

**LeDeR Annual Update Report
April 2018 – March 2019
(Also now including mid-year updates from April – September 2019)**

LEARNING DISABILITY MORTALITY REVIEW (LEDER) PROGRAMME

Shropshire, Telford and Wrekin

1.0 Executive Summary

The Learning Disabilities Mortality Review (LeDeR) programme is a national project to review the deaths of all patients with Learning Disabilities. The programme was established to support local areas to review the deaths of people with learning disabilities, identify learning from those deaths, and take forward the learning into service improvement initiatives. The programme is led by the University of Bristol, and commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England. This is a joint health and social care project, involving healthcare providers across the health economy, Local Authority and CCG's.

There is no accurate record of the total number of people with learning disabilities in England, nor of the number of deaths each year. In 2017/18 it was estimated that there were approximately 1.5million people in the UK with an LD diagnosis. National QoF is around 0.49% of the population with LD, although research suggests 2.16% of adult population has an LD, indicating QoF is low. Estimates from Public Health England data suggests the approximate number of deaths of PWLD of all ages each year to be more than 3,400 (0.02% of the population).

Locally the county's population is estimated at 472,770. The Quality and Outcomes Framework (QoF) data indicates there are 1,612 in Shropshire (0.52% of the population) and 793 (0.47%) in T&W registered with a Learning disability. This indicates that the prevalence of PWLD locally is higher than the national average in Shropshire and lower in T&W.

During 2018/2019, 29 deaths of patients with Learning Disabilities were reported to the LeDeR programme, Shropshire, Telford & Wrekin. 17 patients were from Shropshire and 12 T&W. Of the eleven deaths which have been reported locally between April 2019 - September 2020, nine are from Shropshire and two from T&W.

2.0 Review process

LeDeR reviews are not investigations of care but aim to develop learning and improve care. The focus of the reviews is to:

- Identify potentially avoidable factors that may have contributed to a person's death.
- Identify differences in health and social care delivery across England and ways of improving services to prevent early deaths of people with learning disabilities.
- Develop plans of action that will guide necessary changes in health and social care services in order to reduce premature deaths of people with learning disabilities

For each death, there is an initial review. Someone who knew the person well, such as a family member, is invited to contribute their views. This is a fundamental part of the review. The reviewer will also look at relevant case notes relating to the person who has died, and will make contact with relevant organisations/ agencies to discuss cases and access notes if required. This involves the range of agencies that have been supporting the person who has died, (e.g. health and social care staff).

The review looks at three levels of care:

- a) Initial diagnosis and management of the condition

- b) Ongoing management of the condition from initial diagnosis to critical illness
- c) Management and care received during final illness

3.0 National Picture

From 1st July 2016-31st December 2018, 4,302 'in scope' deaths have been notified to the programme. In 2018, this was approximately 86% of the estimated number of deaths of people with learning disabilities in England each year. One in 10 included a multi-agency review.

The median age at death for people with learning disabilities (aged 4 years and over) who died from in year was 59 years. (Males 60 years; females 59 years).

38% of the deaths were still waiting to be allocated to a reviewer, indicating continuing and Significant problems with the timeliness with which reviews of deaths take place nationally.

Of the deaths of children (aged 4-17 years), 42% were from BAME groups. None of the children deaths locally were BAEM. A quarter (25%) of people from BAME groups had profound and multiple learning disabilities, twice the proportion (11%) of white British ethnicity. All deaths locally were white British.

There was a rise in deaths through autumn and early winter. Over a third (37%) of people who died from aspiration pneumonia did so between Octobers – December.

The proportion of people with learning disabilities dying in hospital was 62%; in the general population it is 46%. In the 2016/2017 64% of deaths were in hospital.

Reviewers felt that the majority (79%) of DNACPR orders were appropriate, and correctly completed and followed. However, 19 reviews reported that the term 'learning disabilities' or 'Down's syndrome' was given as the rationale for the DNACPR order. This has not been the case on any of the local DNACPR orders.

The most common individual causes of death

- Pneumonia
- Sepsis
- Aspiration Pneumonia

4.0 Local Findings

2018/19:

Locally 29 deaths have been notified to the LeDeR programme, between April 2017 and March 2019 within 2018/19. 22 of these reviews have now been completed; quality assured by the LAC's and submitted to the LeDeR team in Bristol. Of these, 16 patients died in Hospital (1 in Birmingham) and 12 died in their usual place of residence i.e. either a care home or their own private home. One of the notifications was withdrawn due to the patient not meeting the LeDeR eligibility of an LD diagnosis.

Three of the 29 deaths were in the 4-25 age group; 9/29 deaths were in the 26-55 age group; 4/29 were aged 56-65 and 13/29 were aged 65 plus (4 aged 80+ and 7 aged 70+). The mean age of death in 2018/19 was 58 years. 18 of the deaths were males, (the mean age 60years) and 11 females (mean age 56 years).

The cause of death most commonly reported were: generalised pneumonia (6); Heart Disease (5); Respiratory failure (4); Sepsis (4); Aspiration Pneumonia (3). Other causes of death reported were: multi-organ failure (2); Batton disease (1); Volvulus (1). Three cases are still to be confirmed.

Grading's of Care:

Two of these reviews were graded with a score of one (excellent care).

Ten reviews have been graded as a score of 2 which indicates (good care).

One was graded as 4 (some gaps in care but did not contribute to the death),

One was graded as a six (gaps in care which may have contributed to the death). This case went to coroner's inquest with the learning has been shared via the steering group across the Trusts.

The key learning from this case is identified below:

- Use of the LD passport - All patients with LD should carry or have easy access to an LD passport to share with health care staff.
- Referral for LD specialist support - Staff within emergency care service should familiarise themselves with the contact information of their local Community Learning Disabilities Team. Awareness that a referral can be made to the CLDT where the named nurse has any concerns
- Assessment of pain - references were made to the patient having pain. The hospital need to utilise tools to assess pain in patients with a learning disability. The trust are now looking at non-verbal aids for communication; EASY READ pain management literature.
- No specific pathway or adjustment for emergency care of patients with LD. ED requires a specific care pathway/protocol for identifying and caring for patients with a learning disability.
- Admission and discharge pre-planning - The CCG and the trust are reviewing the contract and commissioning arrangements of the hospital LD liaison nurses.

2019/20 (6 month update):

Ten deaths have been reported to date between April 2019 - September 2020. Seven died in hospital, 2 in their usual place of resident and 2 within a care home that was not their usual place of residence. Five of the reviews have been fully completed and submitted to the national LeDeR team.

None of the deaths reported this year have been in the 4-25 age range; 7/10 deaths were in the 26-55 age range; 2/10 were aged 56-65 and 1/10 were aged 65 plus. The mean age of death in the first 6 months of 2019/20 is 46 years. 6 of the deaths were males, (the mean age 42 years) and 4 females (mean age 53 years).

The cause of death most commonly reported was respiratory failure (4). Other causes sited are: peritonitis (1); multiple organ failure (1) and cancer (1). Three cases are still to be confirmed.

The most commonly reported gaps in practice of the reviews from 2018 to date are:

- Delays in diagnosing and treating illness.
- The quality of health and social care received by the person.
- Delayed discharge from hospital.
- Delayed recognition of approaching end-of-life.
- The coordination of care.
- Information sharing.
- Transition planning for those moving from children's to adults' services, including ongoing screening requirements.
- Policies for specialist referral.
- Staff resources and skills, including application of MCA for PWLD.

This learning has been shared with providers but further assurance is required as to how these recommendations are being actioned at an operational level.

Good Practice has been cited in many of the reviews. The main themes are in relation to:

- Strong, effective inter-agency working.
- Person-centred care.

- End-of-life care.
- The provision of 'reasonable adjustments'

This report has been shared with the four main providers at CQRM. Work is ongoing through the steering group to ensure the actions required are implemented.

There is variance across the county in how General Practices code people with a learning disability. The LeDeR Programme uses the definition included in the 'Valuing People', the 2001 White Paper on the health and social care of people with learning disabilities which states:

'Learning disability includes the presence of significantly reduced ability to understand new or complex information to learn new skills (impaired intelligence), with reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development.

The community learning disability team (CLDT) is working closely with GP's to cleanse registers and support the completion of Annual Health Checks using the new Shropshire AHC tool which is combined with the HEF (Health Equalities Framework). The aim is to get 100% of PWLD being offered an AHC, with a coded reason if a check is not completed. Work is also in place to improve the consistency of the quality of the checks and how the health action plan is used to inform care planning.

5.0 NHSE Assurances

There are 3 key priorities for LeDeR as a programme across the Midland and East

1. Improving the rate at which reviews are assigned. NHSE have now specified that reviews should be allocated within 3 months and CCGs have to report on this monthly. 90% of local reviews have been allocated within 3 months. Nationally the average is 36% of cases being allocated within 3 months.
2. Improving the length of time which it takes for the reviews to be completed. NHSE have now specified that reviews should be completed within 6 months and CCGs have to report on this monthly. Locally 40% of reviews have been completed within 6 months. England average is 10% being completed within 6 months.
3. Ensuring action is taken to address the recommendations emerging from completed reviews.

Shropshire/ Telford and Wrekin remain one of the highest performing footprints in Midlands and East, having the lowest number of unallocated cases. Shropshire/ T&W are also in the top three nationally of allocated cases and in the top two CCG areas for completion of reviews.

Currently there are 12 reviews that have taken over 6 months to be completed. NHSE have requested further information on the cause of the delays. In the main this is due to awaiting information and other investigations or police enquiry to be completed. The LACs continue to support the reviewers.

Nationally NHSE have developed a project with CSU to be able to work with CCGs to support the back log of cases to be reviewed. As Shropshire Telford and Wrekin are performing well, we were not included within this project due to there being no back log of cases. To support the CCG to continue to perform well NHSE have allocated some additional funding to CCGs who opted out of the CSU project. This funding has now been approved. £15,000 (non-recurrent funding) is to be received to support the development and implementation of improved plans to ensure that the CCG continue to:

- Completing reviews within 6 months of notification
- Allocating reviews within 3 months of notification
- Embedding action from learning

To support us locally in achieving this the CCG is developing a bank of health and social care professionals who can independently support the reviews if required to prevent a back log occurring.

Locally the Term of Reference for the steering group have been amended. The group now also has the same functions of a task and finish group in order to ensure that the actions are taken forward and the group have ownership and responsibility for the implementation of the improvements required. Progression of the action plan is now a key focus of the group.

It is also to be noted that the national team have asked the Shropshire Local Area Contacts (LAC's) to provide support to other CCG's who have challenges in establishing systems and process to embed LeDeR into practice.

6.0 Recommendations to committees

CCG Boards/ TCP Board/ Safeguarding Board/ QC and PPQ are asked to:

1. Receive and acknowledge the key points identified in this report.
2. To note that the capacity of reviewers may become a concern if the number of notifications continues to rise and the plans to develop a pool of bank reviewers.
3. To note that further assurances are requested from providers regarding the implementation of learning and improvement to ensure robust processes are in place to address the gaps identified and improve care for people with learning difficulties.