, which had a positive impact on the individual and the care they received

#### Upcoming Learning Opportunities:

In collaboration with the Warwickshire Learning and Development Partnership, we have commissioned a range of training sessions linked to themes that arise from LeDeR learning. These sessions are open to anyone who cares for or supports a person with a learning disability and/or autistic people.

If you or anyone you know are interested in attending any of the two upcoming sessions listed below, please email:

[warwickshirelearninganddevelopmentpartnership@warwickshire.gov.uk](mailto:warwickshirelearninganddevelopmentpartnership@warwickshire.gov.uk)

Course: **Dysphagia**

Date: 12<sup>th</sup> October 2023

Time: 10:00 – 12:00

Venue: Webinar (Microsoft Teams)

Course: **Dysphagia**

Date: 7<sup>th</sup> December 2023

Time: 10:00 – 12:00

Venue: Webinar (Microsoft Teams)

**In each edition of this newsletter, we will share information based upon a key theme of our LeDeR learning.**

### **Spotlight on: Constipation**

Deaths that can be attributed to constipation are still a leading cause for people with a learning disability and autistic people, both locally and nationally.

In 2022/23 we made a local priority for focused reviews to be conducted where constipation was the cause of death. Now with the learning extracted from these reviews we will work collaboratively across the system, looking specifically at education on signs and prevention of constipation, and relaunch constipation awareness for this community.

The 2021 National LeDeR Report identified the proportion of deaths where constipation was attributed was 23%.

In our region in 2022/23 there were three deaths from constipation with early warning signs that were missed. All three people were living in residential or nursing homes.

Someone with a learning disability may be less likely to recognise the symptoms of constipation and be able to communicate their symptoms, increasing the risk of serious consequences.

People with a learning disability mainly get constipated for the same reasons as other people. These may include:

- inadequate diet and fluid intake
- reduced mobility and lack of exercise
- side effects of certain medications
- anxiety or depression

People with a learning disability may have conditions that make it more likely for them to have constipation, such as:

- poor diet
- reduced physical mobility
- being prescribed medication such as antipsychotic, antidepressant or anticonvulsant, that can all have a negative effect on bowel movement

Symptoms can include:

- abdominal pain
- bloating
- nausea
- faecal impaction
- twisting of the bowel leading to ischaemia and septicaemia
- cramps
- loss of appetite
- overflow diarrhoea
- faecal vomiting

#### **Useful resources:**

This following link is for an accessible video for people with a learning disability, to facilitate conversation around constipation and what to do about it. The video has been developed in partnership with NHS Derby and Derbyshire ICB and is a light-hearted way of conveying a serious message:  
[Poobusters: constipation awareness video](#)

The following two links from NHS England contain a variety of constipation related information:

[Leaflets for families/carers, healthcare professionals and easy-read](#)

[Video \(signs of constipation\), leaflets/posters and Bristol stool chart](#)

#### **Points to note:**

- At the next LeDeR Focus Group, taking place in October, we will focus on and discuss the subject of constipation with Grapevine's experts by experience
- Constipation Awareness Month is taking place in December 2023, so look out for details of this online nearer the time.

## Other News & Information:

### **Change to LeDeR Policy**

As of 1st July 2023, national LeDeR policy relating to the deaths of children and young people under the age of 18 has changed. There will no longer be any requirement for deaths of children with a learning disability to also be notified to LeDeR. This change is being made because it is important that the deaths of children with a learning disability and autistic children are reviewed by the national mandated processes that look at the deaths of all children.

No new notifications of the deaths of children can be made on the LeDeR platform from July. All child deaths should be notified via the ICB child death overview panel. The approach will reduce duplication of effort for systems. Autism will be added to the national child mortality review child notification which will enable more in-depth analysis of the deaths of autistic children and young people for the first time.

With regards to Coventry & Warwickshire, as at the beginning of August, two Child LeDeR reviews are open on the LeDeR platform. These are being progressed through Child Death Overview Panel (CDOP) as part of the national mandated process. We are in wider talks as a system on how to ensure the LeDeR Programme will still be sighted on learning from child death reviews. The two child deaths that remain on our system will be marked out of scope as advised by NHS England; however learning from these reviews will be shared with the wider system.

### **Grapevine: Help and Connect**

The local charity, Grapevine, is running the *Help and Connect* project, which supports people with a learning disability and autistic people to make a plan, get connections, get work, stay healthy and stay safe.

This service is available in **Coventry only** and further details can be found via the following two links:

[Help and Connect - Overview & How to Refer](#)  
[Help and Connect - Case Studies](#)

## **USEFUL ONLINE LINKS**

[LeDeR - Home](#)

(For more information about the national LeDeR programme)

[Coventry & Warwickshire Partnership NHS Trust - Learning Disability Services](#)

(Overview of services, contact details and Learning Disability Annual Health Check resources)

[What are Reasonable Adjustments and why are they important?](#)

## **KEY CONTACTS**

**For further information about our local LeDeR programme, please feel free to contact:**

Sophie Meszar – LeDeR Local Area Contact: [sophie.meszar2@nhs.net](mailto:sophie.meszar2@nhs.net)

Amy Williams – Senior LeDeR Reviewer: [amy.williams23@nhs.net](mailto:amy.williams23@nhs.net)

Karen Morris – LeDeR Support: [karenmorris3@nhs.net](mailto:karenmorris3@nhs.net)

**Feedback on the usefulness of this newsletter would be welcomed and appreciated, such as whether you find the content useful, whether you feel that anything in particular is missing, or whether you feel that less or more detail is needed. Please email any feedback to [dougie.philippou@nhs.net](mailto:dougie.philippou@nhs.net)**