# Learning from the Lives and Deaths of People with Learning Disabilities and Autism (LeDeR)

***Newsletter – 7th edition – June 2022***

## Welcome back!

Take a look at our latest LeDeR newsletter – we've had a bit of a break from the newsletter and have lots to share with you.


## 2021 updates to LeDeR

- There is a new national policy and LeDeR website where you will find lots of background information about LeDeR *leder.nhs.uk/about.* **This is also where you report the death of someone with a Learning Disability.**
- The LeDeR programme now includes people with autism without a learning disability and these deaths should also be reported via the LeDeR website
- We are now able to do either an ***Initial Review*** or a more detailed ***Focused Review*** of the lives and deaths of people with a learning disability. Which type of review is carried out is decided by our team although NHS England has asked that people with autism and certain other groups of people must always have a focused review.
- Our team has changed and grown since the new LeDeR policy came into effect last year – meet the team on page 4.


## Making a notification

It's important to remember that anybody can notify a death to the LeDeR programme – GPs, health and social care staff, family members, friends and carers.

Timely and detailed notifications help us to have accurate information and to carry out prompt reviews. The reviews are a chance for us to highlight what has worked well for the person as well as influencing where services may need to improve.

This is the link to the webpage for Notifications: *leder.nhs.uk/about.*


# LeDeR deaths in Somerset 2020-2021

Our most recent complete year of data is 2020-2021.

- 54 deaths were notified to LeDeR for Somerset
- 49 reviews were completed (with two waiting for other investigations/coroner reports)
- 3 were for children and young people aged 4 -18 years and are covered by a different review process
- 15 of those who died were female
- 39 were male

27 died in their usual place of residence (residential / nursing home)
15 died in an acute hospital
5 died at home
7 died in other settings, including hospices, supported living, etc

In many of our reviews where Covid-19 has not been the cause of death, it is evident the Covid-19 restrictions in place at the time of the death had some impact on the person's health and care experience at the end of their life.

The table below shows the most common causes of death in Somerset. The impact of Covid-19 on people with a learning disability, who are especially vulnerable, is evident.

| Cause of Death | No | % | Cause of Death | No | % |
|---|---|---|---|---|---|
| COVID-19 | 11 | 21% | Heart Disease / Cardiac Failure | 4 | 7% |
| Aspiration Pneumonia | 7 | 13% | Neurological Conditions | 4 | 7% |
| Pneumonia | 5 | 9% | Old Age / Frailty | 4 | 7% |
| Other Conditions (including cancer, chest and respiratory tract infections, Sepsis and stroke) | | | | 18 | 36% |


# Other News

- The LeDeR team is continuing to raise the profile of the health needs of people with Learning Disabilities across the system.
- We are in the very early stages of working with ***Open Storytellers*** to help us understand and develop how we can engage service users in the LeDeR governance process.
- ***Biggerhouse Film*** is working with us to produce a film looking at supporting and encouraging people with learning disabilities' conversations about death and dying.

# Good Practice…..

Through the LeDeR reviews we identify areas of good practice as well as highlighting possible areas of service improvement. Below are examples of good practice we have found.

*Care hours continued to be commissioned when the person is in hospital so they continue to have care from people who know them well and can speak up for them.*

*During the COVID-19 pandemic the GP practice were in weekly contact with the care provider and digital technology was used to assess patients with a virtual ward*

*A care provider who adapted a person's living environment to enable her to remain and die at home as she had wanted.*

*Bespoke visual resources made to support a person's understanding of his care plan.*

*Support from the GP, hospice, palliative care team and district nurses, including a 24/7 helpline for carers, with robust TEP in place to ensure a person's end of life needs were met and a peaceful death achieved*


# … and Service Improvement

Below are some examples of **service improvement work** we are involved with:


## The Annual Health Check Programme

To improve people's experience and outcomes. This includes launching new pre-health check questionnaires – My Health Check – for men and women. Further consultation is going ahead with My Health Check for young people aged 14-18 years. For more information see *Learning Disability Annual Health Checks – Registered Care Providers Association* (rcpa.org.uk)

## TeamNet

The launch of a **Learning Disability LeDeR** page on the TeamNet platform and shared with GPs, primary care networks, health and social care staff and the public via this link https://teamnet.clarity.co.uk/Announcements/ViewItem/0fffd186-e2b6-46a4-89bb-ae3600c28282

# Meet the Team

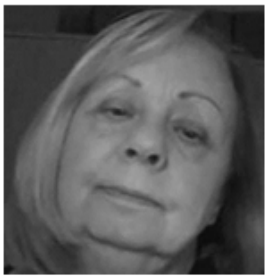
**Dr Rachel Donne–Davis** is our LeDeR Local Area Contact. Rachel's professional background is as a Health Psychologist. She has worked in Learning Disability Health Services in a variety of clinical and management roles for 16 years, and has previously acted as a reviewer for LeDeR. She is now looking at how we implement change across systems to make meaningful improvements to the lives of people with learning disabilities.

**Carolyn Arscott** has varied experience in supporting people with learning disabilities across social care and health and most recently she was based with Somerset Public Health. Focused on reducing health inequalities and improving access to services to make a difference, Carolyn is the Lead Reviewer for the Somerset LeDeR programme.

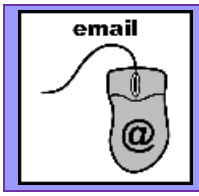
**Helen Morris** is a speech and language therapist, with experience of working within Learning Disability specialist health services both in the UK and overseas. Most recently Helen was the Clinical Lead SLT (Learning Disabilities) with Somerset Foundation Trust and has a particular interest in working with people with complex physical health needs. Helen is a LeDeR reviewer.

**Mel Axon** is a learning disability nurse by training who has worked in health and social care services in Somerset since 1982. She has recently retired from Somerset Foundation Trust where she was the West Team manager in the community team and is now working part-time as a LeDeR reviewer.

**Julie Ticehurst** has many years' experience as a senior PA in the private sector, working across a variety of industries. More recently she spent 12m in the IFR / EBI team at Bath and North East Somerset CCG before joining Somerset as administrator for the LeDeR team.



**AND** goodbye to **Wendy Murray** who has been with the LeDeR team for six months on a fixed-term contract. Wendy brought skills as a nurse, nurse prescriber, health visitor and as a previous safeguarding lead in an acute Trust. Wendy had also completed LeDeR reviews in the past. Thank you Wendy and good luck.




**Contact Us**

If you would like to contact our LeDeR team with any questions or queries, please do so using the email address *somicb.leder@nhs.net* - we would love to hear from you. And if there is anything you'd like to see included in a future newsletter, please let us know.