



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

Newsletter – 9th edition – April 2023

Bowel Cancer Awareness Month

Bowel cancer is the fourth most common cancer in the UK, and the second biggest cancer killer.



- ❖ Nearly 43,000 people are diagnosed with bowel cancer every year in the UK.
- ❖ 1 in 15 men and 1 in 18 women will be diagnosed with bowel cancer during their lifetime.
- ❖ Did you know that research has shown that around half (54%) of all bowel cancers could be prevented by having a healthier lifestyle? You can reduce your risk by having a healthy diet, being more physically active and keeping to a healthy weight.
- ❖ Evidence shows that people with a learning disability who are eligible for bowel cancer screening are less likely to take part compared to the general population. Because of this they may be at increased risk of undetected bowel cancer.
- ❖ In Somerset a new scheme will help support people with learning disabilities to ensure they access screening programmes – not just for cancer – with a nurse appointed for this role. More details will follow in our next Newsletter.



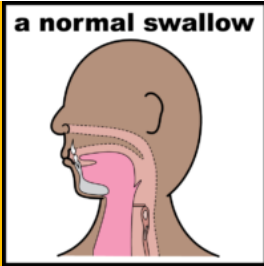
Say Hello to ...

Hi, I'm Sophia I am 20 years old and a second year Learning Disability Nursing student at the University of the West of England. I am really grateful to have a placement with NHS Somerset ICB and am very excited!

My experience at university includes Learning Disability CAMHS (Child and Adolescent Mental Health Services), an Assessment and Treatment Inpatient unit and a Care home for older adults with a learning disability.

LeDeR (Learning from lives and deaths – People with a learning disability and autistic people) is often discussed within my course at university as a way of learning from practice and constantly improving the way we, as professionals, care for people with a learning disability, which I feel is incredibly important.

I will also be working alongside CHC to learn more about the role of a nurse within the team and the importance of their work. It is a big passion of mine to improve the accessibility and quality of healthcare for people with a learning disability, so I am very enthusiastic to be here and to learn from you all!



Dysphagia Call to Action

In December 2022 NHS England SW Learning Disability and Autism Programme co-ordinated a Dysphagia webinar. This was in response to dysphagia frequently being highlighted in LeDeR reviews as one of the most common long-term conditions experienced by people with learning disabilities.

The webinar included presentations of good practice from a care provider and from Speech and Language Therapy teams across the region, a discussion and feedback on the barriers and bridges to effective dysphagia management, and highlights of local work in care homes, nursing homes, LD residential homes and for domiciliary care providers. One outcome of the webinar was the formation of an NHS England SW working group which is currently working on a simplified dysphagia skills and knowledge document to be used for and with health and care staff.

If you were unable to attend, a recording of the webinar along with the presentations can be found on the Futures NHS workspace: <https://future.nhs.uk/SWLearnDisAut>. (Please note: anyone in health or social care can sign up to NHS Futures.)

For free basic dysphagia awareness training online click on this poster for availability and to book a place:

Or follow this link <https://portal.e-lfh.org.uk/> to find out about further dysphagia training and how to access it.



Adult Speech and Language Therapy.pdf

The link takes you to a Dysphagia guide containing six online dysphagia-related modules. The three key training modules are **Dysphagia Essentials**, **Dysphagia Food** and **Dysphagia Quality and Safety**. This training can be accessed by both health and social care staff.

Somerset & Avon Rape and Sexual Abuse Support

SARSAS provides a specialist support service for women aged 16+ affected by rape and sexual abuse, who have learning disabilities and / or autism, in Somerset. They provide up to six months of 1:1 trauma-informed support.



Contact info@SARSAS.org.uk or call **01823 324944**.

LeDeR Learning Briefs



Keep an eye out for more to come in this series. Over the next few issues we will be looking in more detail at Oral Care, and Epilepsy and SUDEP.

- * Poor mouth care impacts on general health and is significantly linked to major health conditions such as cardiovascular disease, diabetes, respiratory disease and stroke.
- * Around 1 in 3 people (32%) who have a mild to moderate learning disability will also have epilepsy. The more severe the learning disability, the more likely that the person will also have epilepsy.

TeamNet

We have recently added two more pages to our **TeamNet** site



- **Annual Health Checks (AHCs)**: templates for invitation letters and pre-health check Questionnaires, and information about Health Action Plans and making Reasonable Adjustments.
- **Cancer screening for people with a learning disability**: videos and sources of information covering various screenings.



Positive Practice

LeDeR Reviews are primarily about learning – What can we do better? How can we improve? But there are also frequent examples of good practice, or where someone has made a special effort to make things better.

Here are a few things that have come out of some recent reviews.

- A consultant who visited the care setting to deliver the news of a cancer diagnosis to the care team and family.
- A GP practice who flagged a patient's record to show they ALWAYS needed a double appointment.
- The care team who were able to carry out a person's funeral wishes even though they had died before they had finished writing them.
- Occasions where care teams have provided excellent round the clock care and support for service users at the end of life.
- A GP who did home visits as the person had a phobia around health appointments and in particular, visiting the GP practice.
- A dental team who made bespoke reasonable adjustments for someone to have dental treatment in the car park.

End of Life Training

Communication in End of Life Care is a very popular course run by Somerset End of Life Care. The course covers communication, advance care planning, treatment escalation planning, spiritual care, palliative rehabilitation and care after death.

Somerset Foundation Trust staff can book a place [here](#); if you work anywhere else you can book through [Eventbrite](#).

Somerset End of Life Care are also happy to bring their courses direct to your team - contact them [here](#) regarding bespoke dates and education.



Become a Primary Care 'LD Champion'

The health needs of people with a learning disability (LD) and autism are increasingly a focus for Primary Care. Join our LD Champions network and help widen LD awareness within your practice and improve patient outcomes as a result.

There are resources on our TeamNet page and we hold regular drop-in sessions to discuss issues and topics.

"The meetings are proving to be very informative. Thank you." TM, Patient Services Administrator

Please do get in touch if you work in a GP practice and would like to find out more about the LD Champions network - somicb.leder@nhs.net.

New!

Specialist Learning Disability Primary Care Liaison Team Somerset Foundation Trust



A new team is supporting people with a learning disability in Somerset working with Primary Care and GP practices. Their role includes:

- Assisting with early identification of escalating health care needs
- Supporting the implementation of reasonable adjustments
- Providing input around healthy lives to reduce risks around developing long term chronic conditions that impact on quality of life, life expectancy and cancer
- Enabling social and healthcare providers to access training and support on setting up and implementing reasonable adjustments
- Ensuring GP practices can access training around Annual Health Checks particularly for patients who miss these appointments

Contact the team via PrimaryLiaisonTeam@somersetft.nhs.uk



We need YOU to notify LeDeR when someone dies

It helps us all to have a better understanding of the needs of people with a learning disability and autistic people; helps improve services in Somerset and provides an opportunity to shout about good practice!

It's very simple to do and will only take about 10 minutes. Here is the link to the form [Report the death of someone with a learning disability \(leder.nhs.uk\)](https://www.leder.nhs.uk).

If you provide care or support to someone with a learning disability, or an autistic person, are a GP or other health professional, a family member, friend or carer **we need you** to notify us if someone dies.

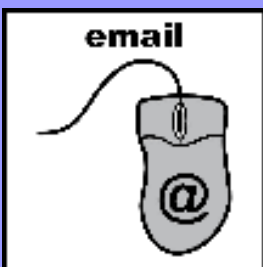
Personalisation Webinars

NHS England SW are holding a series of webinars supporting the development of the Learning Disability and Autism programme.

- ❖ 19 April – Personalised care and support planning (click [here](#))
- ❖ 10 May – Feel the fear and do it anyway (click [here](#))



email



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.