This special focus on bowel care was produced in partnership with the Association for Continence Advice

Not having the right bowel care is demeaning

THE PATIENT

Reg Penn, who is paralysed from the chest down, discusses his distress at the bowel care he recently received

I was 18 years old when my spinal cord was almost completely severed in a road traffic accident in 1975. I've some movement in my arms and can breathe by myself, but can't move my hands or legs.

A district nurse visits me once a day and carries out a manual evacuation. Normally this works fine. However, in 2009, due to a reduction in the amount of time the nurse was allowed to support me, I developed compacted bowels.

I was admitted to hospital and given a phosphate enema, which treated the problem. However, after a few days in hospital, where I was eating a normal diet, the problem started to build up again.

I asked the nurses: "What are you going to do about my bowels?" and they said they were not allowed to do manual evacuations – even though the doctor thought they should – because it was an invasive procedure and they could be sued if anything went wrong.

My mother offered to do the evacuation, but was told she couldn't for health and safety reasons. Staff knew I would only develop a compacted bowel again if I didn't have an evacuation, yet they were not prepared to do it. So they discharged me.

Last year, I was admitted to hospital with pneumonia and, again, developed compacted bowels because I had no bowel care. I was given the same excuses, just from different people.

Being in this situation saps your confidence. To keep your bowels moving you're loaded up with laxatives. This makes you frightened to breathe or cough. On one occasion, I was put in a hoist and left hanging in a sling with a bedpan on the bed beneath me. I spent that time in hospital hoping I'd get through the experience without making too much mess.

Nurses no longer seem to be doing manual evacuations, but you can't just abolish a procedure and replace it with nothing. Each hospital department needs at least one person trained in manual bowel care.

Some healthcare professionals don't seem to understand the importance of bowel care for people with spinal injuries. You're not just treating someone who needs a bit of help because they're feeling weak after an operation – you're dealing with people who do not have full sensations and need special support.

Not having the right sort of bowel care is a demeaning experience. I don't like to think about the incontinence side of my injuries as a manual evacuation is a degrading procedure. But it is one that has to be done. **NT**

EXPERT COMMENT

Nurses in spinal cord injury settings will find Mr Penn's report depressingly familiar. It seems nurses in general hospitals have a near universal lack of understanding of neurogenic bowel dysfunction (NBD) and are equally reluctant to manage it.

Nearly all individuals with spinal cord injury suffer NBD, which places them at risk of severe constipation and faecal incontinence. During rehabilitation, "bowel programmes", put them in control of their bowel, to restore dignity and maintain health. The commonest intervention in these programmes is manual evacuation or "digital removal of stool" (DRS).

A rumour persists that DRS is not acceptable, illegal or an "assault". This is not true. Not regularly emptying the rectum sentences patients to the indignity of faecal incontinence and the risks of impaction. For people like Mr Penn with high spinal cord injury, these include autonomic dysreflexia with risk of stroke and death.

The importance of bowel management to physical and psychological health, dignity and quality of life are clearly illustrated here. The nurses failed to meet a vulnerable patient's needs. They are at far greater risk of legal action by refusing to provide appropriate care to maintain dignity, continence and health than they would have been by providing DRS.

Learning points

- Digital removal of stool is safe, effective and acceptable for people with neurogenic bowel dysfunction (see MASCIP guide at tinyurl.com/spinal-cord-injury)
- Ensure at least some staff in your ward or unit are competent in DRS and that your trust's continence guidelines support its use appropriately
- Listen to patients and be their advocate

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