Learning Disability Mortality Review (LeDeR) Programme Coventry & Warwickshire

2019/20

LeDeR annual report (2019 – 2020)

The Learning Disabilities Mortality Review (LeDeR) programme was established to drive improvements in health and social care for people with learning disabilities, and to help reduce premature mortality and health inequalities in this population. This is the second Coventry and Warwickshire LeDeR annual report, which presents information about the deaths of people with a learning disability aged 4 years and over notified to the programme from 1st April 2019 to 31st March 2020. This report includes those deaths reported to the LeDeR programme and may not be a direct comparison of all deaths of people with a learning disability within Coventry and Warwickshire. The issues and causes of death identified within this report reflect the many challenges that people with learning disabilities continue to face, and give an indication of how we must do more to support them to live well within their local communities.

Deaths notified to the programme

There were 67 deaths notified to the programme from 1st April 2019 to 31st March 2020 across Coventry and Warwickshire; this compares to 47 in the same period 2018 – 2019. The LeDeR programme uses the information and learning gained from completed reviews of these deaths, to develop recommendations for health and social care partners across the system. Deaths are reported according to the general practice where the person was registered, and the corresponding clinical commissioning group (CCG) is notified via the LeDeR information system.

In this period there were 34 (51%) deaths reported to Coventry and Rugby CCG, 20 (30%) to South Warwickshire CCG and 13 (19%) to Warwickshire North CCG, which reflects the population split across the CCGs. The proportion of male and female death notifications is:

39 Male

58%

28 Female

42%

The majority of people (89%) were reported to be of white British ethnicity, and 6 (11%) were from Black Asian and Minority Ethnic (BAME) groups.

Progress in completing reviews

Of the 62 notifications in the reporting period, 44 (71%) were completed and four (6%) were in progress; three (5%) reviews are on hold pending other investigations (i.e. Coroner, Safeguarding Adult Review). Whilst deaths of people aged 4-17 years are reported to the LeDeR programme, the review of the young person's death is completed via the child death overview panel (CDOP) process; the findings of these reviews are then shared with the LeDeR programme. There were 11 (18%) child deaths in the reporting period.

Age at death

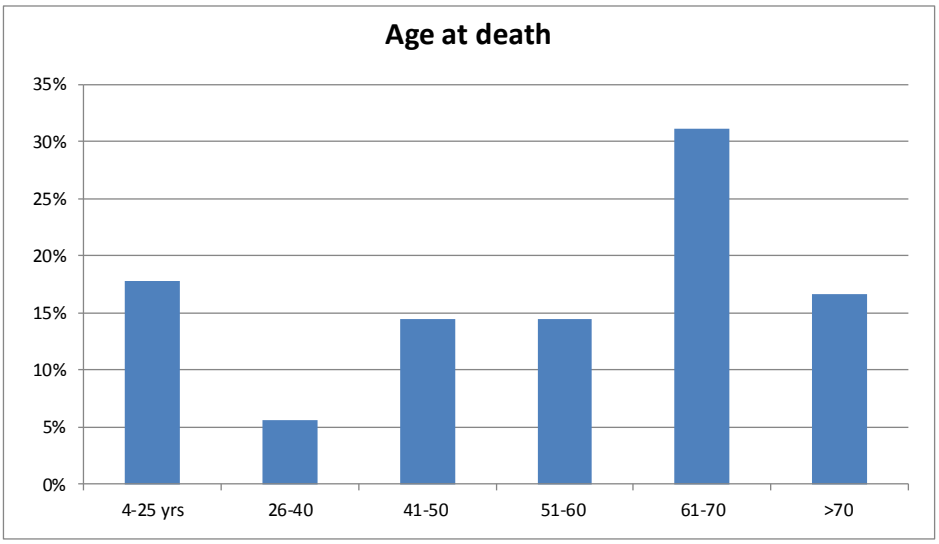
The median age at death of people with a learning disability is significantly lower than that of the general population. However, it is important to remember that direct comparisons with the general population cannot be made, as the deaths notified to the LeDeR programme commence at age 4 years and many have complex medical or genetic conditions that may make an earlier death likely.

The age range at death for the 67 people reported to the LeDeR programme in Coventry and Warwickshire was 4 – 87 years, which is comparable to the national LeDeR data. For both males and females the median age at death was 59 years, compared to the national LeDeR data of 60 and 59 years respectively (Table 1). The disparity between the age of death for individuals with a learning disability compared to the life expectancy of the general population in Coventry and Warwickshire still remains at 20 years for males and 24 years for females.

	LeDeR		General Population (2016-18)[1]		
	National	C&W	National	Coventry	Warwickshire
Male	60	59	79.6	78.5	79.9
Female	59	59	83.2	82.3	83.7

Table 1: Average age at death

Notifications of death were highest in the 61-70 year age group (31%) and young people 4-25 years (18%). Seventeen percent (17%) of deaths were over 70 years, and 14 percent of deaths were in both the 41-50 years and 51-60 years age groups.



Place of death

Of the 67 deaths of people with a learning disability with the place of death reported, 45 (52%) died in hospital, compared to 62% LeDeR nationally and 46% of the general

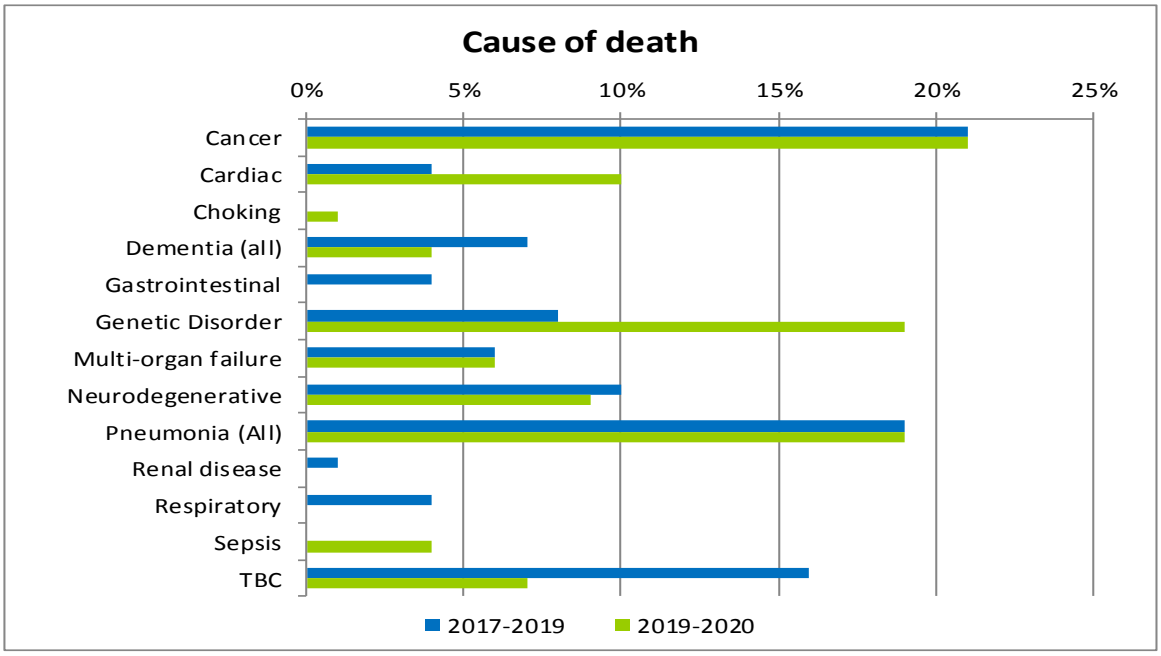
[1] Public Health England – https://fingertips.phe.org.uk/profile/health-profiles

population nationally. Thirty-five percent (35%) of people died in their usual place of residence (including residential care).

Cause of death

The cause of death reflects the many health challenges that people with learning disabilities face. The cause of death is reported using, where available, a completed Medical Certificate of Cause of Death (MCCD). Nationally, nineteen percent (19%) of people had an underlying cause related to diseases of the respiratory system, and diseases of the circulatory system. Many people with learning disabilities also had congenital malformations and chromosomal abnormalities.

Locally, carcinoma was the most frequent cause of death (21%), with pneumonia (acquired and aspiration) attributed as the cause of death for 19% of deaths reported; this compares to the cause of death reported in the last annual report. Genetic disorders were identified in 19 percent of deaths, which reflects the higher number of deaths in young people under 25 years. The cause of death has not been confirmed for five (7%) of deaths, as the review is in progress. There were no Covid-19 related deaths reported up to 31st March 2020.



Indicators of the quality of care provided

The LeDeR review asks about several aspects of the quality of care provided, including any best practice, concerns about the death, delays in the person's care or treatment that adversely affected their health, and gaps in service provision that may have contributed to the person's death.

Examples of Best practice

There were key areas in which best practice was frequently mentioned, such as effective multidisciplinary and multiagency working, end of life care and 'reasonable adjustments'. Below are a few comments from completed reviews:

"A holistic approach with range of providers enabled the best possible care. The benefits of staff who know a persons' needs being present and listen to is a practice that should be encouraged and facilitated wherever possible.

*The care staff had prepared a pack to be taken with ***** should he be admitted to hospital, this contained a hospital passport, a communication passport, About Me -medication list, feeding regime and a list of important things you need to know about me.*

This was exemplar and should routinely be considered by every care providers as good practice".

"All healthcare needs met including spiritual and emotional care"

"Respect in place and family involvement in DNACPR. Had bowel cancer screening. Regular visits from GP and practice nurse. Respect document completed and followed".

*"Best interest meetings help provided at appropriate stage. Excellent support provided by care provider. Visiting times adjusted to support **** wife. Whole team worked together to support *** and his wife. Plans for his funeral were made as requested".*

"Completed annual health checks. The care staff at his home reported that his needs were minimal and that all the staff knew how to make a referral if required. The GP surgery was situated around the corner so when needed the staff would walk round to ensure he had the earliest and most convenient appointment. The staff did not feel there were any identifiable outstanding gaps in service".

"Familiar night time carers were used at home. Parents were allowed to stay with him at hospital. DNACPR in place. Dad commented on the speed and efficiency of the Paramedics on the 29th April 2019. They arrived at his home within 5 minutes of XX's father's call and on making their initial assessments radioed for assistance and a second crew arrived within 10 minutes and managed to get XX in the ambulance and he was blue lighted to Hospital".

*"Involvement of the community learning disability nurse supported staff in understanding *** needs in relation her learning disability. She put in place tools to support identification of pain, advised around reasonable adjustments"*

"Near to end of life advised around how to offer social support (i.e. parties) within the home rather than take patient into the community where she may have been in discomfort. Best Interest - MCA Completed, Respect - DNACPR Completed From diagnosis patient received full and proper care"

Assessment of the quality of care

Once all evidence is considered at the end of the review, the reviewer provides an overall assessment of the quality of care provided to the person; rated at *1 (excellent care) to 6 (care fell short of expected good practice)*. Those reviews where the quality of care was rated 5 are referred for multi-agency review and recommendations developed; these may also referred to safeguarding. Whilst two reviews in 2019/20 were rated 5, a multiagency review was not convened as one was referred for a safeguarding review and a police investigation is underway for the second.

7% 1. This was excellent care (it exceeded expected good practice)

64% 2. This was good care (it met expected good practice)

22% 3. This was satisfactory care (it fell short of expected good practice in some areas but this did not significantly impact on the person's wellbeing)

4% 4. Care fell short of expected good practice and this did impact on the person's wellbeing but did not contribute to the cause of death

3% 5. Care fell short of expected good practice and this significantly impacted on the person's wellbeing and/or had the potential to contribute to the cause of death

0% 6. Care fell far short of expected good practice and this contributed to the cause of death

Review learning and recommendations

Of the 67 notifications in the reporting period, 59 (88%) reviews were completed on or before 31 March 2019; including the 10 child deaths for review by CDOP. There was a wide variety of learning elicited from the reviews, but most commonly they were in relation to:

- Access to multidisciplinary services such as speech and language therapy (SALT), physiotherapy and dietetics;
- Communication with and involvement of family/relatives in care and/or treatment decisions;
- Training for staff supporting people with learning disabilities in all areas;
- End-of-life care.
- Annual GP reviews required with referrals to specialist services
- Age appropriate health screening

Learning from initial reviews

Theme	Learning
Annual Health Check	GP health check for people with a learning disability not completed annually GP practices should be aware that an annual health check at home is a reasonable adjustment if the patient cannot access the surgery
Routine health screening	Not called for age appropriate screening.
Multidisciplinary services – referral, assessment and treatment	No evidence of multidisciplinary involvement, such as SALT, physiotherapy, dietitian, LD nurse referral (community and hospital)
Cause of Death	Health care professionals should not list having a Learning Disability as a cause of death.
Hospital Passport	Hospital passport not routinely provided by the social care provider on transfer to hospital.
LD assessment	LD assessment or care plan to address specific needs in hospital
LD awareness/training	Need to identify depth of staff awareness and understanding of LD to support person-centred care (health and social care providers) The use of an area LD champion to assist in cascading information and to drive forward improvements.
Family/relative liaison and involvement in care and/or decisions	Incorporate family/relative contribution into the development of care plans and delivery of care
Poor treatment of constipation	Learning and developing knowledge around constipation in people with LD
Understanding of LD and associated health needs	The link to LD and aspiration pneumonia in care home resident care plans Diagnosis of a cancer should generate a referral to the community LD team for nursing support
Capacity assessment/MCA	Evidence of MCA and best interest discussions should be clearly documented and updated as indicated

Theme	Learning
Reasonable adjustments (Hospital)	All people with an LD admitted to an acute hospital should be referred to acute liaison for support and have a routine assessment on admission. Independent advocacy services should be involved for all clients who not have capacity whilst in hospital Building good patient pathways that support communication and patient centred outcomes.
Communication across agencies	Long stays in hospital should not alter someone's package of care so they have to reapply when discharged
Sepsis	Care bundle for risk of sepsis should be implemented when indicated
End-of-life care	Access to dual nursing when end-of-life (LD/palliative) Early recognition of a dying patient to support appropriate care in the best environment Improvement of clinical record entries to clearly document EOL decision making process
General inpatient care	Use of appropriate language by clinical staff when discussing needs of people with a LD Review whether out-of-hours transfer of patient with a LD to a ward is deemed safe given the complex patient needs
Spiritual/emotional needs	Spiritual/emotional needs should be considered and/or supported

Learning into Action

Recent changes to the local LeDeR governance structure includes a thematic review group, with nominated representatives across partner organisations, to focus on making further recommendations from completed reviews. This will enable assurance that these recommendations are embedded across the local system.

To support and facilitate this work, a Coventry and Warwickshire system-wide 'Reducing Health Inequalities for People with Learning Disabilities Steering Group' is in place with membership from across health, social care and the voluntary sector, including a charity with direct links to the local LD population. This group dovetails and works in tandem with the LeDeR Steering Group to prioritise strategies across the health and social economy.

The group's work plan priorities focus on increasing the uptake and delivery of annual health checks, implementation of a LD specific subsection of the local cancer plan and increasing awareness and knowledge amongst care providers about the health needs of the LD population. The activity planned includes:

- A promotional campaign, co-designed with people with a LD, aimed at increasing awareness of annual health checks (AHC) for people with LD.
- Improve access to AHC data to enable focussed health facilitation activity with primary care colleagues;
- Delivering ongoing LD/AHC training for primary care colleagues;
- Reviewing LD AHC delivery in relation to the potential to provide virtual checks during the COVID-19 response;
- Delivering education and awareness raising content to people with LD and their formal and informal carers regarding cancer screening and prevention;
- Launching a LD Health Champion Network for local care providers regarding the health needs of people with learning disabilities, using a train-the-trainer approach to educate and cascade information to the care workforce.

The group reports regularly to the Coventry and Warwickshire Learning Disability and Autism Board.

A copy of the action plan is appended.

Conclusion and next steps

This report presents the findings from reviews following the death of people with a learning disability across the Coventry and Warwickshire area notified to the LeDeR programme from 1st April 2019 to 31 March 2020. Of the 62 notifications in the reporting period, 44 (71%) were completed, four (6%) were in progress, and three (5%) were on-hold pending other investigations at the time of the report. There were 11 (18%) child deaths notified during the reporting period, and these deaths are reviewed via the CDOP process.

The LeDeR reviews completed across Coventry and Warwickshire since commencement of the programme in October 2017 has identified key learning about the local provision of health and social care services to support people with a learning disability. The local LeDeR Steering Group continues to review the learning and recommendations to identify areas where service improvements could be made. Progress towards translating this learning into action has been made this year to improve the quality of health and social care services for people with a learning disability. This work is supported by the 'Reducing Health Inequalities for People with Learning Disabilities Steering Group' and in collaboration of health and social care providers across the system.

End of Report

Priority Area	Activity Planned for 20/21
1. Improve the number and quality of annual health checks	1.1 Increase identification of people with LD eligible for enhanced service
	1.2 Develop and disseminate resources for primary care to support delivery
	1.3 Establish local data dashboard to monitor and review PCN level AHC delivery
	1.4 Review alternative delivery models for AHC delivery and implement GP Alliance Model
	1.5 Develop and Launch AHC campaign led by Grapevine for Promotion/Increasing Awareness of AHCs
	1.6 Progress QOF Quality Improvement Module for Primary Care during 20/21
2. Develop Local Health Facilitation Resource	2.1 Implement Service Specification for CLDT and Health Facilitation elements
	2.2 Review Health Facilitation elements of CLDT specification
	2.3 Increase awareness of role of CLDT amongst Primary Care and local providers
	2.4 Work collaboratively to identify and prioritise local Health Facilitation activity
3. Reduce the overmedication of people with learning disability/autism (STOMP/STAMP)	3.1 Community Learning Disability Team (CLDT) to continue to deliver STOMP/STAMP activity, reviewing and auditing progress around this
	3.2 Develop and promote medication advice routes
	3.3 Raise awareness of STOMP/STAMP initiatives
4. Address determinants of health inequalities	4.1 Learning from deaths (LeDeR) is shared and influences local priority activity
	4.2 Develop and promote a range of health and well-being resources and health promotion activities to people with LD, their carers and supporters
	4.3 Develop and Implement LD specific sub plan of system wide Coventry and Warwickshire Cancer Plan
5. Embed evidence based best practice to reduce inequalities	5.1 Develop LD care provider Health Champion Network scheme across Coventry and Warwickshire
	5.2 Engage with people with LD and their supporters to co-produce solutions
	5.3 Research best practice initiatives for local development