Clear information can cut inequalities in learning disabilities

In this article...
- Healthcare providers’ responsibilities on information-giving
- How to produce easy-read information
- How to test information before distribution

Author Simone King is staff nurse, pre-admission assessment, Royal Bournemouth and Christchurch Trust.

Abstract King S (2011) Clear information can cut inequalities in learning disabilities. Nursing Times; 107: 4, 22-24. Healthcare providers have a legal responsibility to ensure that people with learning disabilities have their health needs met to the same level as the general population. As part of this, they should be empowered to make as many decisions as possible about their healthcare. Providing information in an easy-read format can help them to understand health issues and therefore make more decisions for themselves.

There are 1.5 million people in the UK with learning disabilities. Since many also suffer from a sensory loss and are prone to poorer health than that of the general population, they are more likely to need hospital treatment (Mencap, 2007).

In 2001, Valuing People addressed inconsistencies in these services (Department of Health, 2001), while Mencap (2004) emphasised that hospitals must fulfil their legal duty of care and that healthcare professionals should not rely on relatives or carers to communicate with patients who have learning disabilities. Healthcare providers must ensure these patients have their needs met and this includes having access to easy-read information.

Death by Indifference (Mencap, 2007) highlighted six cases in which a lack of knowledge and understanding of people with learning disabilities had resulted in their deaths. It said widespread ignorance about people with learning disabilities could be addressed by training healthcare professionals. In response, the DH commissioned a report that made 10 recommendations to ensure effective healthcare for those with learning disabilities (Michael, 2008). These emphasised the need for “reasonable adjustments” to improve access to health services, including provision of accessible information.

After consulting more than 10,000 people, the DH (2009) published Valuing People Now. It discussed how services should progress further and set priorities. These included ensuring people with learning disabilities receive a good service from the NHS, and that they should be given both choice and control over their own healthcare.

The Care Quality Commission (CQC) is reviewing how healthcare is provided for patients with learning disabilities and how it is assessed, particularly in acute general trusts. This includes evaluating communication methods, making sure patients are given information in the appropriate form. It will assess local performance and publish the results, developing action plans and recommendations for the worst performers.

Having had difficulties communicating with a patient (see case study), I decided to look at our trust’s policy for patients with learning disabilities to see whether any changes were required within the pre-assessment unit. Three relevant points were:
- Healthcare professionals have a responsibility to keep their knowledge of people with learning disabilities up to date;
- Information should be provided in a way that meets their needs and enables them to make choices and access services;
- At the pre-admission assessment these patients should be offered the opportunity, where possible, to familiarise themselves with the hospital.

Despite these recommendations I could find no easy-read information or communication aids within the pre-assessment area.

Effective communication
I needed to gain some insight into the communication methods used by people with learning disabilities and was surprised by the wide range available. They may use a mix of signing, body language, facial expression, gesture, photographs, pictures, easy words, symbols and objects to get their message across. This is known as “total communication” and means not relying on just one method of communication (Dorset People First, 2010).
People with learning disabilities have varied levels of understanding and therefore need communication to be adapted to their individual needs (Mencap, 2004). When they are to be pre-assessed for surgery, like anyone else they have the right to have their fears listened to, be able to understand safety instructions and be fully informed of the procedure and aftercare (Mencap, 2004). All reasonable steps should be taken to help communication between nurses and patients. The DH (2007) suggested this might involve using interpreters or communication aids to empower patients and enable them to make informed decisions about treatment.

The common theme emerging from Mencap (2007; 2004), the DH (2009; 2001), the CQC (2009) and the trust policy, seemed to be the need for enhanced communication skills and staff education. Anecdotal evidence from my own area suggests healthcare professionals often feel apprehensive when communicating with people with learning disabilities – mainly because they think they do not know how to. So it seems that it is not patients with learning disabilities who have a “problem” with communication, but healthcare professionals because they do not understand these patients’ needs and the way they communicate. Ultimately, nurses should be responsible for educating themselves and developing skills that will allow them to communicate effectively.

Improving communication

Nurses can take some practical steps to improve their communication with patients who have learning disabilities. Mencap (2002) suggested using short simple sentences, pictures or photographs and checking understanding rather than making assumptions. Patients also need the opportunity, where possible, to look around the department they will be admitted to familiarise themselves with the area and staff. Patients can also help hospital staff by making them aware of their communication needs. In many areas patients with learning disabilities are encouraged to use a Health Action Plan or a Health Passport (DH, 2001). These documents contain information such as allergies, past medical history, current health problems and who helps with those problems. They also include details of appointments, medication, preferred method of communication and eating habits. They record what individuals need to do to stay healthy, and specify any support they may need.

Scope (2010) suggested that documents like these enable people to take responsibility for their own health and to communicate accurately their health status and needs to others. Locally, patients with learning disabilities have a “Yellow Health Book”, which is a combination of the Health Passport and the Health Action Plan and also includes the Traffic Light assessment. This consists of three pages, the first (red) lists things health professionals must know about the patient; the second (amber) includes things that are important to the patient; the third (green) is for likes and dislikes. It particularly useful in emergency situations where there may not be time to read the entire health book.

Easy-read information

Easy-read information is written in a way that makes it easy to understand. Mencap (2002) suggested simple words supported by pictures are often an effective way to convey information to people with learning disabilities. It can be also used for patients with poor eyesight or poor reading skills, those who speak little English or who may be confused (Moss, 2008).

Method

It was vital to find out how to produce easy-read information to ensure it would benefit patients with learning disabilities. A toolkit on how to produce patient information (DH, 2003) stated the people using the information should be involved in developing it. If people with learning disabilities cannot be involved in producing easy-read information, they should at least be invited to give feedback before it is distributed.

Initially, I had a meeting with the trust’s disability lead nurse. I then contacted Bournemouth People First, a local charity and action group run by people with learning disabilities, which campaigns for services, provides training, and holds conferences.
“People find it easier to discuss blindness through a dog rather than a white cane” Chris Tye p28

**EASY-READ INFORMATION**

- Use simple everyday words.
- Ensure it contains clear instructions and facts.
- Avoid detailed explanations.
- Use short sentences and simple punctuation.
- Do not use abbreviations or jargon.
- Use at least 14 point font size.
- Use bold letters for emphasis rather than italics, block capitals or underlining.
- Use bullet points or boxes to break up text and highlight important information.
- Do not try to squash too much information onto one page.

Source: Mencap 2002

**USEFUL LINKS**

- Adaptable symbol: tinyurl.com/mayer-johnson
- Picture bank on CD: tinyurl.com/change-picturebank
- Easy-read information: tinyurl.com/easy-health; tinyurl.com/picture-southwest
- Photosymbols: tinyurl.com/photosymbols
- Widgit (symbol producer): tinyurl.com/widgit-symbols

We agreed that producing easy-read information would benefit people with learning disabilities. Having found overwhelming evidence, we started putting the information together.

Due to the variety of written information held in the pre-admission assessment unit I decided to begin by converting the most frequently used documents. These included: "Coming in for your operation", which initially made me feel I was trivialising the information I was omitting text, and patients who cannot be shown around these areas before admission. Finally, we also need to formally evaluate the effectiveness of the information.

**Recommendations**

This initiative is still in its early stages. Although we have produced some of the core leaflets, we still need to produce easy-read information for many more operations. We also need to depict the patient’s journey in photographic form from pre-admission assessment to discharge after surgery, for patients who cannot be shown around these areas before admission.

**Implications for practice**

We are making progress but need to raise awareness across the trust. I have given presentations to other pre-assessment areas, including the eye unit and orthopaedics and they will now be using the easy-read information. However, this sort of information should not be confined to pre-assessment or surgical procedures. I will therefore be liaising with nurses in such specialities as oncology and genitourinary medicine.

**Conclusion**

Patients with learning disabilities have the right to receive information in formats they can understand.

It is our responsibility as healthcare professionals to not only identify and familiarise ourselves with various tools to aid communication, but also to devise ways of using them effectively for our individual areas. When doing this we should always remember that simplicity is key.

**References**


Dorset People First (2010) Total Communication. tinyurl.com/Dorset-people-first


**The final touches**

I sent the draft copy to the trust’s graphic designer, who added extra colour, the trust logo and more pictures. I then arranged a meeting with the local learning disability group, to show the finished leaflets and ask for feedback. They were pleased with the leaflets and did not recommend any further work. The leaflets were then submitted to the trust’s Patient Information Group, to be approved for use within the organisation.

**Benefits**

The information leaflets enable patients to make informed choices about their care and be more independent in preparing for admission to hospital. They also give staff more confidence in working with this group, as they know they are giving information patients can understand, and ensure the trust will meet government and strategic health authority targets.

**Quick Fact**

1.5 million The number of people in the UK with a learning disability

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