

In this article...

- Health risks, comorbidities and mortality in people with learning disabilities
- Behaviour as a means of expression in people who have communication difficulties
- Examples of reasonable adjustments improving care for people with learning disabilities

Improving equality of healthcare for people with learning disabilities



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Key points

People with learning disabilities have poorer health and die earlier than the general population

Negative attitudes towards, and poor understanding of the needs of, people with learning disabilities still exist

Reasonable adjustments are needed so patients with learning disabilities are not disadvantaged

Relatives and carers are well-placed to pick up behavioural changes indicative of ill health

Good practice often involves thinking creatively about how to deliver care

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Abstract People with learning disabilities die, on average, 20 years earlier than the general population but many of these premature deaths could be avoided by giving these patients equal access to healthcare services. All nurses will care for people with learning disabilities but some may have inappropriate attitudes or lack the knowledge and skills to respond to their needs. This article looks at what nurses need to know and what they can do to reduce inequities in the health and care of this patient group.

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Too many people with learning disabilities die prematurely, often of preventable causes; reviews published over the past decade have repeatedly identified the same failures in healthcare (Learning Disabilities Mortality Review [LeDeR] Programme, 2018; Hosking et al, 2016; Heslop et al, 2013). People with learning disabilities have poorer health than the general population and experience significant barriers in accessing healthcare (Bowness, 2014). The failure of health services to meet their needs – and make reasonable adjustments to prevent them from being at a disadvantage – contributes to the health inequalities and inequities they experience (Hosking et al, 2016).

Although people with learning disabilities live longer than they used to (Coppus, 2013), there are signs their life expectancy is stagnating (LeDeR Programme, 2018) and their health and life expectancy are still poorer than that of the general population: they die, on average, around 20 years earlier (LeDeR Programme, 2018; Glover et al, 2017). The reasons for this are many and include health as well as social factors (Rickard and Donkin, 2018; Bowness, 2014), but a major

contributing factor is the difficulty they have in accessing timely, appropriate and effective healthcare. As such, it is vital to improve access to, and equality of, care across health and social services for this group. This includes earlier detection and management of physical and mental health conditions, as well as timely and effective treatment for more urgent and serious medical conditions (Hemm et al, 2015).

Findings and recommendations

The LeDeR Programme was commissioned by NHS England in 2015 to help local areas review deaths and improve services. This followed the final report of the Confidential Inquiry into Premature Deaths of People with Learning Disabilities (CIPOLD), which found that the quality and effectiveness of health and social care for this group was deficient (Heslop et al, 2013). Problems included:

- Fragmented services and poor communication between agencies;
- Lack of understanding of the needs of people with learning disabilities;
- Negative attitudes and unhelpful assumptions;

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- Failures to make reasonable adjustments;
- Poor compliance with the Mental Capacity Act 2005 (Bit.ly/MCA2005) (Heslop et al, 2013).

Although the LeDeR Programme found some progress since the CIPOLD review was undertaken – including improvements in hospital discharge arrangements and the provision of reasonable adjustments – most of its findings and recommendations echoed those of the CIPOLD and earlier reviews. So far, the LeDeR Programme has reviewed 103 deaths – that is less than 10% of the 1,311 deaths reported from July 2016 until November 2017 in England. Of the 103 cases reviewed, 13% were found to have been adversely affected by poor care, with one or more cases of “delays in care or treatment, gaps in service provision, organisational dysfunction, or neglect or abuse” (LeDeR Programme, 2018).

Fewer than half of the 1,311 cases (576) indicated an underlying cause of death at the time of notification. The most common underlying cause was disease of the respiratory system (31%), with 16% of the 576 patients having died from pneumonia and 9% from aspiration pneumonia caused by swallowing difficulties. The second-most common cause was disease of the circulatory system (16%), followed by cancer (10%). Sepsis was cited as a cause, or contributory cause, in about 10% of the 576 deaths (LeDeR Programme, 2018).

The LeDeR Programme report stressed the need to improve, in particular:

- Inter-agency collaboration and communication;
- Awareness of the needs of people with learning disabilities;
- Understanding and application of the Mental Capacity Act 2005.

The report also made nine national recommendations broadly similar to those of the CIPOLD (see Table 1), with the addition of:

- Mandatory learning disability awareness training for all staff, with participation from people with learning disabilities and their families;
- Furthering the integration of health and social care records;
- Raising awareness of the prevention, identification and early treatment of pneumonia and sepsis.

The LeDeR Programme report was followed by the launch of learning disability improvement standards for NHS trusts (NHS Improvement, 2018). Furthermore, strategies for improving the health and lives of people with learning disabilities in all UK countries are building momentum;

Table 1. Summary of LeDeR mortality review recommendations

Recommendation	Responsible agency
Strengthen collaboration and information sharing, and effective communication, between different care providers or agencies	Commissioners
Push forward electronic integration (with appropriate security controls) of health and social care records	NHS England
Health Action Plans, developed as part of the Learning Disabilities Annual Health Check should be shared with relevant health and social care agencies	NHS England Commissioners Providers
All people with learning disabilities with two or more long-term conditions (related to either physical or mental health) should have a local, named health care coordinator	Commissioners
Providers should clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision	Providers
Mandatory learning disability awareness training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families	Commissioners Providers
There should be a national focus on pneumonia and sepsis in people with learning disabilities, to raise awareness about their prevention, identification and early treatment	NHS England
Local services strengthen their governance in relation to adherence to the Mental Capacity Act, and provide training and audit of compliance	Commissioners Providers
A strategic approach is required nationally for the training of those conducting mortality reviews or investigations, with a core module about the principles of undertaking reviews or investigations, and additional tailored modules for the different mortality review or investigation methodologies	NHS England

for example, the recently published *NHS Long Term Plan* for England proposes specific actions to help tackle health inequalities affecting people with learning disabilities (NHS England, 2019).

What nurses can do

In England alone, more than a million people have learning disabilities (Public Health England, 2016), so all nurses – and not just those qualified in learning disability nursing – will encounter this group. Nurses can make a huge contribution to reducing inequalities and inequities of care for this group. This requires an understanding of their needs and when to refer them for specialist support, such as that provided by learning disability nurses. A coordinated nursing effort is particularly important in the face of the recent decline in registered NHS learning disability nurses in England and the sharp fall in the numbers of students in the field (Royal College of Nursing, 2016).

Inter-agency collaboration

The LeDeR Programme’s (2018) recommendations on how to improve collaboration and

communication between agencies include:

- Ensuring a health passport is created when a person with a learning disability is admitted to hospital (if they do not already have one);
- Improving signage in accident and emergency departments showing expected waiting times and what to do if the condition of a person with a learning disability deteriorates while they are waiting;
- Addressing poor or unsafe discharges from hospital at quality review group meetings;
- Ensuring good coordination of care.

Annual health checks

Another recommendation is for GP practices to investigate reasons why people have not attended their annual health check and inform community learning disabilities teams. Annual health checks for people with learning disabilities help identify unmet health needs and provide a baseline from which changes in health status can be measured (Robertson et al, 2014). However, there are still local variations in

Box 1. Health risks of people with learning disabilities

- People with learning disabilities are three times more likely to die from respiratory disease than the general population because of a higher risk of respiratory tract infections caused by aspiration or reflux due to dysphagia
- They are less likely to receive vaccination
- The prevalence of epilepsy among people with learning disabilities is 20% (1% in the general population)
- Dementia occurs in 22% of people with learning disabilities over the age of 65 (6% in the general population in that age group)
- People with Down's syndrome are at increased risk of hypothyroidism with a prevalence of 9-19%
- Around 40% of people with learning disabilities have some degree of hearing loss
- They are up to 200 times more likely to be visually impaired
- One in three adults with learning disabilities (and four in five of those with Down's syndrome) have unhealthy teeth and gums

Source: Bowness (2014)

quality and uptake. The *NHS Long Term Plan* for England sets a target to "improve uptake of annual health checks so at least 75% of those eligible have a health check each year" (NHS England, 2019).

An annual health check should result in a personalised health action plan, detailing the individual's health needs and actions required. With the person's permission, that plan "should be shared with relevant health and social care agencies involved in supporting the person" (LeDeR Programme, 2018). Practice nurses and community nurses have a role in this: they can review how patients are invited to attend their annual health check and whether reasonable adjustments are needed, such as providing written communication in an easy-read format and contacting non-attenders by phone.

Health passports and electronic flags

The LeDeR Programme (2018) report said providers should clearly:

- Identify people requiring reasonable adjustments;
- Record the adjustments required;
- Regularly audit their provision.

Electronic flagging systems such as hospital health passports can help. However, nurses and other staff do not always access patients' health passports, so consulting these, when they exist, should become standard practice (Tuffrey-Wijne et al, 2014).

The NHS in England will introduce electronic 'reasonable adjustment flags', which, with a patient's permission, can be added to their health record so staff know to do things differently. These electronic flags, planned for 2023/24, will have the potential to contain extra information about specific support needs and will be linked to annual health checks and action plans (NHS England, 2019).

Screening and health promotion

Annual health checks can lead to targeted actions to address identified needs, such as screening and other health-promotion activities (Chauhan et al, 2012). For example, in 2015, the community learning disability service at South Tyneside Foundation Trust increased the uptake of bowel screening in people with learning disabilities from 47% to 61% through measures such as easy-read communications, training for community staff and better use of mental capacity assessments (Bowler and Nash, 2015). Collaboration between the community learning disability team, the screening service and patients' GPs allowed GPs to compare the list of non-responders with the learning disability database, then follow up non-attenders.

Specialist support and liaison

Learning disability nurses can provide specialist support to help staff improve care and access to services. Nurses often seek the help of a learning disability nurse to get advice about:

- Reasonable adjustments;
- Increasing access;
- De-sensitisation work;
- Emotional support;
- Mental capacity and consent.

Many trusts now employ learning disability liaison nurses, who use their specialist knowledge to support staff working in acute hospital settings. These nurses have been shown to drive improvements such as the use of health passports; however, these posts are not universal and staff need to make the case for investing in them (Sheehan et al, 2016).

Healthcare providers also increasingly train learning disability champions – nurses or other staff members with an interest or

specialty in learning disabilities – who can help drive improvements at a local level.

Working with families

A common thread in many high-profile cases in which people with learning disabilities have died unnecessarily is that the family's views were not listened to or not communicated to other staff members. Nurses need to work more closely with carers and families – they will often know what is normal for the person and when something is wrong, so their views are key, especially when patients are unable to communicate what is wrong themselves.

What nurses need to know

Studies show that many healthcare staff, particularly in mainstream services, lack the knowledge, skills and attitudes needed to support people with learning disabilities (LeDeR Programme, 2018; Hemm et al, 2015; Heslop et al, 2013).

Impairments and comorbidities

People with learning disabilities are more likely to have impaired mobility, vision, hearing, understanding and verbal communication. For example, they may have difficulty:

- Recognising they have a health problem and communicating this to others;
- Reading or understanding written information;
- Consenting to undergo certain investigations.

These are all likely to affect their access to healthcare. They are also more likely to have more comorbidities and long-term health problems than the general population and are at higher risk of heart disease, epilepsy, diabetes and dementia (Bowness, 2014). In the CIPOLD final report, of 247 people who had died, nearly 97% had one or more long-term and/or treatable health condition and 17% had four or more (Heslop et al, 2013).

The risk of diseases other than long-term conditions is also higher; for example, the risk of gastrointestinal cancers is twice as high as in the general population (Bowness, 2014). Furthermore, because people with learning disabilities find it harder to access health services, they are more likely to present late and have unrecognised and unmet health needs. Box 1 shows the increased health risks to which people with learning disabilities are exposed.

Perceptions and attitudes

Staff sometimes wrongly attribute symptoms of illness and associated behaviours

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Box 2. Barriers to care

Created by health professionals

- Poor awareness and understanding
- Lack of training and education
- Assumptions and biases
- Diagnostic overshadowing

Created by organisations

- Rigid appointment systems
- Time constraints
- Reliance on written forms of communication
- Poor signage
- Lack of awareness of the Mental Capacity Act 2005
- Lack of inter-agency and inter-professional communication and coordination

Source: Bowness (2014)

to the learning disability itself. As a result of this 'diagnostic overshadowing', necessary investigations and treatments may not happen. For example, people with Down's syndrome are at increased risk of hypothyroidism, so if they are putting on weight and becoming more lethargic, they should be tested for it; however, diagnostic overshadowing means these signs are easily overlooked or ignored.

Nurses may fail to understand that people with learning disabilities may react in slightly different ways to other patients; for example, becoming agitated when asked to eat may be due to a bad toothache and the inability to communicate this in words. The LeDeR Programme (2018) report recommends that learning disability training for staff stress the

importance of behaviour as a means of communication. Nurses need to talk and listen to relatives and carers to establish a patient's normal behaviour and how they usually communicate – any changes could be a sign of pain or deterioration.

Healthcare staff have been shown to adopt less-positive attitudes towards patients with learning disabilities (Hemm et al, 2015). In one study in general hospitals, nurses said they were more likely to segregate people with learning disabilities from other patients because of the way they present, and less likely to undertake invasive procedures, spend time explaining treatment plans or ask them about pain (Lewis and Stenfort-Kroese, 2010). As well as barriers created by health professionals, there are also several that are created by organisations; both types are summarised in Box 2.

Reasonable adjustments

One of the most significant barriers is the lack of reasonable adjustments, which need to become standard practice. Questions nurses can ask to assess the need for such adjustments include:

- Does this person need a longer

appointment time?

- Could tests be done at home?
- Might the person benefit from visiting the facility first?

Reasonable adjustments may include dedicated pathways and specialist clinics. Sunderland Royal Hospital set up a weekly specialist asthma clinic for people with learning disabilities, which reduced emergency attendances by 25% (Stothard, 2017). The clinic was set up with no extra funding; appointments lasted 30 minutes and easy-read literature produced with a local support group was provided.

James Paget University Hospitals Foundation Trust created a VIP ('very important patient') pathway for patients with learning disabilities needing elective surgery – the initiative won the Learning Disabilities Nursing category in the 2017 Nursing Times Awards. Patients are supported throughout their journey and carers can be present at every stage, except during surgery. Adjustments include pre-operative theatre tours and a 'de-sensitisation kit' containing theatre scrubs so patients become familiar with the operative environment beforehand. The surgical

Box 3. Case study: increasing diabetic retinal screening uptake

In South Devon, a project conducted at Devon Partnership Trust to improve diabetic retinal screening for people with learning disabilities increased uptake from 81% to 96% in its first year. Five years on, uptake is still high, with 93% of eligible people on the retinal screening register screened in 2017-18.

Diabetic retinal screening is non-invasive but takes 20-30 minutes and requires the person to tolerate eye drops, sit still with their chin on a chin rest long enough for four photos to be taken, and follow requests to look left and right. The equipment is too large for home visits, but the procedure can be carried out in primary care and community hospital settings.

The project involved collaboration between specialist learning disability services, secondary eye care and the diabetic retinal screening team. Learning disability primary care liaison nurses worked with the screening team and failsafe coordinator at the local hospital to identify people who had not attended appointments or were unable to undergo the procedure. They then contacted patients, their families or carers (or the managers of care homes where patients lived) to establish individual barriers and assess reasonable adjustments needed.

Wherever possible, screening is now carried out in primary care and there is an efficient system for referring patients who have difficulty with the procedure. Much of the work of the primary care liaison team is around de-sensitisation, helping patients to overcome anxieties and staff to do things differently. Katy Welsh, learning disability primary care liaison team manager, says the project "is about delivering targeted support and drawing up care plans for individuals, but also getting staff on board and helping them think creatively in the way they deliver care".

Ms Welsh cites an example: "A patient with learning disabilities and autism, who refused to go to the GP surgery, was invited by one of our diabetic eye screeners to look round the hospital facility while staff were on lunch. The learning disability liaison nurse accompanied the patient, who, once on the premises, put his chin on the chin rest and decided he was happy to be screened there and then. The screener put down his sandwich and seized the moment. This is what our work is about: supporting people and finding ways to overcome barriers to healthcare."



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Box 4. Case study: ensuring safer emergency medicine care

Cardiff and Vale University Health Board has introduced an electronic flagging system to ensure safer and more-effective care for patients with learning disabilities who are admitted as medical emergencies. This followed an independent review into the deaths of three patients at University Hospital Llandough, as well as the 2014 launch, in Wales, of a care bundle setting out the steps general hospitals need to take to ensure timely, effective and person-centred care for people with learning disabilities (Bowness, 2014).

Patients on health and social care learning disability registers are automatically flagged up to staff working in hospital emergency units and clinical workstations. By clicking on an icon, staff can access documents including:

- The patient's traffic-light assessment or hospital passport – or, for those who do not have one, a template to fill in
 - An immediate care risk assessment tool, giving reasonable adjustments and acting as a basic care plan
 - A modified National Early Warning Score chart that ensures review and response within six hours for patients unable to undergo, or unwilling to allow, a full set of observations.
- Other information includes:
- Contact numbers for the learning disability team
 - Learning disabilities resources
 - A pain risk assessment tool.

Nurses can apply the flag to any person they believe has a learning disability but is not on the register. The system provides a daily list of all patients with learning disabilities admitted to hospital (which allows the project lead, Andy Jones, to make sure they receive appropriate care) as well as a weekly report of any death.

Mr Jones – who is a lead nurse in surgery, urology, ophthalmology, ear, nose and throat, and wound healing – has also secured an agreement with the Welsh Ambulance Service to take people with learning disabilities to University Hospital of Wales rather than peripheral sites. Work is in progress to train staff as local champions and secure funding for a learning disability liaison nurse. Mr Jones hopes some of this work will eventually be rolled out nationally. “We know patients with learning disabilities present late, deteriorate quickly and struggle to explain their symptoms. Staff may not have encountered a person with a learning disability before. Our work is about making the right thing the easy thing to do, and ‘handholding’ nurses in terms of the things they need to think about.”

team may visit certain patients, and sometimes even anaesthetise them, at home (Crossley et al, 2018).

Assessing mental capacity

Learning disability liaison nurses spend much of their time supporting nurses in relation to mental capacity assessments, which are governed by the Mental Capacity Act 2005 and other legislation.

Responsibility lies with the health professional providing care or treatment to determine whether or not a patient has mental capacity to make a decision about that care or treatment. Mental capacity can fluctuate over time: if a patient is found to lack capacity one day, this might not be the case in the future, so it needs to be assessed every time the question of capacity arises. Nurses (and all health professionals) also have a duty to make reasonable adjustments to enhance patients' decision-making capacity, for example, by

providing information that is easy to understand. The *Mental Capacity Act 2005 Code of Practice* (Bit.ly/MCACode) contains detailed information and case scenarios, about mental capacity in people with learning disabilities.

Conclusion

Despite numerous investigations and reports outlining the inequalities and inequities of healthcare provision for people with learning disabilities, approaches to adapt services and meet the needs of this patient group are still under-used in clinical practice. Some of the best examples of good practice occur when staff are prepared to think ‘outside the box’ and be flexible in terms of where, when and how care is delivered. Two such examples are described in Boxes 3 and 4. It is worth noting that measures to make health services more accessible can benefit all patients, not just those with learning disabilities. **NT**

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