

LeDeR Newsletter

A newsletter brought to you by CWCCG – March 2022

Welcome to our first issue of the Coventry & Warwickshire 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>

The local LeDeR Team:

We have a new LeDeR team with Jenny Burgin in post as Senior Reviewer and Amy Williams as reviewer.



I'm Jenny and I have previously worked as a reviewer for LeDeR in a different area. I also currently work as a Paramedic one day per week. I have worked in the NHS for 10 years, starting as a cleaner and working my way through various roles.



I'm Amy, I have been a Registered Mental Health Nurse for over 15 years, my career has encompassed a wide variety of settings over different trusts and CCG's. I have previously worked as a LeDeR reviewer in a different area, and I am now enjoying transferring my skills to this new team.

We also have two bank reviewers, Jayne and Philomena who assist us with LeDeR reviews.

Michelle Cresswell is the Local Area Contact and Karen Morris supports the team.

Since 1st April 2021, Coventry & Warwickshire LeDeR Programme has had:

75 Notifications

Of these:

43 reviews have been completed, **7** were out of scope and **25** are ongoing or on hold whilst we await the outcome of other investigations.

Key learning taken from reviews:

- Reviews show that people die from a wide range of causes – the most common causes of death recorded in completed reviews are sepsis, aspiration pneumonia and pneumonia.
- Some people aren't accessing age-appropriate cancer screening
- Annual health check uptake is improving but some people are still not accessing these important checks
- We need to improve the use of hospital passports, where utilised they have positive impact on patient care
- We need to promote the use of reasonable adjustments, there are many examples of good practice to share
- The Mental Capacity Act requirements aren't always followed, more training and awareness is needed
- Some people have a poor experience as they transition from Children's to Adult services.

Examples of Positive Practice:

Primary Care:

- ❖ The GP was very involved. The person received Learning Disability Annual Health Checks and medication reviews
- ❖ Excellent relationship between the person and the Practice Nurse ensured positive interventions to maintain their health for longer than may have been expected.

Coventry & Warwickshire Partnership NHS Trust:

- ❖ Art psychotherapy was very effective for the management of emotions and behaviours, highlighting the value of talking therapies for behaviour management
- ❖ The Learning Disability Nurse provided continuity throughout a person's five hospital admissions and was also a support to the family.

Acute Trusts:

- ❖ A Father was allowed to attend hospital with his Son despite COVID restrictions, to give support
- ❖ An Acute Liaison Nurse was involved during admission to provide guidance and support to the hospital ward and family. The nurse was able to ensure access for the family.

Multiple organisations working well together:

- ❖ Excellent reasonable adjustments were applied by the GP and the Breast Screening service
- ❖ Input was given from many members of the multi-disciplinary team, who communicated effectively with the care provider and the acute service. This highlights the importance of communication.
- ❖ The Mental Capacity Act was adhered to. Good evidence of all parties' views being considered, relevant people involved in the multi-disciplinary team, decisions were clearly in best interest and were recorded.

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.

We are currently working with Grapevine to recruit Experts by Experience to be involved in our LeDeR programme.

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

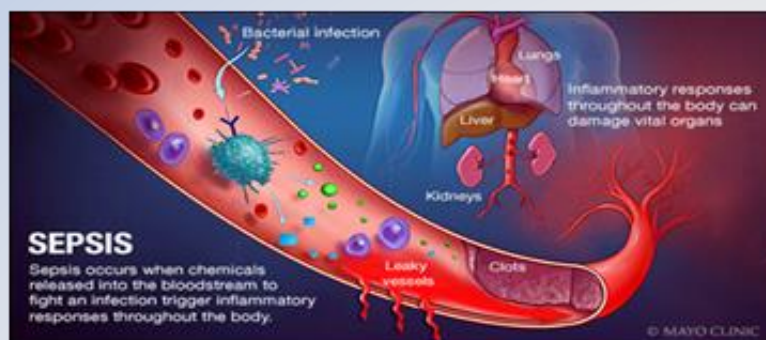
Spotlight on:

Sepsis

Nationally, the LeDeR reviews shows that 7 out of every 100 people who died, did so from Sepsis. It was the 5th most common reason why people died in 2020/21

What is Sepsis?

- Sepsis is an abnormal response to infection
- Rather than the body responding to the infection in the local area e.g., the chest, the response is systemic and affects the whole body
- It causes damage to the organs which can cause them to fail
- If untreated, this will ultimately lead to death



How to recognise Sepsis

- New confusion
- Reduced conscious level
- Breathing faster
- Cyanotic/mottled skin
- Pale and clammy
- Rigors
- Non-blanching rash
- Cold to touch
- Not passing urine
- Fast heartbeat

Sepsis danger signs

- S**lurred speech or confusion
- E**xtrême shivering or muscle pain
- P**assing no urine (in a day)
- S**evere breathlessness
- I**t feels like I am going to die
- S**kin mottled, discoloured or very pale

DIAL 999 AND SAY 'SEPSIS'

Additional information about Sepsis

- In the UK, Sepsis claims as many as 52,000 lives per year
- 25,000 children are admitted to hospital with Sepsis annually
- 40% of all sepsis survivors suffer permanent, life changing after-effects
- Sepsis costs the NHS between £1.5 and £2 billion each year and costs our wider economy at least £11 billion and possibly as high as £15.6 billion.

Please visit the website for *The UK Sepsis Trust* for more information and useful tools:

<https://sepsistrust.org/>

There is also a short video that you may find useful:

[Sepsis: Recognising deterioration in people with a learning disability \(short video\)](#)

Upcoming Learning Opportunities:

In collaboration with Warwickshire's 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

Course: ***Dysphagia Awareness***

Date: 28th April 2022

Time: 10:00 – 12:00

Venue: Webinar

Course: ***Bowel Health Awareness***

Session 1 - Date: 5th May 2022

Time: 10:00 – 11:30

Session 2 - Date: 19th May 2022

Time: 13:30 – 15:00

Venue: Webinar (Please note that both sessions will contain the same content as each other)

Useful online links:

[Coventry & Warwickshire Partnership NHS Trust - Learning Disability Services](#) (Overview of services and contact details)

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

[Learning Disability Annual Health Check Information and Resources](#)

[LeDeR - Home](#) (For more information about the national LeDeR programme)

KEY CONTACTS

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

Jenny Burgin – Senior LeDeR Reviewer: jennifer.burgin1@nhs.net

Karen Morris – LeDeR Support: karenmorris3@nhs.net

Michelle Cresswell – LeDeR Local Area Contact: michelle.cresswell2@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 evdokios.philippou@nhs.net