

Nursing Practice Innovation Learning disabilities

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Nurses without a learning disability qualification can feel unsure of how best to care for patients with a learning disability but simple changes can have a large impact

Learning disabilities: reducing inequalities

In this article...

- › Things to consider in care for people with a learning disability
- › Five areas in which changes to practice can improve care
- › Case study showing how small changes can make a difference

Author Karina Marshall-Tate is project lead, The Estia Centre, South London and Maudsley Foundation Trust, London.

Abstract Marshall-Tate K (2015) Learning disabilities: reducing inequalities. *Nursing Times*; 111: 49/50, 12-13.

This article introduces five small changes that nurses who do not usually work in the field of learning disabilities can make to improve healthcare and reduce avoidable, premature deaths of people with learning disabilities. The changes are small, cost little and enable nurses to creatively meet the needs of their patients.

People with learning disabilities experience poorer health and multiple morbidities, have lower uptake of primary care services and experience significant health inequalities compared with the wider population (Emerson et al, 2012). The final report of the confidential inquiry into premature deaths of people with learning disabilities (CIPOLD) found that, on average, men with learning disabilities die 13 years younger than those without; women with learning disabilities die 20 years younger; and for every one person in the general population who dies of an amenable, preventable death, three people with learning disabilities will do so (Heslop et al, 2013). This extrapolates to more than 1,200 avoidable premature deaths a year (Emerson and Glover, 2013; Glover et al, 2012).

Five changes to make

CIPOLD found five areas that contribute to avoidable premature death in people with learning disabilities and five small changes in practice can have a positive impact on individuals' care and health outcomes:

- › Identifying people with learning disabilities, anticipating their likely needs and making reasonable adjustments;
- › Diagnosing and treating illness quickly;
- › Coordinating care and sharing information;
- › Understanding and adhering to the Mental Capacity Act 2005;
- › Listening to people with learning disabilities, their family and carers.

Anticipation and adjustment

Paper or electronic notes of patients with learning disabilities should be flagged to alert staff – from receptionists to clinicians – to enable equal access to services, such as:

- › Extending appointment times;
- › Enabling face-to-face booking of appointments (telephone or online “choose and book” systems can be highly confusing);
- › Making information easier to understand by using pictures or easy-read documents;
- › Changing the environment to reduce noise or lighting, or equipment that may appear intimidating, or even conducting the consultation elsewhere;
- › Avoiding lengthy waiting times (waiting in an unfamiliar environment can provoke anxiety). Fast-tracking the patient can avoid this.

Patient handheld records, like the hospital passport, can be extremely helpful to all clinicians working with people with learning disabilities. They detail in a quick, easy format the health needs and adjustments required to nurse that person. The learning disability liaison nurse or community learning disabilities team can also be contacted for advice and support.

5 key points

- 1** People with a learning disability die at a younger age than the general population
- 2** Compared with the general population, more people with a learning disability die a preventable death
- 3** Seeing the patient as a person is vital to providing high-quality care
- 4** Nurses should check which support systems are in place for patients with a learning disability
- 5** Staff must understand, and adhere to, the Mental Capacity Act 2005



Making information easier to understand can help patients with learning difficulties

The hospital passport is held and completed by the person with learning disabilities and their family or carers. It tells staff what they need to know about the patient to get the best out of the appointment. It also provides important information about their specific day-to-day health and care needs, and should be adhered to by all staff. The hospital passport allows all staff to provide person-centred care and maintains the patient's dignity. For more information and a template hospital passport, go to bit.ly/NHSHospitalPassport.

Diagnosis and treatment

As people with learning disabilities have poorer health than the general population and experience significant barriers to accessing healthcare (Michael and Richardson, 2008), they may present with late stages of common disorders.

Many disorders can be misconstrued; for example, symptoms of a thyroid disorder in people with Down's syndrome may be ascribed to a psychotic disorder, or an individual who becomes distressed after meals might be seen as "challenging" but, in fact, is in pain because of undiagnosed gastro-oesophageal reflux disease. People with learning disabilities should be treated as a high-risk group and receive proactive referrals to specialists. Do not assume the presentation is due to learning disabilities. Nursing staff should:

- » Act quickly to find out whether there has been a change in the patients' demeanour or physical health, what is happening and why;
- » Look for clues about changes to behaviour or mental health;
- » Beware of missing serious illness.

Care coordination

Sharing information about individuals' health and social care enables them to receive joined-up care – plans made in one service can be carried over and implemented in another. People with learning disabilities often use many services, with each one only being responsible for a certain aspect of their life. For example, they may have a support worker who you think sees them every day and can help with medication; in reality, the worker may only see them for one hour a week to help with household bills. Make use of patient-held records, such as the hospital passport.

The Mental Capacity Act 2005

In England, all adults are assumed to have capacity unless assessed as otherwise, and this includes people with learning disabilities. The law also states that all reasonable

BOX 1. CASE STUDY

June has learning disabilities and poorly controlled type I diabetes, for which she is seen regularly at her local outpatient clinic. Clinic staff have noticed she always arrives first thing in the morning, even though her appointments are not until late afternoon.

June sits in the waiting room, rocking and humming to herself, and becomes distressed as the day goes on. When the time comes for her appointment, she is too agitated to meaningfully participate in the consultation and is told to book another. This happens several times over a number of months. Concerned staff contact the local community team for learning disabilities (CTLTD) for help.

The CTLTD see June at her home over several visits to assess the situation. They find out that although she can read, she cannot tell the time and is fearful of missing appointments, as she has been told it is "very bad to waste NHS time", so she goes to the clinic early to be sure she does not miss her appointment. However, once at the clinic, June explains that she becomes upset because she does not know how long it will be until she is seen. She fears getting up to go to the toilet, or to eat or drink, in case she is called in. By the time her appointment comes around, she is so tired, hungry and desperate to use the toilet, things become too much for her.

Clinic staff worked with June and the CTLTD to make reasonable adjustments, so that she could use their services. They agreed to always give her the first appointment of the day so that she could arrive "after breakfast". When this couldn't happen, or if June needed to wait for results, they would help her to set an alarm on her mobile phone, so that she knew when to return to the department.

Clinic staff used the electronic patient records to "flag and alert" other departments about June's reasonable adjustments to access health services.

adjustments should be taken to aid comprehension and decision making, so you may have to adapt your communication to present material about a decision in an accessible way. If you still think a patient may lack capacity, a capacity assessment must be done.

Care and treatment should not be delayed, but if an individual lacks capacity, any decisions taken for them should be made in their best interests and with the least restrictive option (the course of action that would have minimum impact on the individual's right to freedom). If you are not sure about your patient's mental capacity, or what would be in their best interests and the least restrictive, then:

- » Discuss your concerns with your team;
- » Contact your local learning-disability liaison nurse or learning-disability team for advice.

All capacity decisions should be clearly and accurately documented.

Listening

People with learning disabilities are, first and foremost, people. Their views and opinions should be sought at every occasion, using means that are accessible and meaningful to them. The family members and carers who support them are likely to know them best, and their views and opinions should be listened to and accounted for.

If families and carers stay in hospital to care for a patient with learning disabilities, clear agreements should be put in place

about roles and expectations, such as offering breaks or meals, and outlining types of procedure and who – informal carers or staff – should carry them out.

Conclusion

Even if you are not a registered learning disability nurse you are highly likely to nurse such a patient during your career; how you choose to do so will have a significant impact on their lives. The case study above (Box 1) shows the positive impact that can be made when their needs are identified and met. **NT**

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- » Premature death in people with learning difficulties
- » [Bit.ly/NTLDDeaths](http://bit.ly/NTLDDeaths)

