IMPROVING ACUTE CARE OF PEOPLE WITH LEARNING DISABILITIES

This is a summary: the full paper can be accessed at nursingtimes.net

AUTHOR Allyson Kent, BSc, RNMH, is specialist practitioner and head of profession, learning disability nursing, Humber Mental Health Teaching NHS Trust. ABSTRACT Kent, A. (2008) Improving acute care of people with learning disabilities. Nursing Times; 104: 5, 32–33. This article reports on the development of a patient passport system for use by people with learning disabilities entering acute care settings. The passport contains information on patients’ individual needs to help hospital staff with the care-planning process. The aim is to help patients take part in the decision-making process where possible, as required by the Mental Capacity Act 2005, and to improve their experience of acute care.

Numerous studies have highlighted that people with learning disabilities have greater unmet healthcare needs than the general population (see Background box). The evidence base is well established, with areas of concern highlighted in the literature. However, while this is widely known within specialist services, it receives little or no attention in primary or acute healthcare services or as part of commissioning arrangements (NHS Quality Improvement Scotland, 2006). Death by Indifference (Mencap, 2007) highlighted the limited communication between primary, acute and specialist services.

Humber Mental Health Teaching NHS Trust has been working closely with Hull and East Yorkshire Hospitals NHS Trust to improve the patient experience for people with learning disabilities and their carers, supporting them to give informed consent where possible or to ensure that treatment is in their best interests. We have been working together for over five years, developing strong working relationships at all levels of the organisations.

Locally, people with learning disabilities are often admitted to acute wards through A&E or outpatient departments with little or no information on their previous medical history or how they normally present. This makes it difficult for nursing and medical staff to assess them adequately. The situation is exacerbated when patients are cared for by inexperienced staff members.

DISABILITY EQUALITY DUTY

Since December 2006 there has been a legal duty on all public sector organisations to promote equality of opportunity for all people with disabilities. All NHS trusts need to demonstrate that they provide services to all people irrespective of their disability.

Also, as part of their risk management standards, they must show how they care for people deemed vulnerable. The patient passport supports acute services in fulfilling this duty and improves the care and treatment of vulnerable people in hospital.

The patient passport can be completed: with the person/carers in their own home; by learning disability services staff before admission to hospital; within primary care; at pre-assessment; or in the acute hospital on admission. Unlike an official passport it is not intended to be kept for years. Instead it provides a current ‘snapshot’ of the person.

The passport is a simple tool to inform acute staff about important aspects of a person’s life, to help them to ‘get it right first time’ as required by The NHS Plan (Department of Health, 2000). It can hold a lot of information but need not necessarily hold all patient details. It can also indicate to acute staff where further information can be obtained if required, for example: ‘Please see my epilepsy management plan; the person who knows me best is Fred Bloggs.’

The passport is a double-sided A4 document that articulates the important aspects of individual patients’ lives. It seeks to reduce their vulnerability by making a connection between the people who know them best, such as parents, carers, community nurses or key workers, with those who know them least – acute staff.

It provides key information such as known medical conditions and details of any medications taken, which can help acute staff to understand patients’ needs and so develop appropriate care plans. It is vital that these details are checked with patients’ GPs on admission to ensure accuracy.

The patient passport has been developed on a database but is available on CD-ROM and can be downloaded and printed out on paper so it can be shared with acute staff.

It provides guidance for completion and holds a large amount of information that is known within specialist learning disability services but may not be widely known within mainstream services. It also includes details of relevant websites.

The CD-ROM provides access to a wealth of literature on consent, which is a real area of concern for people with learning disabilities and their carers.

IMPLICATIONS FOR PRACTICE

- If we are to reduce health inequalities and ensure that the needs of people with learning disabilities are met, all NHS staff need to understand and take responsibility for meeting the additional needs of this group.
- Learning disability nurses can provide leadership by working with this group, carers, service commissioners and colleagues in acute trusts and local authorities in order to ensure that patients receive care where their individual needs are respected.
- By developing mutual respect and trust, and seeking to learn rather than apportion blame, with ongoing review we have ensured that discussions on care delivery have changed practice. This process has also made a positive difference to the lives of people with learning disabilities.

PATIENT PASSPORT

The patient passport can be completed: with the person/carers in their own home; by learning disability services staff before admission to hospital; within primary care; at pre-assessment; or in the acute hospital on admission. Unlike an official passport it is not intended to be kept for years. Instead it provides a current ‘snapshot’ of the person.

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The passport database is held in one trust with password-protected access to it from the other. This ensures that both services work with only one passport, which staff in either trust can update at any time.

We are working to make the system accessible within primary care so the tool is available from the beginning of the patient journey. This would ensure that all who are involved in the care and treatment of people with learning disabilities understand patients’ individual needs.

THE MENTAL CAPACITY ACT 2005

One aim in developing the passport was to enable the trust to meet the requirements of the Mental Capacity Act 2005. This provides the legal framework to protect vulnerable people who lack the capacity to make decisions for themselves, and to help them to take part in the decision-making process as far as they are able (Department for Constitutional Affairs, 2006).

The patient passport lists the five principles of the act, which makes it a criminal offence to neglect the needs of people who lack capacity. This may be through a single action or omission or a series of repeated actions or omissions and can include ignoring a person’s medical or physical needs, failing to provide necessary healthcare or withholding medications or food and drink (DCA, 2006).

Decision-making and best interests

As a nurse leader in learning disability services, I became aware of an increasing number of adverse incidents in acute services, with proposed care and treatment not always being in a person’s best interests. Locally, a consent pathway was developed to help staff understand the legal framework and provide care and treatment in the best interests of people lacking capacity. This received positive feedback and has since evolved into two pathways:

- The first helps patients to think through their decision-making;
- The second assists staff so they can work through the best-interests process in a lawful manner.

The pathways have been approved for use across the acute trust, the specialist mental health and learning disability trust and both local authorities in the area. They are available within the patient passport and as posters on all wards and departments across all four service providers.

Trust and respect

The patient passport has enabled learning disability services staff to help nursing and medical staff at the acute trust to understand the additional healthcare needs of people with learning disabilities.

We also hold bi-monthly meetings where we review both policy drivers and the reality of care delivery within the acute hospital setting. This process has raised awareness of the needs of this patient group at all levels of the organisation. Open and honest discussions enable both trusts to take responsibility for implementing agreed actions in the clinical setting.

A key activity in recent bi-monthly meetings has been to review patient journeys. These may have been positive or negative, since we recognise that there are things to be learnt from both, as well as feedback that changes practice in the clinical arena.

Examining negative experiences was initially challenging. However, by focusing on the facts and individual needs of the patient concerned, we identified why adverse events occurred and together looked at what could be done differently in the future.

CONCLUSION

The health inequalities faced by people with learning disabilities are clear. The patient passport is a simple tool that articulates people’s individual needs and seeks to bridge the communication gap that often exists when patients are admitted to acute services.

The patient passport has evolved as a result of listening to the needs of people with learning disabilities, parents, carers and acute staff to ensure that it meets everyone’s needs.

Early feedback has been positive – parents and carers are able to articulate the person’s individual needs, while acute staff find it clear and simple. However, the tool is yet to be formally evaluated, which is planned for later this year. ■

REFERENCES


The National Patient Safety Agency (2004) identified that people with learning disabilities were vulnerable in acute hospital settings and at greater risk of adverse incidents.

When people with learning disabilities are admitted into acute hospitals, communication and issues of consent are two key areas of concern for patients, carers and healthcare professionals (Mencap, 2007; NPSA, 2004).

The NHS Plan (Department of Health, 2000) promised to improve the patient experience for all by designing the NHS around patients’ needs. However, Mencap (2007) has reported that the care of people with learning disabilities does not always take account of their specific needs.