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| **Icon  Description automatically generated** | Learning from the Lives and Deaths of People with Learning Disabilities and Autism (LeDeR) |
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| ***Newsletter – 10th edition – July 2023*** | |

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| **NHS Somerset LeDeR Annual Report 2022-23**  The Somerset LeDeR Annual Report was published at the start of July. The report covers the period April 2022 – March 2023 and provides insight into learning from deaths that occurred during that period.  44 deaths of people with learning disabilities or autistic people occurred during the reporting period. Of these deaths the majority occurred in a hospital setting, which is in line with what is reported nationally. |  |
| In Somerset the most common cause of death reported related to the respiratory system. This is the third most common cause of death nationally. We want to understand more about this locally so will be carrying out a more in-depth review of the 20 deaths identified in this category to ensure that we maximise learning.  In the Report we share people’s stories. There are some examples of where services have made creative reasonable adjustments to meet people’s needs. There are also examples of where things have not been good enough and people have not been able to access the care they need.  To read these stories and to find out what we have been doing in Somerset to make a difference please read the full report [here](https://nhssomerset.nhs.uk/wp-content/uploads/2023/07/LeDeR-ANNUAL-REPORT-2022-23-Final.pdf). | |

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| **A group of people holding signs  Description automatically generated with low confidence** | **Specialist Learning Disability**  **Primary Care Liaison Team**  **Somerset Foundation Trust – *Part II*** |
| In our last Newsletter (April 2023) we told you about the ***Primary Liaison Team*** being formed at Somerset Foundation Trust to work closely with our partners to make a real difference to people with a learning disability and autistic people in Somerset.  Two new screening posts will shortly join this team to support these five national screening programmes: ***Bowel cancer | Cervical cancer | Breast cancer | Abdominal Aortic Aneurism | Diabetic Retinal Eye screening***.  These posts have been set up to ensure equity of access to early diagnostic testing and are funded by the Cancer Alliance and Public Health England. Their work will include communication strategies, liaison with acute and primary healthcare, liaison with specialist areas such as endoscopy and radiology, patient transport, and will undertake face to face contact and chaperone roles where needed.  For further information contact the team via [***PrimaryLiaisonTeam@somersetft.nhs.uk***](mailto:PrimaryLiaisonTeam@somersetft.nhs.uk). | |

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| **People with Learning Disabilities are at increased risk of Heart Disease**  People with a learning disability may be at increased risk of early-onset cardiovascular disease (CVD) – particularly stroke, heart failure, and deep vein thrombosis – according to new research from Denmark published in BMC Medicine. It also found that the risk of heart disease increased with the severity of the learning disability. | A cartoon of a person with a heart  Description automatically generated |
| Cardiovascular disease (CVD) is a leading cause of ill health and death worldwide, accounting for one third of all deaths in 2019. This study concluded that people with a learning disability had a **24% increased overall risk** of early-onset CVD from childhood to early adulthood.  The risks were significantly elevated for the most common specific types of CVD, including cerebrovascular disease (150% increased risk), stroke (120% increased risk), heart failure (256% increased risk), and deep vein thrombosis (110% increased risk).  The severity of the learning disability also had an impact on CVD risk, and the strongest associations were observed in individuals with a severe or profound learning disability.  People with learning disabilities are also more likely to have the major risk factors associated with heart disease eg higher rates of obesity, diabetes, hyperglycemia (high level of sugar in the blood), and hyperlipidemia (high cholesterol).  Certain factors such as social exclusion, lower income, and limited access to healthcare and leisure facilities also predispose people with learning disabilities to a higher risk of developing heart disease.  These findings highlight the importance of routinely screening people with learning disabilities for CVD, as well as supporting people with learning disabilities to lead a healthy lifestyle. The study’s authors also say the findings suggest that healthcare professionals should be aware of the increased risk of cardiovascular disease in patients with a learning disability.  To read the full study click [here](https://bmcmedicine.biomedcentral.com/articles/10.1186/s12916-023-02747-4). | |

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| Shape  Description automatically generated | **Primary Care LD Champions Network**  Our next Learning at Lunchtime session will be held in September when we will be looking at Perimenopause and Menopause.  Join our LD Champions network and help widen LD awareness within your practice and improve patient outcomes as a result. To find out more email us at [***somicb.leder@nhs.net***](mailto:somicb.leder@nhs.net). |

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| A blue and white background with white text  Description automatically generated  NHS England South West Learning Disabilities and Autism team produce a monthly Bulletin to share information about their work. | Back issues have included topics such as:   * regional dysphagia guidelines * LeDeR improvement projects * a call for volunteers for research * assessment of autistic people * career opportunities for LD nurses * National Epilepsy week   If you would like to keep up to date and be added to the distribution list to receive this Bulletin, email  [***england.learningdisabilityandautism-sw@nhs.net***](mailto:england.learningdisabilityandautism-sw@nhs.net)***.*** |

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| In April 2023 Mencap held their first Health Inequalities Summit.  To find out more follow this link  [Health Inequalities Summit 2023 | Mencap](https://gbr01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.mencap.org.uk%2Fhealth-inequalities-summit-2023&data=05%7C01%7Chelen.morris53%40nhs.net%7C8cd15768a1464de0c73808db815d8ced%7C37c354b285b047f5b22207b48d774ee3%7C0%7C0%7C638246011006265877%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C3000%7C%7C%7C&sdata=B3l1aYe%2BLfa3OtDPngpjYEf6sO2k4SohYXIC1RLtBx8%3D&reserved=0) | A logo of a company  Description automatically generated |

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| **We need to talk about death**  We recognise that Death and Dying is really hard to talk about and that people with learning disabilities are sometimes protected from having those conversations. We wanted to start that conversation.  So we have commissioned Biggerhouse Film to work with a group of people with learning disabilities and autism to explore this subject. | | | A grave stone with flowers  Description automatically generated |
|  | Biggerhouse Film, together with some people with lived experience attending My Day Services have been working together to make a film. The project started with a workshop process to find out what was important to the people in the group, and to use this to shape the film and develop the script.  The group then took part in a series of intensive filming days in front of a green screen and on location.  We are now deep in the editing process but here is a clip of filming with the green screen  [www.biggerhousefilm.co.uk/about/current-work/](http://www.biggerhousefilm.co.uk/about/current-work/) | | |
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| We are really excited about this project and can’t wait to share it with you when it is complete.  *Photo credit: Dan Martin from “We need talk about … Death” A biggerhouse film production for NHS Somerset* | | | |

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| A picture containing logo  Description automatically generated | **LeDeR Learning Briefs**  We published our Learning Briefs on Epilepsy and SUDEP (Sudden Unexpected Death in Epilepsy) in June.  Future topics will include: Cancer | Contractures | Dementia | Diabetes | Falls Menopause | Reasonable Adjustments | STOMP and how they particularly affect those with a learning disability and autistic people. |

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| **All about Perimenopause and Menopause**  Dimensions have been working with the Newson Health Menopause Society and the Balance app to produce a resource for women with learning disabilities on perimenopause (the time before the menopause happens and symptoms occur) and menopause.  The result is an easyread document, and a podcast link, where a member of the Dimensions team shares her experiences of menopause – the first time ever the podcast has had a woman with learning disabilities sharing her experiences. [Learning Disabilities and the Menopause Podcast](https://thedrlouisenewsonpodcast.podbean.com/e/209-learning-disabilities-and-the-menopause/) |  |

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| A cartoon of a person holding a piece of paper  Description automatically generated | **Student Placement**  In the Spring we welcomed Sophia as our first student placement. LeDeR Reviewer Mel Axon was her supervisor during her placement, and these are her reflections on the exercise: |
| *As a Learning Disability Nurse I have always been keen to share my knowledge and experience with aspiring nurses, and especially when they are Learning Disability* ***student*** *nurses. I have had some experience of students at Somerset FT, and the LeDeR team were keen to see if we could offer a placement to a student from UWE. We were very pleased to have a second year student, Sophia, for a six week placement - we are the first LeDeR team in the country to have a student nurse on placement. As we are a small mostly part-time team we joined forces with the CHC team in the ICB to give Sophia an opportunity to experience both areas.*  *We benefited as a team and a service. Sophia wrote two learning briefs and contributed to some case reviews. It was a privilege to be part of her nurse training and her mentor in those six weeks. I hope that she will in the future consider ICBs as possible places to work; we need more student nurses to carry on the great work of the NHS. Students are our future so it’s always worthwhile to invest time and resources in helping them along the way.*  *When she left Sophia made these comments: “The LeDeR team adapted quickly to having a student with them, and made me feel welcome and valued. They took time to check my understanding and were well prepared for my first week. I have never received such a lovely and enthusiastic welcome than I have had on this placement, and I am so grateful to everyone within the LeDeR team for making me feel like a respected member of the team.”*  *That feedback says it all. We are already planning the next placement…..* | |

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| **Please remember to notify LeDeR**  **when someone dies** | A picture containing text, screenshot, person  Description automatically generated |
| 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://leder.nhs.uk/report).  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. | |

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| A picture containing shape  Description automatically generated | **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***](mailto: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. |

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