Access to secondary care for people with learning disabilities

The key areas of need identified were to:
- Treat Mr Smith’s depression;
- Reduce the risks associated with his violent and aggressive behaviour;
- Explore options for accessing secondary health care for the operation to correct his hernia.

Mental health
The first priority was to reduce Mr Smith’s level of depression, as it was very difficult to engage him and make any effective progress with him in his depressed state. The consultant psychiatrist prescribed antidepressant medication. Mr Smith was closely monitored and reviewed for the therapeutic effects and side-effects of the medication. The antidepressants had a positive effect on lifting his mood, increasing his appetite and improving his sleep pattern.

Following improvement in his mental health, Mr Smith was more willing to engage with staff and participate in activities. The approach to care centred on building up therapeutic relationships, promoting trust in the nurse, cooperation, and some understanding and motivation for the treatment being proposed – for example, surgical hernia repair.

There was an emphasis on advocacy, promoting choice and decision-making. In this context advocacy meant ‘promoting client rights to choose and empowering them to decide for themselves’ (UKCC, 1998).

Patient consent
Mr Smith was assessed as having the capacity to consent and was keen to have the operation on his hernia. His capacity to consent was based on his ability to understand relevant information, retain the information and appreciate the personal significance of treatment information (Wong et al, 1999).

Mr Smith had received information and an explanation from the community nurse and surgeon in accordance with government guidelines covering the gaining of consent from people with learning disabilities (DoH, 2001b). This included an explanation of what the surgeon wanted to do, what might go wrong and how much better it was likely to make Mr Smith feel. To help Mr Smith with the decision-making process, professionals used simple language, pictures and an orientation of the hospital environment. Mr Smith was also made aware that he had the right to change his mind or withdraw consent at any time.

Preparing for surgery
There had been five previous failed attempts to persuade Mr Smith to have surgery, the last two supported by the learning disability team. Exhaustive efforts had been made to address Mr Smith’s phobia of hospitals and needles. During each of the previous attempts Mr Smith had initially consented to the operation, but had later become increasingly angry, abusive and violent. Eventually he had to be asked to leave the hospital to maintain the safety of staff and other patients.

Mr Smith’s family suggested ignoring his protests but it was explained to them that attempts to anaesthetise him when he was angry and refusing to have the operation could be regarded in law as assault and battery (Wheeler, 2003).

Reflection and making progress
To move forward it was important to reflect critically on past experiences and consider what could be done differently. Reflection can help practitioners take more appropriate action in future situations (Johns, 2000). The team reflected on achievements, such as desensitisation programmes in which Mr Smith progressed to visiting the ward and meeting staff without being aggressive. After further desensitisation work he successfully had a blood test. Networking and a good working relationship had started to develop between the learning disability team and hospital services.

On the days of his previous operations, Mr Smith had presented with classic signs of anxiety – profuse sweating, dizziness, increased breathing and in a heightened state of psychological arousal – as described by Garnham (2001). Mr Smith had been taking diazepam before admission to hospital but this had proven ineffective. It was identified that his fear of hospitals was probably a major trigger to his aggressive behaviour.

Other factors also contributed to the history of problems. On one occasion, for example, although Mr Smith had been first on the theatre list, there was a delay causing unplanned waiting time on the ward. This was compounded by the attitude of a staff member who was confrontational in approach and insisted Mr Smith put on the gown before going to theatre.

It could be argued that Mr Smith’s aggression was a response to a variety of cognitions, emotions and environmental factors. Some people with learning disabilities can develop limited and maladaptive behaviour patterns such as aggression as a means of coping with frustration and anxiety (Raghaven, 1998).

A person-centred approach
In order to promote a positive outcome for the next planned operation, a great deal of preparation was needed. It was important to readdress Mr Smith’s special

REFERENCES


A person-centred approach is needed to improve access to secondary health care for people who have learning disabilities. The Department of Health (1995a) drew attention to this issue when it reported that people with learning disabilities sometimes have problems maintaining their health because hospitals fail to work in an interdisciplinary manner with the specialist learning disability services. This article focuses on a case study where the difficulties in operating on a patient with learning disabilities and mental health problems were overcome through a multidisciplinary and patient-centred approach. The case study provides evidence of mainstream health staff and learning disability professionals working together and breaking down barriers to provide a seamless service.

The Department of Health’s document Valuing People (DoH, 2001a) insists that secondary health services should be accessible to people with learning disabilities. There must be no discrimination against people with learning disabilities and support must be provided to help patients to understand and cooperate with their treatment while in hospital.

**BOX 1. PATIENT PROFILE**

Alan Smith is a 34 year old with moderate learning disabilities. He is usually independent with self-help skills, however, prior to intervention he had been reluctant to wash or bathe. His sleep pattern became erratic. He also experienced loss of appetite, low mood and presented with increasingly aggressive behaviour that was destructive to property and self-injurious.

He has good receptive and expressive communication skills, although he can present as a very shy man and has difficulty relating to strangers. Mr Smith had recently experienced a number of significant life changes that had affected his mental health. In addition he was experiencing pain from a hernia and had been refusing treatment due to his fear of hospitals, needles and of dying from the operation.

Note: The patient’s name has been changed.

Several authors have concluded that health care staff experience difficulties in meeting the health needs of people with learning disabilities (McConkey and Truesdale, 2000; Fitzsimmons and Barr, 1997; Slevin and Sines, 1996; Shapley and Guest, 1995; Slevin, 1995). A number of reasons have been suggested including defici- cits in confidence, experience and communication skills. Until recently the NHS had made little extra provision to help health professionals manage this patient group (Shapley and Guest, 1996).

People with learning disabilities who present with difficult behaviour may be at particular risk of not receiving the treatment they need. However, a high court judge recently ruled that medical treatment could not be withheld from patients on the grounds of the severity of a learning disability or due to concerns over the management of their behaviour (Hartley, 2003).

It is evident that hospital staff require support to ensure this ruling is implemented. Staff need to be given opportunities to develop self-confidence through training and support in clinical settings (Fitzsimmons and Barr, 1997; Slevin 1995). Learning disability nurses should be available to support staff in hospitals as recommended in the documents Signposts for Success (DoH, 1999) and Valuing People (DoH, 2001a).

**A case study**

Alan Smith is 34 years old and has learning disabilities, challenging behaviour, epilepsy and mental health problems. He had been receiving support from the community learning disability team for the previous six years while living at home with his parents (Box 1). He was subsequently detained at a learning disability assessment and treatment unit under section 3 of the Mental Health Act 1983 on the grounds of mental impairment. Mr Smith’s behaviour included threats and actual violence to himself and others.

In addition to his known psychiatric problems, Mr Smith also had a long-standing bilateral inguinal hernia, which was at high risk of strangulation. It was thought that the considerable pain he had as a result, was a contributing factor to his depression and exacerbated his maladaptive behaviour.

**Care programme**

The Care Programme Approach (CPA) was introduced to provide a framework for effective mental health care (DoH and Social Care Development, 1990). The model was reinforced in the document Building Bridges (DoH, 1995b). In 1999 the DoH introduced the National Service Framework for Mental Health (DoH, 1999a) and Modernising the Care Programme Approach (DoH, 1999b).

All these frameworks provide important opportunities to set high standards for people with learning disabilities who have additional mental health needs, and to promote a seamless service (Roy, 2000). The CPA was adopted in a multidisciplinary style, including Mr Smith and his family. The community nurse took on the role of care coordinator.

**REFERENCES**

- **Department of Health and Social Care Development (1990)** The care programme approach for people with a mental illness referred to specialist psychiatric services. Joint Health and Social Services Circular. HC (90) LA SSL (90) 11. London: DoH.

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For related articles on this subject and links to relevant websites see www.nursingtimes.net
references


box 2. The assault cycle’s five stages

Stage 1 Trigger
Stage 2 Escalation
Stage 3 Crisis
Stage 4 Recovery
Stage 5 Post-incident depression

requests and build in other strategies to promote success. This is person-centred planning in practice, placing the patient at the centre of the planning process and recognising his choices (Rudkin and Rowe, 2001). A further protocol and plan was drawn up in consultation with Mr Smith and the learning disability service, working closely with the surgeon, anaesthetist and hospital ward staff.

Listening to the patient’s requests

Requests made by Mr Smith included tablets to help him feel calm. The consultant psychiatrist, community nurse and charge nurse met with the anaesthetist to plan a more effective medication regimen to reduce his preoperative anxiety levels. Anxiolytic medication can be used effectively in reducing anxiety and therefore removing a trigger to aggressive behaviour (Tardiff, 1989).

It was agreed that the previous dosage had not been effective in reducing Mr Smith’s anxiety. This needed to be managed if the operation was to succeed. The situation was discussed with Mr Smith who agreed to start taking the medication the day before the operation and an hour before going into hospital. Prior to the operation it was arranged for him to visit the hospital on at least 10 occasions with his primary nurse. This was to reduce anxiety by familiarising him with the environment, meeting ward staff and signing the consent form.

Other requests that were included in his plan and implemented were that an ambulance would be organised to take him directly to the operating theatre fully dressed. He agreed that staff could change him into a theatre gown once he was anaesthetised.

On arriving at the hospital he was reasonably relaxed, but a little frightened, this was managed by the familiar presence of the community nurse and a significant carer being with him as he went to theatre. No needles were used while he was conscious due to his phobia. He was anaesthetised with gas prior to the cannula being inserted. The operation went to plan and an epidural was placed to help with postoperative pain.

Managing challenging behaviour

In addition to the above steps the learning disability nurses met with the ward staff to discuss behavioural management plans. It was important for staff to understand the sequence of stages of violence and aggression as this provides the basis for effective action on their behalf (Harris and Hewitt, 1996). The five stages of the assault cycle, listed in Box 2, were fully explained (Kaplan and Wheeler, 1983).

The emphasis of the approach was to manage the triggers and prevent escalation. In practice this meant being non-confrontational and calming and responding positively to reasonable requests or needs.

Postoperatively, Mr Smith was separated from his fear of needles and injections by receiving pain management via an epidural pump. He was distracted from the hospital environment by staff giving him lots of praise about having gone through with the operation successfully and reassurance that he would be discharged as soon as he felt well enough.

Patient support

Staff from the learning disability service who were familiar to Mr Smith supported him throughout his hospital stay. They also had a role in supporting hospital staff and managing potentially violent and aggressive behaviour. Mr Smith stayed overnight and insisted that he was discharged the next morning; this was agreed as part of the plan. The ward staff provided advice on postoperative care to the learning disability staff. The GP and district nurse also provided follow-up care after discharge.

Mr Smith was extremely proud of himself after the operation and this helped to boost his morale and feelings of self-worth. It had been crucial to follow the protocol and plan to maintain Mr Smith’s trust and for him to feel in control of the situation.

Conclusion

The multiagency team agreed to Mr Smith’s requests and worked to enable him to have his operation through teamwork. This matched Wiles and Robinson’s (1994) definition of teamwork involving a group of people working together to achieve common health objectives. The case study also demonstrates effective interagency working across disciplines and services. Carrier and Kendall (1995) suggest that interprofessional work implies a willingness to share and indeed give up exclusive claims to specialised knowledge and authority if other professional groups can meet the needs of the person more effectively. The NMC (2002) states that nurses ‘should work in a collaborative manner with healthcare professionals and others involved in providing care, and recognise and respect their particular contributions within the care team’. The case study described is evidence of mainstream health care staff and learning disability professionals working together and breaking down barriers to provide a seamless service.

Mr Smith’s story also demonstrates how progress can be made towards meeting the government’s objectives in Valuing People (DoH, 2001a). It demonstrates that individuals with learning disabilities can be empowered to access health services designed around their individual needs with fast and convenient care delivered to a consistently high standard.

Mr Smith is now fully recovered from the operation with no postoperative complications. His mental health has also improved.