

# LeDeR Newsletter

A newsletter brought to you by CWICB – July 2022

**Welcome** to our second issue of the Coventry & Warwickshire Integrated Care Board (formerly the Clinical Commissioning Group) 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 4+) or was autistic (and was aged 18+).

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

## Our local LeDeR Team:



Hi, my name is Karen Morris. I have worked in the NHS for 23 years in various roles. I have been the **LeDeR Support Officer** since 2018 and I oversee and keep records for all our reviews and I contact GPs, social services and hospitals to obtain records. I also write to families on behalf of the reviewers. I work closely with our Local Area Contact and our reviewers. I enjoy my role and the positive changes that are being made on the back of the LeDeR programme.

## 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.

Since 1<sup>st</sup> April 2022 (up until 30<sup>th</sup> June 2022), Coventry & Warwickshire LeDeR Programme has had:

**16 Notifications.**

8 reviews have been completed (5 x Initial and 3 x Focused) and 2 were out of scope.

There are currently 35 reviews on the system, with 9 on hold whilst we await the outcome of other investigations.

### Key learning taken from reviews:

- Breast and cervical cancer screenings are often not being accessed
- Some people have not been on their GP's learning disability register; therefore they have missed out on having a Learning Disability Annual Health Check and receiving other support
- During hospital admissions, individuals have sometimes not been referred to or were not known to the Acute Liaison Nurse
- Some care packages and/or assessments have not been appropriate or up to date.

### Examples of Positive Practice:

#### *Primary Care:*

- ✓ *Very good use of reasonable adjustments. Appointments were planned at quieter times so the person would not have to sit in the waiting room and instead was able to go straight into the consultation room, whilst accompanied by regular carers and having continuity of the same GP when possible for planned appointments. This helped reduce the person's anxiety. On occasions, the person would be seen by the GP at home if required.*

#### *Coventry & Warwickshire Partnership NHS Trust:*

- ✓ *The family felt totally supported by the Community Learning Disability Team, especially the Community Nurse and Psychiatrist. The team supported the family prior to diagnosis and then 'wrapped' the service required around the person and her family.*

#### *Acute Trusts:*

- ✓ *The patient and his family were Catholic and it was very important to the family that he received the last rites from a priest. The hospital went out of their way to ensure he was seen by a priest before he passed away, which gave the family great comfort.*

#### *Multiple organisations working well together:*

- ✓ *Excellent evidence of the Mental Capacity Act being applied, well documented best interest discussions and decisions within supported housing, social care and health environments.*

### Other News:

- The NHS Coventry & Warwickshire Integrated Care Board have co-produced a survey with the Grapevine Health Team, which has been circulated with a view to receiving feedback from people with a learning disability who are 14 years old or over, who have received a **Learning Disability Annual Health Check** in the last year.

Approximately 3,000 people received a Learning Disability Annual Health Check in the Coventry & Warwickshire area between April 2021 and March 2022, and we are keen to understand people's experiences of this, so we can work to improve these health checks if needed, and where possible to improve access, remove any barriers in place, and continue areas of good practice.

The survey can be accessed via the following link. Please feel free to circulate as appropriate:

[Survey - Learning Disability Annual Health Checks](#)

- Our involvement in the **Reasonable Adjustment Flag Project** continues, as we work alongside NHS England and other pilot sites from the NHS on preparing for the eventual release of a digital flag that will allow reasonable adjustments recorded on local systems to appear on the NHS Spine (Summary Care Record), with the aim of making people with a learning disability receive a better, more comfortable and equal patient experience. The Community Learning Disability Team were also involved in the project from the outset and more recently we have Budbrooke Medical Centre onboard, designing a template in their local system to record Reasonable Adjustments and raise the awareness. Making Reasonable Adjustments for people with a learning disability (and/or any disability) needs to be on every professional's radar, as they have a very positive impact on helping reduce health inequalities.

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

## Spotlight on:

### Dysphagia

The LeDeR: Action from Learning Report 2020/21 stated that:

*Respiratory conditions are a leading cause of avoidable deaths among people with a learning disability and the risk is increased in those with Dysphagia (swallowing difficulties). Preventing, diagnosing, and managing Dysphagia remains a key priority. Bacterial pneumonia (a lung infection) was the stated cause of death in 24% of adult and 20% of child deaths notified to LeDeR in 2019/20 and aspiration pneumonia (following inhalation of anything other than air) in 17% of adults and 3% of child deaths.*

#### **What is Dysphagia?**

*Eating and drinking disorders which occur in the oral, pharyngeal, and oesophageal stages of deglutition (swallowing) - RCSLT 2006.*

There are different causes and types of Dysphagia. Some people have difficulty swallowing specific types of food or liquids. Some people cannot swallow at all. Difficulties in any of the main stages of the eating, drinking and swallowing process can be called Dysphagia.

#### **What is Aspiration?**

*The entry of material into the airway, below the true vocal folds, and it is a potential outcome of Dysphagia - Logemann 1998.*



#### **Signs of concern to look out for when someone is eating and drinking:**

- Coughing
- Choking
- Changing colour (red/grey/purple/blue)
- Gagging
- Respiratory changes  
(panting/wheezing/gasping/stopping breathing)
- Eye-watering
- Eye bulging / looking startled
- Voice / breathing sounding wet or gurgled
- Voice sounding breathy / loss of voice
- Rapid heart rate
- Sweating
- Unexplained weight loss
- Increase in chest infections
- Changes in behaviours around eating and drinking

#### **Useful online links:**

[Public Health England - Guidance on Dysphagia in people with a learning disability](#)

[The International Dysphagia Diet Standardisation Initiative \(IDDSI\) - Texture Modification categories and other guidance](#)

### 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 autism.

If you are interested in attending any of these sessions, please email:  
[warwickshirelearninganddevelopmentpartnership@warwickshire.gov.uk](mailto:warwickshirelearninganddevelopmentpartnership@warwickshire.gov.uk)

Course: **Dysphagia**  
Date: **Thursday 29<sup>th</sup> September 2022**  
Time: **10:00 – 12:00**  
Venue: **Webinar.**

Health Education England, NHS England and NHS Improvement, Experts by Experience and MindEd have launched a collection of new co-produced [stopping the over-medication of people with a learning disability and autistic people \(STOMP\) elearning](#).

The eLearning sessions, available for health and care professionals, carers and family members, explain the meaning of STOMP, discuss opportunities to speak up if they feel someone in their care is receiving inappropriate medication and highlight how they can access reliable information about medicines.

Each of the six sessions can be completed at the learner's own pace and takes approximately 30 minutes. For more information and to access the session, visit the [MindEd programme webpage](#).

### 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 LD 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:***

Jenny Burgin – Senior LeDeR Reviewer: [jennifer.burgin1@nhs.net](mailto:jennifer.burgin1@nhs.net)

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

Deidre Giacomini – Interim LeDeR Local Area Contact (from 1<sup>st</sup> July 2022): [deidre.giacomini@nhs.net](mailto:deidre.giacomini@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)