

Managing the needs of people who have a learning disability

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A recent report from the National Patient Safety Agency has highlighted the risks facing people with a learning disability when they enter hospital. Recent policies and current patterns of care will see increasing numbers of people with a learning disability accessing generic health services, including hospitals. Nurses may need to develop suitable approaches to deal with the demand. This article offers some practical considerations.

A report from the National Patient Safety Agency (NPSA) has highlighted that people with a learning disability are at increased risk of physical and emotional harm while in hospital because nurses and other health care staff lack the skills to manage their needs (Hartley, 2004). Many of the concerns stem from problems with the communication of pain and symptoms and the person's inability to understand their disease or treatment. This can lead to the inappropriate use of, or lack of, informed consent for procedures, and misdiagnoses.

The NPSA recommended that learning disability liaison nurses should be set up in all general hospitals to ensure the safety of patients with learning disabilities.

Definition

Defining learning disabilities is never straightforward, but the Department of Health (2001) provides one of the best definitions, stating that learning disability is:

- A significantly reduced ability to understand new or complex information, or to learn new skills – 'impaired intelligence';
- A reduced ability to cope independently, which started before adulthood, with a lasting effect on development (DoH, 2001) – 'impaired social functioning'.

It is estimated that 1.2 million people have a learning disability where there is a mild to moderate effect on understanding, with an additional figure of approximately 210,000 people who have a severe learning disability (DoH, 2001). All 1.4 million clearly have special needs when they enter the health care system.

Despite these clear definitions there is often a high level of misunderstanding concerning learning disability even among nurses (for example, many confuse a learning disability with mental illness) and this may result in discriminatory practices (Slevin and Sines, 1996; Shanley and Guest 1995).

Communication

Effective communication and interpersonal skills are central to the nurse/patient relationship. Hospital separates people from their ordinary lives and if the patient has a learning disability this separation can be distressing.

Communicating with people with a learning disability seems to present difficulties for health providers (Thornton, 1999). They often fail to alleviate the sense of isolation experienced by people with a learning disability.

Dodd and Bruner (1999) identified communication as the most frequent barrier to people with a learning disability receiving effective health care. Nurses can implement the following measures to combat this:

- Form collaborative partnerships with carers and professionals, particularly Registered Nurses, Learning Disabilities (RNLDs), who are involved in your patient's life;
- Assess the patients' communication skills and their preferred method of communicating.

Behaviour

People with learning disabilities often have difficulty adapting to new situations, therefore admission to hospital may be more traumatic than for those who do not have a learning disability. This means there is potential for problematic behaviour.

The chance of behavioural 'problems' is increased if hospital staff have limited ability to interact with people who have a learning disability, and when they also have limited understanding of learning disabilities they will be unable to anticipate such problems (Slevin and Sines, 1996).

Nurses need to ask themselves: 'What would I do if I was in a strange place, with strange people, who do not interact with me?' Until they have the knowledge to answer this question, there is potential for people with a learning disability to become labelled and stigmatised. However, compliance with nursing interven-

BOX 1. ENSURING AN ACCURATE ASSESSMENT

- Where possible ask the patient questions because this will actively involve her or him and shows you are willing to interact.
- Do not assume that the patient cannot provide accurate information.
- Be prepared to spend time with the patient and allow for this.
- Have a carer or CLDN/RNLD who knows the patient present to clarify patient responses if required, but only seek clarification if necessary.

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BOX 2. ISSUES OF CONSENT IN PEOPLE WITH A LEARNING DISABILITY

- Can the patient express preference? Consent includes the right to say 'no' as well as 'yes'.
- Expression of preference is only valid if opportunities to choose are permitted, therefore you must provide valid information to empower the patient.
- Consenting to treatment also allows the patient a degree of control and therefore understanding.

tions is a key component to effective care and it is an achievable goal.

Preadmission

Where it is known that a person with a learning disability is being admitted, several things can be done before the admission takes place. It would be advantageous to:

- Talk to the patient, parents/carers and any health professionals involved about the patient's communication, and their likes and dislikes;
- Assess the person with a learning disability's knowledge of hospitals and address any potential fears;
- If possible, allow the patient to visit the ward/department with their carers and/or community learning disability nurse (CLDN) or independent advocate to meet the nursing staff;
- If staff are unable to do this, contact the community learning disabilities team, particularly if the patient has a CLDN or social worker, and ask if they could arrange it.

Preadmission visits can alleviate apprehensions and provide opportunities to meet staff. Generally people with a learning disability will come into hospital with their carers and/or CLDN/RNLD or social worker. When this does happen, let them help the patient to settle in. Nurses must use their professional judgement regarding the best time for this. Before the visit is over, nurses must ensure they have the patient's contact details.

Post admission

If a preadmission visit took place, ensure some familiar faces are on duty on the day of admission. Nurses should:

- Be interactive, communicate, remain patient;
- Make eye contact;
- Look and listen;
- Encourage carers to visit;
- Allocate more time for the patient;
- Enable any nurses who may have experience with people with a learning disability to care for the patient (but do not overuse this).

If the suggestions above are implemented then communication will follow. Indeed, carrying out as full an assessment as possible before admission can significantly reduce the trauma of the admission itself. It is important to ensure that an accurate assessment is made on admission. Table 1 details how this may be achieved.

Having a carer or CLDN/RNLD present who knows the

patient can be helpful as they may be able to clarify patient responses. This especially applies if the patient uses an alternative method of communication. Otherwise, perform the assessment as for all patients. Also, be aware that the activities of living (AL) assessment may not be the most appropriate in all instances and nurses should consider other health assessments, for example, the OK Health Check (Matthews, 1998).

Consent

Nurses need to consider the capacity and ability of the person with a learning disability to give informed consent (Green, 1999). This means undertaking a further assessment to determine capacity (Box 2).

This applies to all patients but particularly to patients with learning disabilities. This means:

- Having effective communications with people with a learning disability;
- Thorough assessment of needs so that valid and accurate information can be given;
- Allowing time (and having patience) to let the patient make her or his own choice wherever possible;
- Where necessary remember the patient has the right to have an advocate present.

Dean et al (1998) provide an excellent tool for assessing the capacity of people with a learning disability to consent. It is worth considering how the consent forms currently in use can be made more accessible to people with a learning disability, including using a universal symbol language such as Makaton.

Consent in respect of people with a learning disability is complex and can carry varying degrees of risk for both the patient and health professionals, and there will always be people who cannot give consent. However, this should not be an excuse for not attempting to gain consent, nor should it be forgotten that treatment without consent, except in exceptional cases, is an offence under law. Even when consent is gained, if no explanation of treatment is given to the patient, a charge of negligence can still be pursued (Green, 1999).

Conclusion

In the future more people with learning disabilities will be accessing a wider variety of health services, including those provided by hospitals. Previously the right to access has, unintentionally or otherwise, been denied despite people with a learning disability having health needs that are potentially more complicated than those of the general population.

To ensure that they do as much as possible to recognise risk when caring for people with a learning disability, nurses must:

- Recognise any prejudices and overcome them;
- Acknowledge that people with a learning disability have the same rights to health care as other users of the health service;
- Develop further understanding of learning disability;
- Collaborate with carers and local CLDN/RNLD. ■

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