

# Constipation

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## Dying for a poo

**Constipation can kill. And it is a condition which can affect up to half of all people with learning disabilities. That's why the Learning into Action working group on constipation wants to get more people talking about the problem.**

Unrecognised and untreated constipation in people with learning disabilities has been known to cause death. This is rare, but as an entirely avoidable, and hence unnecessary cause of death, we should do all we can to stop it happening.

Constipation can cause pain and distress, hence the effective monitoring and management of constipation in people with learning disabilities is essential to maintain their safety and well-being.

While it is thought that about 10% of the general population suffer from constipation, between 20 -50% of people with learning disabilities are affected. This results in unplanned hospital admissions which could be prevented by effective interventions in the community. The Public Health England (2016) report states that 10% of district nursing time is spent on the management of constipation. The RightCare data on admissions (2017-2018) shows more than £24 million was spent on admissions due to constipation. There is the potential to save as much as £145 million a year here. And with effective lifestyle interventions, the laxative bill of £101 million a year could also be reduced.

The Learning Disability Programme, NHS England, has established a working group of experts by qualification, professional experience and life experience. They are working together to raise the issue of the risks constipation poses to people with a learning disability.

Two information sheets are currently being prepared – one to inform families and carers and the other aimed at healthcare professionals. The intention is to develop a memorable sheet which conveys the risk of constipation as well as how to recognise the condition, treat and prevent it in a timely manner.

It is hoped that these information sheets will be put on notice boards in care homes and GP surgeries across England to trigger the thought:

**THINK and TALK CONSTIPATION – it can SAVE LIVES!**

### Diagnosis and recognition

It can be difficult to identify and diagnose constipation in a person with learning disabilities. There is a risk of a vicious cycle developing – with worsening constipation, culminating in a large (often loose) stool, which then maybe thought to be 'diarrhoea' and laxatives can be stopped. As a result, stool accumulates again, and the problem recurs. Over a period, the bowel becomes hugely distended, storing very large volumes of stool and the problem becomes very uncomfortable (and risky) for the sufferer. Deaths have occurred because of bowel ischaemia and bowel perforation.

Chronic constipation can prove to be surprisingly difficult to diagnose and faecal overflow/incontinence can be wrongly interpreted as diarrhoea, and the presence of the backed up stool can be overlooked.

Family members, carers and paid supporters have a key role in early recognition of constipation and prompt treatment and we must empower them with the knowledge that faecal soiling can mean constipation and not diarrhoea.

### Prevention and treatment

Prevention of this condition is key, and the information sheets aim to emphasise the importance of a healthy diet with adequate fibre, fresh fruit and vegetables, regular exercise, an active lifestyle and a good fluid intake.

Laxatives do not cause the bowel to be lazy. So in addition to lifestyle changes, laxatives may also need to be prescribed and administered regularly in people at risk of developing chronic constipation. Bowel monitoring is essential to ensure the optimum dose of medication is given.

People with learning disabilities are frequently prescribed medications which add to the risk of constipation, including anti-depressants, anti-psychotics and analgesics. There needs to be an increased awareness of this additional risk and effective monitoring when people are prescribed a cocktail of medications.

It is also important to encourage good bowel habits such as raising the feet onto a low stool ('squatty potty') which is known to help empty the bowel.

The recognition and management of constipation is the responsibility of everyone who cares for a person with learning disabilities as it is a condition that benefits from a holistic approach with multidisciplinary input.

It is hoped that the constipation resources will be ready for distribution by the end of March 2019.

**Written by Nicola Payne, London Clinical Champion for the LeDeR programme and chair of the working group on constipation, with assistance from Jane Kachika, RightCare Pathways lead, and family carer Sheila Handley.**

## How can anyone die from constipation? Richard did.

**He was just 33 years old. Failings across health and social care led to his sudden and untimely death, leaving his family devastated. His mother Sheila Handley explains what went wrong and why it should never happen again.**

My family were left stunned and disbelieving at the sudden and unexpected death of my son, Richard. It happened in November 2012. He was only 33 years old. Within about 12 hours, he'd gone from being "ready for discharge from hospital" following a manual evacuation of his bowel, to being dead. Questions filled our heads: how could anyone die from constipation?

From the start we needed to understand how Richard came to die but, even more importantly, we were driven to fight to ensure that others should not die from constipation.

Richard had suffered from constipation throughout his life; it's fairly certain that he had Hirschsprung's disease, a rare disease that is present from birth and affects the nerve supply to the bowel and results in severe difficulties in passing stool, rather than functional constipation. We were told that, as it was being controlled by diet, fluid intake and exercise, it was better not to subject Richard to the tests required and a possible operation.

Hirschsprung's was never confirmed, but we were devastated to learn, during Richard's inquest in early 2018, that an operation could have corrected the problem. His lifetime of embarrassment, discomfort and pain could have been prevented. I now believe this to be an example of the health inequality experienced by those with a learning disability.

Aged 18, Richard moved into respite care because of deteriorating mental health. Within three weeks he needed the first manual evacuation; after four months it had to be repeated. Following a lengthy period of assessment, a care plan was produced. **Everything** needed to keep Richard safe and well was included. To our delight, a residential care place five minutes from home became available. Staff worked closely with us to ensure they fully understood Richard's needs. All was well.

### What went wrong?

- The perfect care plan was changed without any reference to family, GP, psychiatrist or the commissioners of care.
- Essential knowledge about a health condition was lost over the years.
- The link between physical and mental health was not considered.
- Constipation wasn't even mentioned on Richard's Hospital Passport.
- There was no active monitoring of Richard's constipation despite both the GP and psychiatrist prescribing medications with side effects that included constipation.
- Nobody was taking lead responsibility for coordinating Richard's care. Professionals and carers worked in isolation from one another.
- The GP and psychiatrist didn't ensure that carers had a good understanding of effective constipation care.
- After the change to supported living, social services failed to carry out any placement review or monitoring. They did not ensure that the change was suitable for Richard.
- Junior hospital doctors failed to follow the Early Warning Score protocol when Richard's condition was deteriorating. They denied access to senior clinicians with more experience and the seniority needed to requisition the tests which would have informed the treatment and maybe changed the disastrous outcome for Richard.

If the five agencies involved in Richard's care had done things differently, I believe he would still be alive. Most of the failings can be attributed to a lack of knowledge and understanding of the devastating consequences of poorly managed and treated constipation.

After six years of questions, complaints, responses, investigations, a serious case review and finally an inquest I know that there were gross failings and missed opportunities in the care Richard received. His death could have been avoided. Easy to say "lessons have been learned", but **action** is essential to keep others safe. Constipation should not kill.

## 'Project Poo' leads to reduced hospital admissions

**Constipation is a problem for a significant number of people with learning disabilities. But it doesn't have to be. Katie Hougham explains what actions one liaison service has taken and how it's making a noticeable difference to lives.**

Two people with learning disabilities died in hospital in Surrey as a result of untreated constipation in 2018. The county's learning disability liaison service also observed a number of other people being admitted into hospital for the same reason.

A systemic review of 31 studies published between 1990 and 2016 showed that 25% of people with learning disabilities received a repeat prescription for laxatives in one year, compared to just 0.1% of the general population.

In one year, 19% of people with downs syndrome were prescribed laxatives compared to 3% of people without learning disabilities.

Constipation was registered as a health problem for 60% of people with profound intellectual and multiple disabilities and 65% had been prescribed laxatives in the previous year. In addition to this, LeDeR released constipation as a common preventable cause of death, which prompted the team to take action.

The service's acute liaison nurses started to record all constipation-related admissions. At the peak, there were five admissions across Surrey in just one month.

'Project Poo' was then created by primary care nurses looking at raising awareness in providers and health services.

Posters (see below) were created and sent to: Surrey GP practices, providers across Surrey, online networks, CCGs, SABP learning disability division and within appropriate learning disability related meetings, with the offer of our nurses' support with complex cases and knowledge around constipation.

The posters were offered out at various learning disability week events in Surrey and within events that the team were facilitating.

The enhanced service training package delivered to GP practices was altered, to include "hot topics", one of which was constipation.

The project outcomes are: an increase in referrals, more discussions around constipation within training sessions and the teams' monthly incident form recordings reducing – the most successful month being December 2018, where there were zero admissions as a result of constipation.

There was also a request from a local team to adapt our documents for use in working with people with dementia.

The work around Project Poo will continue to be shared, with the aim of making constipation an everyday consideration for clinicians and support staff to improve health outcomes for individuals with learning disabilities.

**Katie Hougham is lead nurse for primary care at Surrey's Learning Disability Liaison Service. It is a nursing service which supports mainstream staff working in GP practices and hospitals across the county.**

**CONSTIPATION**

*DID YOU KNOW MORE PEOPLE WITH A LEARNING DISABILITY SUFFER FROM CONSTIPATION THAN WITHOUT?*

*DID YOU KNOW THAT LOOSE STOOLS CAN BE A SIGN OF CONSTIPATION?*

*NOT TREATING CONSTIPATION OVER A LONG PERIOD CAN LEAD TO DEATH!*

WHAT TO LOOK FOR?	WHAT CAN YOU DO?
SYMPTOMS SIMILAR TO DIARRHOEA TUMMY ACHE BLOATING NOT WANTING TO EAT VERY MUCH DIFFICULTIES ON THE TOILET DRY, HARD AND LUMPY POO GOING TO THE TOILET LESS THAN 3 TIMES PER WEEK	EXERCISE HAVE A POO DIARY A STAFF MEMBER WHO KNOWS YOU WELL CAN SUPPORT YOU TO YOUR GP APPOINTMENT. YOUR GP WILL WANT TO SEE YOU. EATING FOODS HIGH IN FIBRE SUCH AS FRUIT AND VEGETABLES. DRINK PLENTY OF FLUIDS! STAFF WHO SUPPORT YOU SHOULD HAVE A CARE PLAN IN PLACE FOR YOU.

IF YOU ARE WORRIED ABOUT ANY OF THIS PLEASE CONTACT YOUR GP – ASK YOUR CARER TO HELP YOU  
IF YOU NEED ANY MORE INFORMATION PLEASE CONTACT YOUR PRIMARY CARE LIAISON NURSE – DETAILS ON THE BACK.

## Next issue:

In March's bulletin, we will be focusing on the Mental Capacity Act. Please let us know about your best practice actions by emailing [chris.allen@bristol.ac.uk](mailto:chris.allen@bristol.ac.uk) by Friday March 8, 2019.

## Briefing for Carers poster: [PDF version here](#)

**BRIEFINGS FOR CARERS**

**CONSTIPATION**

**What is constipation?**

Constipation is characterised by:

- Not having a poo for 3 or more days
- Not having a poo at least 3 times in a week
- Having poo that is sometimes difficult to push out without straining
- Having poo that is larger than usual, dry, hard or like pellets OR after a long time between poo's passing lots of soft, smelly poo

**Constipation can be dangerous because:**

- There is a risk of developing longstanding (chronic) problems
- Over time the bowel may become very distended (like a big saggy bag) and hold a lot of smelly poo. When poo is eventually passed it is loose, like diarrhoea. Sometimes, laxatives are then stopped so the poo backs up in the bowel again. There is a cycle of 'no poo' for many days followed by a huge poo
- Very occasionally the bowel becomes so big it can burst or overgrow its blood supply. This is life-threatening.

**Recognising constipation**

It is very important that constipation is treated quickly before it becomes a big problem. If a person can't tell you about their pooing, you will need to observe and record their bowel movements. Watch out for:

- Stomache ache, cramps and/or bloating
- Behavioural change – this may be the only way a person with a learning disability tells you they are constipated
- loss of appetite, nausea or vomiting
- rectal bleeding or pain
- soiling of underwear from leaking of poo (overflow diarrhoea) – where constipation causes poo to partially block the person's bowel and watery poo from higher up in the bowel leaks out around the blockage. It can look like diarrhoea, but is a warning of severe constipation
- Some medicines can cause constipation eg painkillers, anti-depressants and anti-psychotics
- **THINK and TALK** constipation – it may save a life

**Managing constipation**

Eat a health diet including bran, oats, fruit & veg. Drink plenty of fluids

Regular exercise – helps the bowel to work and maintain a normal weight

Regular toileting – keep to a regular time and place for toileting but don't delay if the urge to poo is felt

Allow plenty of time to use the toilet and relax. To make it easier to poo, rest feet on a low stool while on the toilet

Ask GP to check for health conditions and medicines that cause constipation

Check with GP whether abdominal massage might be helpful

Laxatives are medicines to help a person pass a poo. Ask the GP or pharmacist for advice. Sometimes laxatives are needed long term and should not be stopped without medical advice

Ensure prompt treatment for constipation is given and check if the constipation gets better. See the GP if not.

**Constipation can be life-threatening**

Call 999 or go to A&E if:

- Stomach ache comes on very suddenly or is severe
- Stomach remains bloated, or is hard or painful to the touch
- Person is vomiting blood or vomit looks like ground coffee or diarrhoea
- Poo is bloody or black and sticky and extremely smelly
- The person can't poo or fart at all