

Why has Suffolk's Safeguarding Adults Board commissioned these *notes about constipation*?

Its starting point is the experience of two adults with learning disabilities, "James" and "Amy" whose deaths are associated with chronic and severe constipation. These notes may be read as a preface to the resulting reviews of the circumstances leading up to their death. Also, it has been produced because the topic of constipation cries out for acknowledgement since it is in danger of being undiagnosed and untreated until it is too late.

The Safeguarding Adults Board is keen to present these notes as "open source," that is, as a means of inviting ideas and suggestions from people with learning disabilities, their families and friends as well as health and social care professionals, including those who are supporting people with learning disabilities on a day to day basis. The Safeguarding Adults Board is especially keen to add to these notes the experience of making progress on a topic which has been regarded as embarrassing and "off limits" for too long.

So...

We would encourage you to read these notes in the spirit in which they are offered – as ideas to get you thinking and questioning ways of providing intimate care and support to people with learning disabilities. Since some contributors to the reviews about Ben and Amy admitted that they did not know about the insidious consequences of being constipated, we begin with some ideas about language. Even though we all have some experience of what it is to feel constipated, it is not a topic that readily features in general discussions about our well-being, for example, perhaps because we are cautious about using particular words.

The words we use...

It is a major developmental achievement being able to "go the toilet"- being (potty) trained, being 'dry' and no longer wearing nappies. A further milestone involves going to the toilet without requiring assistance to wipe ourselves, adjust our clothing, and leaving the toilet "as others would wish to find it," or being reminded of the significance of privacy. Our families introduce us to the language of the toilet and over time this may be embellished by our peers. While some families may be very concerned to hear particular descriptions of "going to the toilet" from their children, this may be the everyday usage of other families, for example, most of us understand: *having a poo; doing a number two; having to "go"; having a cack/ shit/ crap/ shat/ dump/ a move; going to sit; opening bowels; having a plop; and doing poopy plops*. Most of us understand also that some of these terms and similar "toilet language" may be associated with being rude, offensive or funny.

The experience of being constipated and/or full of wind similarly has a rich vocabulary: *bunged up; can't go; want to poo but can't; blown out; flatulent; breaking wind; passing*

wind; popping; letting off; letting rip; having a blow; windy pop; blowing raspberries; farting; bottom burping; bofting; rumbling; pumping; trumping; back firing; making smells/a rude noise; silent but deadly/violent; and gassed.

Things to consider: what other words do you know? Are you familiar with the words and terms used by the people you support? How might you find out what words they use or respond to?

Don't forget to flush...

Most of us acquire bladder and bowel control skills as children, along with expectations about when and where we may relieve ourselves and how to deal with bodily waste. We may laugh as others recall their experiences of having to get to the toilet urgently because of “an upset tummy” or more accurately diarrhoea (also known as *the runs; the shits; the squits* and *Delhi belly*). Such accounts are unlikely to be shared if the narrator lost control of their bowels and did not get to a toilet in time. Or, if such a scenario was disclosed, we may empathise with the sense of shame, humiliation and embarrassment – not merely because of the shock of seeing an adult lose control of their bowels (*involuntary soiling*) and soiling their clothes – but also because of the unmistakable accompanying smell. Also, we may experience some empathy with the undoubted disgust of onlookers.

There are people whose daily lives include the management of their incontinence – whether of urine (*wee; pee; waterworks; number 1* and *piss*) or faeces. They may have delayed seeking medical assistance because of feelings of shame and distress. They may also have become accustomed to carrying changes of underwear, frequently changing and washing their underwear; and always carrying materials with which to wash after “an accident.”

Things to consider: How do you suppose wearing incontinence pads affects the way people see themselves? What impact does using incontinence pads have on the transition to adulthood?

We may decline to enter a public toilet which smells, even though we may be about to open our bowels, and we may experience disgust if the previous occupant has not flushed the toilet. We may have learned the rule “If it’s brown flush it down. If it’s yellow let it mellow.” While we may think this is fine in our own homes, we are unlikely to adhere to it when we visit other people’s homes or work in other people’s homes. (It should be noted that menstruating women (*having a period; time of the month*) typically flush.)

What does this mean for people with learning disabilities?

The challenges faced by people with learning disabilities and complex support needs in making sense of their world are not known. To begin to understand their world requires attention to all that they are doing in context rather than considering fragments of behaviour. They are likely to require sustained and supportive assistance in developing skills in self-care, including eating, going to the toilet, dressing, bathing and communication. Some are subject to seizures and they may also live with sensory losses, physical disabilities, mental health problems and chronic conditions – such as constipation. However, their differences tend not to reveal themselves as a crude distinction between what they can and cannot do. Individually, they have unique forms of communication, ways of demonstrating awareness and understanding of others and unique means of communicating their intent and purpose.

Many people with learning disabilities will require lifelong help. However, this diverse group of citizens is more like non-disabled people than unlike them. Patients with learning disabilities experience some familiar influences when thinking about their health, namely, their families, the people with whom they spend their days, their experience of caring for others, their past experiences in health settings, and television programmes such as *Casualty*, *Holby City*, *ER* and *24 hours in A&E* for example. Some patients with learning disabilities may have been sexually assaulted and this may not be known because they may not have had the language to describe what had happened – or were too distressed to do so. Such experience may stir deep feelings, fears of some interventions, embarrassment or may even create high expectations. We do not yet associate high expectations with the health care of people with learning disabilities.

Mothers in particular have always had a major role in lives of their daughters and sons with learning disabilities. Parents in general do not easily relinquish the care of their daughters and sons because they are uncertain that provider services have the requisite skills and compassion to address their care and support needs. Some parents have long memories and they may recollect services which were insensitive to their offspring when they were children. Most parents would wish not to live with continuing uncertainty about the future care of their adult children, most particularly since they witness a lot of discontinuity in terms of service personnel which, in turn, results in disrupted relationships and lost information. The following refrains may be familiar to social workers and service

commissioners, *How many times do I have to tell them that X: must wear her glasses/he has to have his anti-convulsant medication/needs someone to check his hearing aid before inserting it/ vomits most days and because of the danger of choking, needs someone to be with her/needs reminding to stop eating because he will overeat and he's prone to putting weight on/needs at least an hour to feed himself. He cannot be rushed/cannot tell you when she's in pain, so you have to be attentive to how she is.* Statements of what individuals require may also be described as “non-negotiable,” that is, it is essential that they are attended to.

Things to consider: what are the “non-negotiables” of the people you support? How might you ensure that these are known by support staff now and in the future?

People with learning disabilities may be taking medication with constipation as a side effect and/or they may have conditions which are associated with constipation, for example, hypothyroidism. The use of prescribed drugs should be carefully monitored since people should not remain on drugs for long periods where the positive effects are questionable. Being immobile can result in constipation – which is why exercise is so important for all of us, not least since the activity levels of adults with learning disabilities resemble those of very elderly people.¹ Tiredness and lethargy which are not associated with activity or exercise should always be investigated.

Rectal digging and faecal smearing (also known as scatolia or *diaper digging* and *paint the town brown*) serve many purposes – including trying to relieve abdominal discomfort or a sensation of incomplete bowel evacuation. Smearing and incontinence may also be disguised means of communicating sexual assault(s).

Things to consider: Do you/does your service use symptom – checker websites? Do people's doctors advise *what* you should be monitoring and *what to do* if you suspect that there are side-effects?

¹ See for example, https://www.improvinghealthandlives.org.uk/uploads/doc/vid_7479_IHaL2010-3HealthInequality2010.pdf

Some facts about constipation

Constipation affects people of all ages. Definitions of constipation generally have three elements:

- Difficulty in emptying the bowels
- Infrequently passing faeces
- Descriptions of faeces, e.g. hard and lumpy, large and small²

The frequency with which we empty our bowels varies a great deal. “Counts” of bowel movements only make sense if we know what is normal for each of us, for example, once a day or once every three days?

When we are constipated we might feel the need to strain when sitting on the toilet, we might develop stomach ache, feel sick and bloated and even lose the desire to eat. We might appear to be agitated.

Measuring intestinal transit time, that is, how long it takes for food or markers that show up in x-rays to work through the body is one procedure used to diagnose constipation and/or rule out other complications.

Chronic or long term constipation increases the risk of developing faecal impaction, that is, the build-up or dried, hard faeces in the rectum and anus. This worsens the constipation and can result in bleeding from the anus and swelling of the rectum for example. The bleeding might result from a tear through the lining of the anal canal or around the anus (an anal fissure) or haemorrhoids – also known as piles – which are swollen blood vessels in the lower rectum and anus.

If this impaction is untreated it can cause “overflow incontinence” that is, where a watery diarrhoea-like fluid leaks around the impacted and hard faeces. This may be mistaken for diarrhoea and it may even be assumed that the person is no longer constipated. This would be incorrect.

A wide range of laxatives are used to treat constipation. These include suppositories which are inserted into the anus and enemas, where liquid treatment is inserted into the rectum. It should not be assumed that because a person is taking laxatives that their constipation has been resolved.

² See for example, the Bristol Stool Chart <https://www.nice.org.uk/guidance/cg99/chapter/appendix-d-bristol-stool-form-scale>

Things to consider: how do the people you support let you know that they need to go to the toilet? How do you know when the people you support need to go to the toilet? How do you find out about the normal bowel frequency of the people you support? Do you know what to do if the people you support become constipated?

Preventing constipation

Typically, eating breakfast initiates the urge to have a bowel movement as the intake of food gets the digestive system moving. It is important that we respond to the urge to go to the toilet when we feel the growing urgency – and we should give ourselves enough time.

Attention to diet and fluid intake is the first step in preventing constipation. Diets without enough fibre intake, enough vegetables, fruit, rice and bread for example are unlikely to maintain normal bowel functions. Also, drinking plenty of fluids, particularly when it is hot, and taking regular exercise are important.

Suffolk Safeguard Adults Board would like to hear your views about these notes; and your experiences of promoting bowel health

Please send us your contributions and help us to develop this resource.

Contact:

Some useful references

<https://www.nice.org.uk/guidance/CG49/chapter/introduction> (accessed 12 August 2015)

<http://www.nhs.uk/conditions/Incontinence-bowel/Pages/Introduction.aspx> (accessed 12 August 2015)

<http://my-bowel.co.uk/bowel-problems-and-solutions/bowel-faecal-incontinence/>

(accessed 14 August 2015 – this contains visual displays of the passage of food through the digestive system)