How to ask about bowel problems – and why it matters to patients

When nurses raise the tricky subject of faecal incontinence they’re really talking about quality of life

By Jennifer Trueland

Perhaps it is because it is something that most of us, from toddler upwards, have done alone and behind closed doors, but people are not good at talking about poo. That means that when something goes wrong with our bowels, many of us don’t seek help and, indeed, aren’t even aware of what help is out there.

Yet faecal incontinence is a relatively common problem – the National Institute for Health and Care Excellence (NICE) suggests that 1-10% of adults are affected by it, with between 0.5% and 1% experiencing regular faecal incontinence that affects their quality of life.

This shouldn’t be underestimated, says RCN bladder and bowel forum member Karen Irwin. She works as a specialist nurse at Manchester University NHS Foundation Trust and as a service manager and specialist nurse with the charity Bladder & Bowel UK, part of Disabled Living. She wishes that everyone, nurses included, would be more open to talking about faecal incontinence.

Restricts work and social life
‘It has a massive impact, and it’s a real quality of life issue,’ she says. ‘It prevents people working, it might prevent them from going out and socialising. They might well stop doing activities that they love doing – you might get someone who likes walking with their friends but is too afraid to go out with them.

‘It’s that constant worry of “where’s the toilet” – it’s always on their mind. They’re thinking “will somebody notice if I have an accident?” “will somebody notice if I smell?”

‘People only need to have one accident or one near-miss and it just knocks their confidence and you can understand that. And it goes across all ages: it’s not just something that affects adults.’

There are many reasons why someone might have faecal incontinence, and it is more common in some groups – such as new mums, people with neurological issues and people with cognitive difficulties. But there are also plenty of treatments and management strategies available, ranging from simple lifestyle changes to (in a small number of cases) surgical options.

One major issue is identifying people who need help – and equipping nurses to support those who do or signpost other services.

This is a topic that the RCN’s bladder and bowel forum will address in an updated version of its 2012 guidance on the management of lower bowel dysfunction. The new version, to be published this month, expands on topics such

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Christine Norton, pictured, King’s College London professor of clinical nursing research

The RCN’s continence resource
rni.com/continence-resource
Talking about bowel health

» All nurses, whether in acute, community, primary care or schools, should ‘think bowel’ when they are seeing patients

» Asking the trigger question ‘do you have a bladder or bowel problem?’ in a kind, empathetic way can give people the chance to talk about something they might be worried about, but have not felt comfortable to volunteer information about

» Give the person time to talk about their symptoms – it might be the first time that anyone has asked about it and it can help just to feel listened to

» Be aware that bladder problems can have an impact on bowel health and vice versa – if you are talking to someone about urinary incontinence, ask about faecal incontinence too

» Use natural language, particularly when talking to children and young people

» Don’t assume that faecal incontinence is inevitable, for example, as people age, and make it clear that there are options for treatment and management

» Educate yourself about specialist bladder and bowel services in your local area so that you can signpost or refer patients if necessary, and also so that you know when to refer

» Do not assume that pads are the inevitable solution for faecal incontinence, particularly in care home settings

who chaired the committee behind the NICE guidance on faecal incontinence in adults. ‘I used to see young women with childbirth injuries who wouldn’t walk their children to school because they were afraid of having an accident at the school gate.

Every day is a stay-at-home day
‘If you have a continence issue and it’s unpredictable, it’s the fear that it might happen today that makes every day a stay-at-home day. I would see people having to plan every bit of their lives around this and they were too scared to tell anyone what was going on.

‘These are people in their early thirties who are too scared to go out because they fear humiliation. Just being able to talk about it to someone is a huge relief.’

And then there’s constipation, she adds. ‘It’s almost as bad – it sounds trivial until it happens to you, but for a lot of people with quite severe constipation, it’s not having any control of gas, never knowing when they’re going to fart, never knowing if they’re

Raising awareness
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It is hoped it will help to raise awareness of an issue that has too often been neglected, even by specialist continence services.

King’s College London professor of clinical nursing research Christine Norton is also raising awareness of the impact of faecal incontinence. She is researching how people with inflammatory bowel disease can be supported to self-manage, but her previous research has shown the huge impact that faecal incontinence can have.

Professor Norton’s most recent clinical role was as nurse consultant (bowel control) at St Mark’s Hospital in Harrow, a specialist bowel facility. She applied for the post after working for many years as a continence nurse, then setting up her own continence charity, which had more of a focus on the bladder.

‘I just got hooked because there were so many people with problems – and such big problems. They were being largely ignored, even by the nurse specialists who were continence nurses – as I had been – who were focused on bladder problems.’

She believes there are several reasons why faecal incontinence has been relatively neglected. ‘It doesn’t have a natural medical home. With bladder problems you have urology and gynaecology, but the bowel problems are sort of dispersed.

‘It’s partly that “yucky” factor – because it is yucky – and partly because there’s so little research that people didn’t know what to do about it.’

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suddenly going to get the urge that they want to go, taking laxatives and then being housebound because they don’t know when they are going to work.

‘And there is a lot of abdominal pain and feeling wacky with it. Incontinence and constipation are each horrible in their own ways – and often what you try to do to help one will tip you into another.’

It is vital to be open about bowel problems and shift the culture, says Professor Norton. ‘We’ve been in that “don’t ask, don’t tell” scenario, where people didn’t want to open that can of worms because they wouldn’t know what to do about it.

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Professor Norton

‘Even with people with obvious likelihood of bowel problems, such as people with spinal cord injury or multiple sclerosis, people just weren’t asking,’ she says. ‘So, there’s been a culture of silence. That is something that we’ve found repeatedly in our research.’

Professor Norton says the vital message for nurses is that they should be proactive in raising it with patients. ‘We need to break down the taboo and ask, especially in patients with a predisposing issue, such as a neurological disorder. Nurses should ask patients in a kind and empathetic way if there’s a bowel issue going on, and be prepared to revisit the question over time. And if there is a problem, they need to act on it.’

Dramatic improvement possible

Although most bowel problems will be handled in the community, specialist services are also needed. Provision is variable, but there are some extremely good services out there, says Professor Norton.

One such service is run by Southern Health NHS Foundation Trust, which provides community health, specialist mental health services and learning disability services for people in the south of England. It is led by Alison Wileman, chair of the RCN’s bladder and bowel forum (formerly the continence forum) and an advanced nurse clinical specialist.

The eight registered nurses and nine healthcare support workers at this community-based service work within the local health and care environment to provide support for patients and for staff. Working in locality-based teams, they aim to triage referrals (which can come from any part of the service, or people can self-refer) within five working days. Patients are then seen within 28 days, either at home or in a clinic.

Often patients can see a dramatic and almost immediate change, just with a few lifestyle or diet tweaks, but in other cases they will have to be offered more specialist services, either from the community team or in secondary care. One of the best-regarded features of the service is its dedicated booklet that brings information about all aspects of bladder and bowel care together. This has been seen as an invaluable resource for patients, 900 of whom are referred to the service each month.

‘Think bowel!’

The four specialist nurses interviewed for this feature want nurses in all settings to ‘think bowel’, and to raise awareness of potential problems – and empower patients to benefit from help and support. But there’s also a wider societal message, and that’s to be more open about natural bodily functions.

‘A lot of families grow up not mentioning this at all,’ says Professor Norton. ‘We don’t talk about poos and bowels, and as soon as you can [after potty training] you get it all privatised behind closed doors and it’s never mentioned again.

‘We can all play a part in changing that.’

Jennifer Trueland is a health journalist

RCN bladder and bowel forum
tinyurl.com/RCN-bladder-bowel

Ever heard of the Poo Ladder?

Children experience faecal incontinence too, and it’s almost always caused by constipation, says paediatric specialist continence nurse Brenda Cheer, who works for ERIC, The Children’s Bowel and Bladder Charity.

However, as with adults, it can slip under the radar because many health professionals simply don’t ask the right questions.

‘People are reluctant to talk about wee and poo,’ says Ms Cheer, pictured. ‘In general society, we don’t talk about it after potty training, and that promotes ignorance.

‘But children do have faecal incontinence – although we tend to call it soiling – and there is lots that can be done about it.’

Unfortunately, says Ms Cheer, opportunities to pick up potential bowel issues in children and young people vary. School nurses, who used to have continence as part of their remit, no longer have that responsibility, and specialist services at a local level are variable.

Use age-appropriate language

She also would like to see questions about bowel issues included in the age/stage checks conducted by health visitors, so that problems can be identified and treated at an early stage. Using appropriate language is also important, she says. ‘People talking to young children will probably ask about poo, but with older children they might ask if their bowels had opened that day. The young person might say yes, but they don’t know what they’ve said yes to – the language is too stilted.’

The charity has developed a resource, charmingly called the Poo Ladder (pictured), that gives health professionals a clear view of escalation of treatment. This ranges from lifestyle changes to a stoma.

As well as the Poo Ladder, the ERIC website offers a range of resources and publications on tackling bowel issues in children and young people eric.org.uk