Newcastle Gateshead
Clinical Commissioning Group

Learning Disability Mortality Reviews (LeDeR) Annual Report 2019

All people should be given the same respect, value, access to treatment and rights.

Our lives are not valued as much as other people's.

This has to change and it starts with you.

You need to understand our rights and know the Law.

Start by listening to us - hear our worries but also what we want from our life.

Listen to the people who know us best. This might be our family, friends or paid support.

Know how to make reasonable adjustments so that it is easy for us to get health care.

Information, information, information - make it Easy Read and don't use jargon.

Don't let us die too young.

Thank you to the members of the North East and Cumbria Stop People Dying Too Young Group

This is the second annual report reviewing the deaths of people in Newcastle and Gateshead who have died during 2019 and who also have a learning disability. This review is of high importance to Newcastle Gateshead Clinical Commissioning Group and is also a requirement as detailed in the NHS Long Term Plan (January 2019).

The persistence of health inequalities between different population groups has been well documented, including the inequalities faced by people with learning disabilities. Today, people with learning disabilities die, on average, 15-20 years sooner than people in the general population, with some of those deaths identified as being potentially amenable to good quality healthcare.

The Learning Disabilities Mortality Review (LeDeR) 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. It was implemented at the time of considerable spotlight on the deaths of patients in the NHS, and the introduction of the national Learning from Deaths framework in England in 2017.

The programme has developed a review process for the deaths of people with learning disabilities. All deaths receive an initial review; those where there are any areas of concern in relation to the care of the person who has died, or if it is felt that further learning could be gained, receive a full multi-agency review of the death.

Key processes to deliver mortality reviews of people with learning disabilities have been established in Newcastle Gateshead with a local steering group established since Jan 2018. The Director of Nursing, Patient Safety and Quality from the Clinical Commissioning Group (CCG) chairs and takes the Strategic lead for this area of work. The CCG has developed a robust quality assurance process to ensure that reviewers are supported, and that ultimately the system delivers high quality reviews and shares the lessons learned across local systems feeding into both North East and Cumbria and Nationally.

The most significant challenge to the delivery of the programme has been the timeliness with which mortality reviews have been completed, largely driven by the limited resources available to undertake reviews and the low proportion of people trained in LeDeR methodology who have gone on to complete a mortality review. The challenge for trained reviewers having sufficient time away from their other duties to be able to complete a mortality review is significant. Newcastle Gateshead

CCG has recruited experienced independent reviewers to ensure reviews are completed and lessons shared in a timely way.

NHS
Newcastle Gateshead
Clinical Commissioning Group

Deaths notified in Newcastle and Gateshead to the LeDeR programme

During 2019 there were 31 deaths of people with a diagnosis of a learning disability reported through the LeDeR programme for Newcastle and Gateshead. Of these 31, 22 reviews of the circumstances surrounding the individuals have been reviewed and reported on to Newcastle Gateshead CCG and through the National LeDeR programme. This report details key findings from the 22 completed reviews and includes any Themes, Learning Points and Recommendations.

Table 1 below details deaths reported by year, the numbers of reviews completed, numbers still with a reviewer, reviews awaiting allocation and those awaiting a Multi-Agency Review. It should be noted that 1 additional review was completed in 2017 from a death in 2016 which is not included in data as prior to the start of the National LeDeR programme. At the time of writing this report there are 3 Multi Agency Reviews scheduled for completion before the end of 2020 relating to 2 deaths from 2018 and 1 death from 2019.

Table 1 Number of Deaths and Completed reviews 2017-2019 inclusive

Year	Number of deaths notified	Completed reviews	Reviews allocated	Awaiting allocation	Awaiting Multi Agency Review
2017	17	17	0	0	0
2018	31	23	5	1	2
2019	31	22	8	0	1

- Table 2 shows the average age of deaths of people with a learning disability in Newcastle and Gateshead during 2019
- Table 3 shows the setting where the death occurred
- Table 4 the main identified cause of death.

Table 2 The average (Median and Mean) age at death for All Age and for those aged 18years and over, this shows that if the 3 children are removed from the all age calculation (2 Male, 1 Female) it increases the median age from 59yrs to 67 yrs. Compared to the average of death in general population.

	Average age of death for people with a Learning Disability All age in Newcastle and Gateshead (2019)		Average age of death for people with a Learning Disability aged over 18 years in Newcastle and Gateshead (2019)		Average age of Deaths general population in Newcastle and Gateshead (2019)	
	Median Age at Death	**Mean Age at Death**	**Median Age at Death**	**Mean Age at Death**	**Median Age at Death**	**Mean Age at Death**
Total	**59.00**	**54.86**	**67.00**	**61.74**	**88.00**	**77.00**
Men	55.50	49.58	63.00	57.40	77.00	74.20
Women	66.00	61.20	73.00	66.56	83.00	79.80

Table 3 shows the setting where individuals died with over half of those who died doing so in Hospital (55%) and 32% dying in their own homes.

Setting where death occurred	**Number of individuals in each setting**	**Percentage**
Hospital	12	55%
Home	7	32%
Residential/Nursing Home	1	5%
Hospice	1	5%
Unknown	1	5%
Total	**22**	**100%**

Table 4 shows the cause of death for those who died in 2019 and where the reviews have been completed. Over half (55%) of all individuals with a learning disability who died, and review completed review in 2019, their deaths are attributed to Respiratory failure caused by Bronchopneumonia, Pneumonia, Aspiration Pneumonia and Chest Infection.

Cause of death	**Number of individuals**	**Percentage**
Respiratory	12	55%
Metastatic Endometrial Carcinoma	1	5%
Renal failure	1	5%
Peripheral Vascular Disease	1	5%
Cerebrovascular accident	1	5%
Ischaemic bowel Disease	1	5%

General deterioration in health	1	5%
Sepsis	1	5%
Ischaemic Brain Injury	1	5%
Unknown	1	5%
Sudden unexpected death in epilepsy (SUDEP)	1	5%
Total	**22**	**100%**

Themes, Learning points and recommendations from reviews

Adults (those aged 18 years and over)

There was a need for improved documentation to support reasonable adjustments and person-centred care planning tailored to individual needs. Identify reasonable adjustments which could encourage engagement with healthcare.

Recommendation: Awareness raising with professionals related to their duty of care to provide reasonable adjustments as stipulated in the Equality Act 2010. Hospital staff to make records of reasonable adjustments made for individual, this should include those needs which are unable to be met. Lead clinicians to be identified to enable trust and rapport to be developed considering communication difficulties. Implement reasonable adjustments to ensure continuity of acute care and reduce transfers between hospitals. Clear communication of patient location on transfer and transfer sheet identifying those individuals with a learning disability. Discussion with patient family and carers if not present about transfer.

Although many people who died did have Hospital Passports in some cases the information contained within was minimal and generally quite inadequate.

- **Recommendation**: for GP's to identify those who could populate and maintain good Hospital Passport with relevant and useful information. There is an opportunity to link the Annual Health Checks for people with a learning disability

There was reported that no consultation with family of the deceased and other professionals were taken when initiating original DNA CPR form.

- **Recommendation**: It should be clearly indicated which route the DNACPR has been put in place by (e.g. MCA) and noted the consultation with family members and other professionals involved.

Some evidence that Annual Health Checks were not delivered even though regular contact with GP and Hospital staff.

- **Recommendation**: GP's to develop a system which flags an individual is due an Annual Health Check and the system should continuously flag if the check has not been delivered.

Care home not being aware that their resident had a learning disability and therefore their interaction with individual could be improved engaging in a more positive and therapeutic way.

- **Recommendation:** Communication between medical, nursing, and social care staff should ensure that a thorough, patient-centred assessment of need and social background is undertaken and shared with care homes thus ensuring the provision of a comprehensive package of care. Care home staff should ensure they are aware of any complex needs and individual needs are met. The transfer of information between agencies to clearly state individuals have a learning disability to enable providers to adapt their services accordingly.

Reluctance of individuals with a learning disability to engage with health care and concerns related to capacity to make decisions and being fully aware of implications on health of those decisions.

- **Recommendation:** Awareness raising with professionals around the principles of Mental Capacity Act 2005. Agencies to work in partnership to achieve positive outcomes for those individuals who might find it difficult to engage in healthcare. Any decision made by individuals should be documented in their care record clearly.

Adherence to the principles of Mental Capacity Act 2005.

- **Recommendation:** Records should clearly show assessment of capacity. Involvement of family members in decision making if individual incapacitated. If individual is unfriended or family member unable to be involved or it is inappropriate for them to be involved an Independent Mental health Advocate should be requested.

Care co-ordination and joint working including for those with forensic history. Importance of multi-agency working for complex people with learning disabilities.

- **Recommendation:** Community Teams to provide a co-ordinated response which includes raising support needs as a priority and contingency planning. Improved access to Positive Behavioural service and working with probation to support and manage behaviour plans. Care co-ordinator roles have a remit to escalate any concerns via enhanced MDT or Dynamic Support Register as appropriate ensuring issues are addressed in a timely manner. Consider

complex multi professional clinics to include Neurology and learning psychiatry.

Recognition, intervention, and support for carers who experience stress.

- **Recommendation:** Ensure carers are always offered carer assessments which identify stress management strategies for family members.

Sourcing appropriate care providers who have the capacity and skills to meet needs of people with a learning disability and provide quality person centre support to those with complex needs.

- **Recommendation:** Health and social care teams to work collectively to engage providers and identify provision that can support and provide scaffolding when required thus avoiding placement breakdown and developing workforce capacity and skills.

Nursing staff in acute departments and ward areas may not be able to support people with a learning disability due to pressure of work and environment. Need for companionship, support and reassurance cannot always be met in the hospital environment.

- **Recommendation:** Staff should encourage families to remain with individuals who require a high level of support to ensure that they feel safe and secure in what will be an alien environment.

Movement between care settings, example of 2 hospitals, 3 local authorities and 2 care homes, in a short period of time resulted in distress to individual and family and concerns about management of physical health conditions.

- **Recommendation:** Assessment of need when placing individuals into care systems especially when this will result in a change of area, GP and Social Worker. Any assessment should include individual and family and be thorough and robust with a focus on individual need.

Child (those aged under 18 years)

Respite support for carers of children with complex care needs was sought but not available. For children who are on end of life pathway and have complex needs, hospice provision was not available. Good support from local authority and GP was provided in the community.

- **Recommendation:** Investigate the options available for respite and end of life provision for children and young people with complex needs. Offer additional training and support to GP's caring for patients with complex disabilities.

There is clear evidence that severely disabled children can be cared for at home with family and co-ordinated professional support.

- **Recommendation:** This should be enabled where possible, the complex care of disabled children at home supported by their families and relevant professionals, creating responsive care teams. Ensure training is available to staff to equip them for the demands of caring for severely disabled children in the community.

Good Practice Examples from Completed reviews

Excellent care and support provided to deceased and their family, the review identified high standard of care to the family of a child suffering from life-limiting conditions and should be used as an example to all families in similar situations.
Care home developed their own version of a Hospital Passport.

A double-sided sheet of paper which all the necessary things that someone involved in the care of an individual would need to know immediately. This is an easily accessible reference for those who are not familiar and could be used by nursing and medical staff to ensure good practice.

GP weekly attendance at Care Home to provide medical care to residents ensuring proactive care and support. Offer of continued GP support despite individuals lack of engagement, with the offer of door always open.

Partnership working between primary care and acute learning disability liaison teams thus providing a seamless service from primary care to acute care.

Strong MDT communication and working together with the GP at the centre of care co-ordination. This ensured good quality, consistent care plans in place that were responsive to changing needs and resulted in a peaceful end of life at home.

Independent supported living providers acting on symptoms in an appropriate way showing the importance of meeting individual health needs within a social care provider setting.

Importance of maintain long term relationships with learning disability services across the life course and not transferring to older people provision without their consent or scaffolding from learning disability services.

Importance of end of life care and support for family.

Recognising the needs of other people living together in supported living settings when an individual die. Bereavement support offered and available to those who are in these settings.

Examples clearly demonstrate the excellent care which can be given to people with a learning disability by organisations specialising in a person-centred approach to care.

Organisations commissioned to provide care for people in the community should be trained to a high level in the speciality to which they provide care.

Flexibility of acute provision to allow for visits to wards and departments prior to any treatment thus building confidence for patients and supporting engagement with attendance, advice, and treatment.

The development of a documented death care plan by Independent Supported Living providers to enable providers to follow the persons wishes at their funeral. To ensure that those who know the person best are involved in funeral planning.

Newcastle and Gateshead LeDeR Activity and Achievements in 2019

Newcastle Gateshead CCG has taken a system leadership role and established and embedded its own local LeDeR steering group supported by the North East and Cumbria Learning Disability Network (NE&CLDN) group to oversee the LeDeR programme of work and in particular action local improvements based on the evolving National and Local picture.

This is chaired by the Director of Nursing. Patient Safety and Quality within Newcastle Gateshead CCG and supported by the NE&CLDN. The steering group is well represented by health, social care and the 3rd sector and includes all reviewers of LeDeR cases in Newcastle and Gateshead.

Newcastle Gateshead CCG has formally aligned to the North East Regional steering group and through the local and regional groups learning is shared, priorities for service improvements are agreed based on interpretation of the national, regional and local themes arising from the review programme.

The NGCCG LeDeR group provides robust oversight of quality and governance processes related to LeDeR reviews.

NGCCG consistently receives all notifications of deaths of those with a Learning Disability from the national system and coordinates all LeDeR Reviews across Newcastle and Gateshead. To address the challenge of the backlog of reviews and

the limited resources to complete reviews the CCG have recently increased the number of independent experienced trained reviewers to deliver more capacity to complete reviews.

The CCG is working closely with North East Commissioning Support Unit who are commissioned by NHSSEI to deliver a specified cohort of reviews and support CCG's by reducing the backlog of cases, thus expediting any learning into practice in timely way.

Despite a significant backlog of LeDeR cases awaiting an in-depth review for all those who die when in the care of NHS providers, a Structured Mortality Review does take place and forms a part of the providers own internal mortality governance and learning arrangements. Thus, ensuring any key quality and safety issues relating to clinical practice are reviewed and acted upon in a timely fashion. These reviews are then also available to LeDeR Reviewers to support their work.

The CCG has strong links with the Child Death Overview Panel and has the aligned this with the LeDeR process so that learning is shared across the area.

The CCG worked closely with the Local Adult and Children Safeguarding Boards in the area to share learning and implement recommendations thus improving awareness across wider partners.

An event was planned early in 2020 to share learning for the North ICP however due to recent pandemic this has been postponed but will be rearranged through virtual platform. In the interim work continues implementing recommendations and sharing lessons learnt through existing partnership and developing systems at place.

The CCG commissions Skills for People in Newcastle and Your Voice Counts in Gateshead to support and help facilitate the development of an advocacy based confirm and challenge group to both challenge and support the local programme of work related to LeDeR.

Objectives and plans for 2020/21

Implementing phase 3 of the NHS response to the COVID-19 pandemic include key deliverables in relation to the supporting the care of people with a learning disability in addition to the existing requirement to continue to deliver LeDeR programme. Newcastle Gateshead CCG as below:

1. Accelerate preventative programmes which proactively engage those at greatest risk of poor health outcomes, including more accessible flu vaccinations, better targeting of long-term condition prevention and management programmes such as health checks for people with learning disabilities
2. Urgent action, in collaboration with local communities and partners, to increase the scale and pace of progress in reducing health inequalities, and regularly

assess progress. Focus on inclusion groups including people with a learning disability and or autism.

3. GP practices should ensure that everyone with a learning disability is identified on their register and that annual health checks are completed. As a minimum, by 31 March 2021 systems should aim to ensure that primary care practices reach an annual rate of seeing at least 67% of people on their learning disability register through higher quality health checks. It is particularly important to ensure people with a learning disability from a BAME background are known and included.
4. Reduce reliance on inpatient care for people with a learning disability and/or autism through development of robust community model.
5. Implement Host Commissioner arrangements for all inpatient provision.
6. LeDeR all CCGs are to be a member of Learning from Deaths report (LeDeR) steering group and have a named person with lead responsibility
7. There is a robust CCG plan in place to ensure that LeDeR reviews are undertaken within 6 months of the notification of death to the local area.
8. CCGs have systems in place to analyse and address the themes and recommendations from completed LeDeR reviews.
9. An annual report is submitted to the appropriate board/committee for all statutory partners, demonstrating action taken and outcomes from LeDeR reviews.
10. The CCG aims to continue supporting, developing and integrating the Local Confirm and Challenge Group in to the LeDeR Steering Group and associated programme of work. This group will be led by people with a Learning Disability and have appropriate Family member representation too.
11. The CCG will prioritise all new notifications in to the LeDeR System to ensure learning can be taken forwards in a timely manner. There will still be a parallel commitment from the CCG towards clearing the backlog of cases and work will continue with NHS England and regional colleagues to develop strategies to best to achieve this.
12. The GP lead for learning disability at the CCG and members of the primary care team will ensure that the learning from LEDER is disseminated to GP practices in Newcastle and Gateshead
13. The CCG will support the planned communication campaigns that are being led by the NE&CLDN. These campaigns are focused on the prevention of early death in those with a learning disability and include Get Well For Winter

Conclusion

Newcastle Gateshead CCG continues to be committed to delivering the LeDeR programme. The past year has been exceedingly challenging due to the lack of resources such as the availability of trained reviewers, time for reviewers to undertake the reviews due to competing work priorities and delivering preventative programmes to people with a learning disability in a safe way.

To support future delivery and recover the position additional reviewers have been trained from across the system and within the CCG. Robust governance systems have been embedded to ensure the quality assurance process and share learning from the reviews across the system.

Recommendation

Executive committee are asked to:

1. Note the content of the report and recommendations
2. Support the delivery of 2020/21 objectives
3. Note the ongoing challenges to complete timely reviews
4. Approve the annual report and support development of easy read version