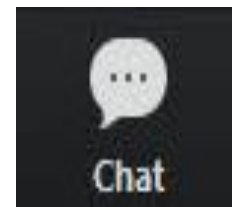




Welcome to the webinar!

We'll be starting shortly! Why not introduce yourselves in the chat box?





Welcome to Health, LeDeR and constipation

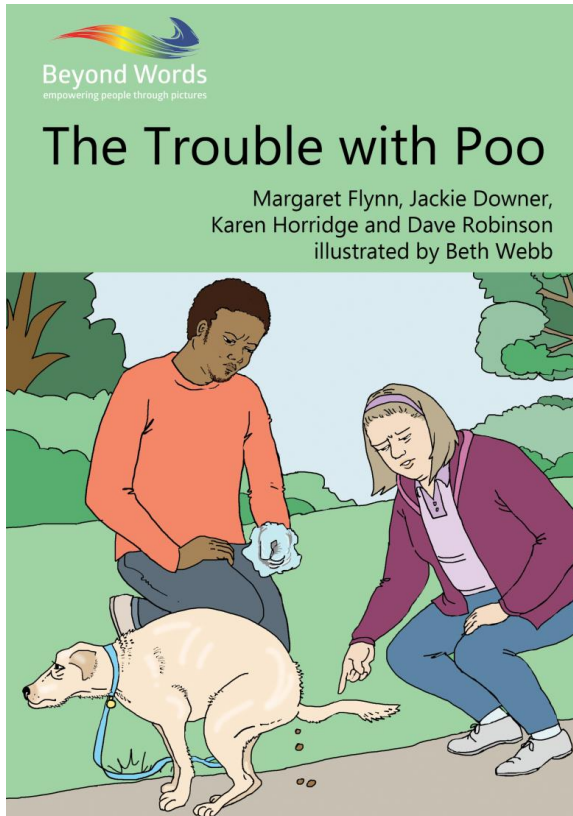
With **Sarah Ormston**, Health, Dementia and Wellbeing Manager at MacIntyre,

Sheila Handley, Mother of Richard Handley

Ruksana Fauzel-Abbas, Specialist Physiotherapist at Guy's & St Thomas NHS Foundation Trust

Chair:

Lindsey Allen, Learning Disability and Autism Manager, Bild



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Books Beyond Words are offering a free copy of this book for all UK attendees of this webinar.

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NHS

Guy's and St Thomas'
NHS Foundation Trust

BILD Conference Constipation

Sarah Ormston,

Health, Dementia & Wellbeing Manager at MacIntyre

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Mother of Richard Handley

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Aims and Objectives of Today's Webinar



- Introduce LeDeR
- Richard's Story
- What is constipation
- Signs & Symptoms of constipation
- Complications that can occur if left untreated
- What we can do about it
- Total bowel management approach
- Introduction to Abdominal Massage
- What MacIntyre do to address this and signposting to resources

What is LeDeR?

LeDeR was commissioned in 2015 with the aim of contributing to the improvement of quality of care and health outcomes for people with a learning disability.

We saw the release of the fifth report from the Learning Disability Mortality Review (LeDeR) programme.



**Learning Disabilities Mortality Review
(LeDeR) Programme**



Overview

People with a learning disability die too young.

The report includes actions taken at a national level and a number of examples of improvements in local areas from across the country.



LeDeR Report

The latest LeDeR Report is about people who have died.

They are people who matter.

In writing their report, they want to avoid people becoming impersonal numbers. They therefore started their report, by sharing stories of real people whose deaths have been reviewed by the LeDeR programme during 2019.



Lets meet Richard



Lets meet Richard



www.inquest.org.uk/richard-handley-conclusion

- Richard was the eldest of 3
- He was an absolute delight through childhood
- He led a full and active life
- He always loved being part of all family activities
- He had a wonderful sense of humour
- He liked to tickle people

Constipation and Learning Disability and why we should focus on this

- **20 – 60%** of people with the learning disabilities suffer from constipation compared to 10% of the general population (Robertson et al 2017)
- **Over 25%** of people with learning disabilities receive repeat prescriptions for laxatives
- Up to **50%** of people with a learning disability have constipation (LeDeR, 2019).
- There have been **12** deaths where constipation was recorded as the cause of death that have been reported to LeDeR (2019).

Service Evaluation – Guy’s and St Thomas’ NHS

Postural Review Data	Lambeth CCG	Lewisham CCG	Southwark CCG	Total
No. of Postural Reviews	54	48	51	153
Constipation	31	30	29	90
Constipation %	57%	63%	57%	59%
Laxative use	32	23	25	80
Laxative use %	60%	48%	49%	52%

What is Constipation?

- Straining when you try to have a poo
- Feeling as though you haven't fully finished
- Passing poo that's larger or smaller than normal, or that's hard and lumpy
- Having less poo's than usual in a week



Categories of Constipation

There are 3 categories of Constipation:

Primary – no underlying medical cause, associated with lifestyle factors i.e. Lack of exercise, diet low in fibre and fresh food, and low fluid intake predispose to constipation.



Secondary – physiological conditions; cerebral palsy, diabetes, Cancer, MS

Latrogenic – caused by side effects of medications.



Signs and Symptoms

- **Any changes in behaviour** - It may be the only way a person with a learning disability can communicate something is wrong. Look for physical causes, including constipation before diagnosing a mental health condition.
- Abdominal pain, bloating, distension, loss of appetite, loss of weight.
- Beware when passing wind stops - It can be a sign of significant obstruction
- An increase in seizures
- Rectal Digging and faecal smearing



Signs and Symptoms

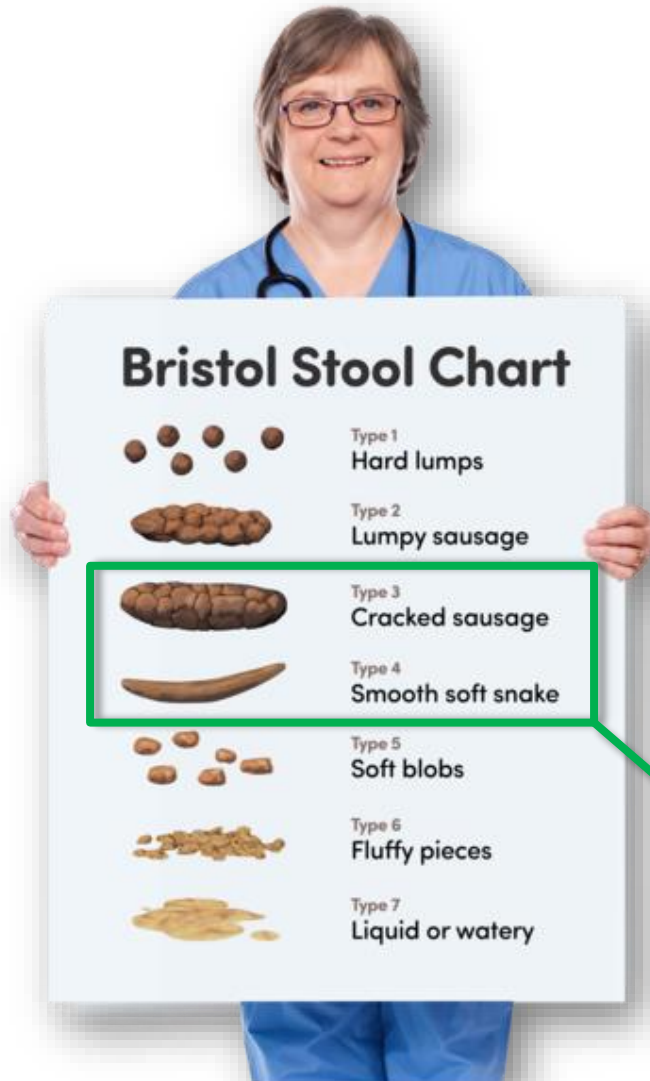
The symptoms of impaction are similar to the symptoms of constipation. But other more serious symptoms can occur.

These include:

- Back pain due to the mass of poo pressing on the nerves in your lower back (the sacral nerves)
- A swollen tummy (abdomen)
- High or low blood pressure
- A fast heart rate
- Dizziness
- Sweating
- A high temperature (fever)
- Confusion
- Explosive diarrhoea or diarrhoea that you have no control over
- Feeling and being sick
- Severe abdominal pain
- Dehydration



Signs and Symptoms



- Rectal bleeding and pain when defaecating. Anal fissures are associated with chronic constipation.
- A person may be going to the toilet less often, find it difficult to go to the toilet and there may be a change in the stool i.e. Dry, lumpy, hard, very big or small. Can also seem like diarrhoea this is called overflow.

→ **The perfect poo!**

Complications



If not treated constipation can lead to:

- Abdominal pain
- Cramps
- Bloating
- Loss of appetite
- Nausea
- Overflow diarrhoea
- Faecal impaction
- Faecal vomiting
- Twisting of the bowel leading to ischaemia or septicaemia
- Breathing difficulties
- **Death**

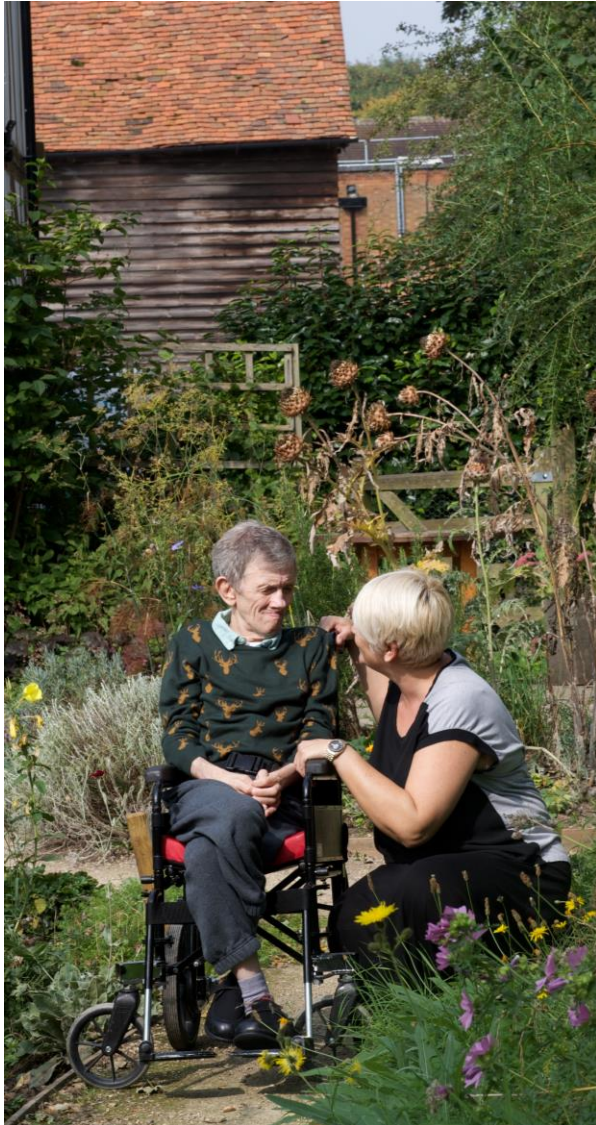


Why does someone with a learning disability have a higher risk of constipation?

- Limited mobility
- Reduced range of activity
- Abnormal muscle tone /spasticity
- Neurological /genetic /cognitive /functional impairments
- Communication Barriers
- Lack of toileting opportunities
- Medications



Why does someone with a learning disability have a higher risk of constipation?



- Toilet not meeting the needs of the person supported e.g. too high, requires sides and so on
- Fear of toileting or unfamiliar environments
- Reduced fluid intake
- Limited diet
- Modified diet takes some food out of natural diet
- Lower expectations from parents /carers for toileting

Public Health England (2016)

- Recommends the need for a **total bowel management approach** delivered by a multi-disciplinary team.
- This **can improve the health outcomes** for people with a learning disability as well as having **potential cost savings** for the NHS.
- Total bowel management can be time consuming but can help to **improve the bowel habits** of people with a learning disability and can lead to a **reduction or cessation of laxatives**.
- **Abdominal massage can be as effective as laxatives** in the treatment of constipation.

Total Bowel Management Approach

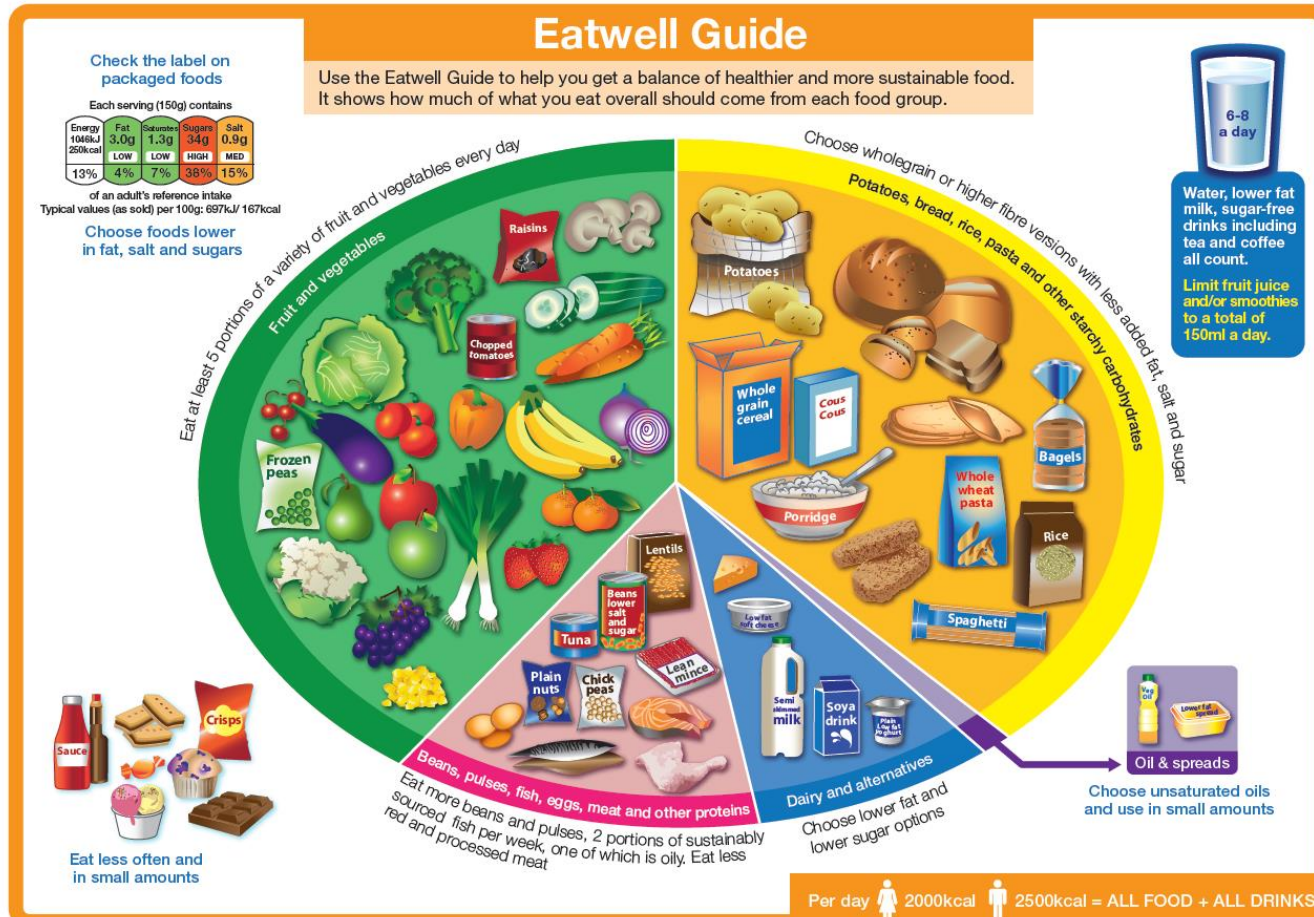
Non pharmacological:

- **Diet**
- **Fluid intake**
- Mobility and exercise
- Toilet positioning
- Social and psychological factors
- Toileting routine
- Abdominal massage

Pharmacological / Medication:

- Bulk forming laxatives
- Osmotic laxatives
- Stimulant laxatives
- Stool softener laxatives
- Bowel-cleansing solutions

Eat well Guide



Source: Public Health England in association with the Welsh government, Food Standards Scotland and the Food Standards Agency in Northern Ireland

© Crown copyright 2016

Total Bowel Management Approach

Non pharmacological:

- Diet
- Fluid intake
- **Mobility and exercise**
- **Toilet positioning**
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Pharmacological / Medication:

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- Stool softener laxatives
- Bowel-cleansing solutions

Optimum Positioning for Opening Bowels



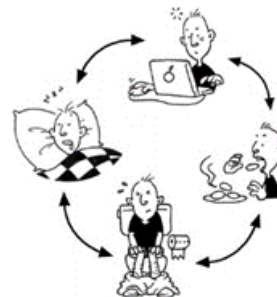
Total Bowel Management Approach

Non pharmacological:

- Diet
- Fluid intake
- Mobility and exercise
- Toilet positioning
- **Social and psychological factors**
- **Toileting routine**
- Abdominal massage

Pharmacological / Medication:

- Bulk forming laxatives: bran, methylcellulose, ispaghula husk
- Osmotic laxatives: lactulose, movicol, macrogols
- Stimulant laxatives: bisocodyl, senna, danthron, sodium picosulphate
- Stool softener laxatives: arachis oil, liquid paraffin oil, sodium docusate
- Bowel-cleansing solutions: picolax



Abdominal Massage

- Non-invasive intervention associated with a low burden of risk.
- The evidence base for abdominal massage in people with a learning disability is limited, however its effects are acknowledged.

Connor et al. (2014) report that abdominal massage can:

- Increase peristalsis in the gut and reduce colonic transit time.
- Make stools easier to pass by softening their consistency.
- Resolve constipation in some patients where diet and laxatives have failed.
- Reduce cost of pharmaceutical treatments of constipation.

Please be aware that staff training is required before attempting abdominal massage on a person with a learning disability.

When not to use Abdominal Massage

- History of malignant bowel obstruction or abdominal growth
- Abdominal inflammation
- Spastic colon experienced in Irritable Bowel Syndrome
- Intestinal obstruction caused by twisting of the bowel
- Severe faecal impaction (prior to elimination by medication)
- Unstable spinal injury
- Recent scarring
- Skin lesions
- Pregnancy
- Fever

Care must be exercised with any abdominal hernia and history of inflammatory disease of the intestine

Abdominal Massage Video



What to do for those at Risk: A Summary

- **Encourage** a healthy diet that includes fibre and at least the minimum fluid intake (6-8 glasses)
- **Laxatives** - Laxido or Movicol are commonly prescribed for constipation. It is important that 125mls of water is used per sachet.
- Support the person the exercise
- **Toileting position** – buy a stool to improve position
- Create a comfortable and stress free environment – don't rush the person



What to do to reduce the risk for those at Risk




- Refer to a Community Learning Disabilities Team (CLDT) to facilitate the total bowel management approach
- **Review:** ask the GP for a medication review
- **Training:** ensure everyone supporting the person knows the signs and symptoms of constipation
- **Encourage** the person to go to the toilet when they want to go– Do not wait if you feel the need to go to the toilet

- **Our aim:** is for a person-centred bowel care plan/passport that includes how to recognise and prevent constipation through good quality monitoring and total bowel management

Key Points


- Hospital admissions and deaths due to constipation **are preventable and treatable** with a total bowel management approach in the community.
- Abdominal massage is **a free, non-invasive, effective treatment for constipation** and generally a pleasant experience for the client.
- **Abdominal massage performed once or twice a day has been shown to reduce laxative medication use.**
- **Staff training is required** prior to completing **abdominal massage to a person with a learning disability.** Who provides it varies between regions from bowel & bladder service, community learning disability team or there may unfortunately be no provision.
- If you feel a clients bowel management requires reviewing, please contact your local community learning disability team, bowel and bladder service or GP.

MacIntyre Resources & Tools





MacIntyre
Wellbeing for Life
Keep Going...Don't Stop!

What is normal for me?




MacIntyre
Providing support...your way

My normal bowel pattern. If self caring please say so, If it's normal for me to have constipation, hard, loose, or diarrhoea in a month, please say





(You can use the Bristol Stool Chart to help you)

My normal menstruation cycle. What is normal for me when it comes to my periods? e.g. Bleeding may be light or heavy lasting 3-7 days. Colour maybe brown to red. Do I show discomfort? If so how do I show this?




June 2019
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MacIntyre
Wellbeing for Life
Keep Going...Don't Stop!



Good Example



MacIntyre
Providing support...your way

What is normal for me?



My normal bowel pattern. If self caring please say so, If it's normal for me to have constipation, hard, loose, or diarrhoea in a month, please say

I have a suppository every other night, I don't often go without the aid of the suppository, but I may occasionally. My bowel movements are usually a Bristol chart 4/5.


I sometimes get constipation as I am not as active and this can be a side affect of my medication.

This doesn't happen often but when it does please use my prescribed laxative to encourage my bowels to open. Just keep communicating with me.

Type 4	Type 5
	

(You can use the Bristol Stool Chart to help you)

My normal menstruation cycle. What is normal for me when it comes to my periods? e.g. Bleeding may be light or heavy lasting 3-7 days. Colour maybe brown to red. Do I show discomfort? If so how do I show this?



N/A

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Above: MacIntyre's Baseline Health Assessment

Above: MacIntyre's Baseline Health Assessment Good Practice example

MacIntyre Resources & Tools


Bowels																									
Date		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
Blood/ Mucous	AM																								
	PM																								
	N																								
Diarrhoea	AM																								
	PM																								
	N																								
Loose	AM																								
	PM																								
	N																								
Hard/Soft	AM																								
	PM																								
	N																								
Constipation	AM																								
	PM																								
	N																								
No Bowel Movement	AM																								
	PM																								
	N																								
Normal	AM																								
	PM																								
	N																								
Self Caring/ Unobserved	AM																								
	PM																								
	N																								

Above: Health Calendar (also known as the Anticipatory Care Calendar)


Bowels	DESCRIPTIONS (Adult)	ACTIONS (Adult)
Blood/Mucous	Mucous or jelly like substance mixed with blood on more than 2 occasions on separate days. A large amount of blood will prompt immediate action	Monday to Friday during practice opening hours call GP practice for an urgent appointment. Collect a sample to show the GP
Diarrhoea	Watery liquid stools, frequent bowel actions with possible stomach cramping may appear brown, yellow or green. More than 10 episodes in 24 hours would change this amber to an	Offer more drinks. If diarrhoea continues for 24 hours contact GP practice for advice
Loose	Very soft stool may be like chocolate mousse, might be frequent Bristol stool chart 5 or 6	Offer more drinks. Monitor bowel pattern for 48 hours. If loose stools continue
Hard	Dry hard stool may cause pain when passing Bristol stool chart 1 or 2	Offer more drinks. If hard stools are still apparent after one week contact GP
Constipation	Difficulty passing stool or going to the toilet for 3 days or more. Bristol stool chart 1 or 2 There may be bleeding or pain passing hard stools.	Offer more drinks. If client has a stool softener encourage them to take the medicine. If bowels not opened after 4 days contact GP Practice for advice
No bowel movement	No stool passed	Offer more drinks. If client has a stool softener encourage them to take the medicine. If bowels not opened after 4 days contact GP Practice for advice
Normal	Regular normal bowel action, normal pattern - this may be every day or every 2 to 3 days. Bristol stool chart 3 or 4 Should be light brown or	No action required
Self caring/ Unobserved	The client is usually self caring and has not displayed discomfort or problems relating to bowel motions	No action required

Above: Descriptions and Actions Sheet

MacIntyre Resources & Tools



Monthly Bowel Movement Chart










My Name: _____ Month: _____ Year: _____

Please use the Bristol Stool Chart below to indicate type in boxes below

Day	Morning Type 6	Afternoon Type 7	Night Type 7
1			
2			
3			
4			
5			
6			
7			
8			
9			
10			
11			
12			
13			
14			
15			
16			
17			
18			
19			
20			
21			
22			
23			
24			
25			
26			
27			
28			
29			
30			
31			








Bristol Stool Chart

	Type 1 - Separate hard lumps, like nuts (hard to pass)
	Type 2 - Sausage-shaped, but lumpy
	Type 3 - Sausage-shaped, but with cracks on surface
	Type 4 - Sausage or snake like, smooth and soft
	Type 5 - Soft blobs with clear-cut edges (easy to pass)
	Type 6 - Fluffy pieces with ragged edges, mushy
	Type 7 - Watery, no solid pieces (entirely liquid)

May 2018
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Page 1 of 1

THE BRISTOL STOOL CHART

Let's Talk POO!

type 1		<p style="font-size: x-small; margin: 0;">LOOKS LIKE</p> <p style="margin: 0;">rabbit droppings separate hard lumps, like nuts</p>
type 2		<p style="font-size: x-small; margin: 0;">LOOKS LIKE</p> <p style="margin: 0;">bunch of grapes sausage shaped hard but lumpy</p>
type 3		<p style="font-size: x-small; margin: 0;">LOOKS LIKE</p> <p style="margin: 0;">corn on the cob like a sausage with cracks</p>
type 4		<p style="font-size: x-small; margin: 0;">LOOKS LIKE</p> <p style="margin: 0;">sausage smooth and soft like a sausage</p>
type 5		<p style="font-size: x-small; margin: 0;">LOOKS LIKE</p> <p style="margin: 0;">chicken nuggets soft blobs with clear cut edges</p>
type 6		<p style="font-size: x-small; margin: 0;">LOOKS LIKE</p> <p style="margin: 0;">porridge fluffy pieces with ragged edges</p>
type 7		<p style="font-size: x-small; margin: 0;">LOOKS LIKE</p> <p style="margin: 0;">gravy Watery no solid pieces, liquid</p>

Above: MacIntyre's Stool Chart

Above: MacIntyre's Monthly Bowel Movement Chart

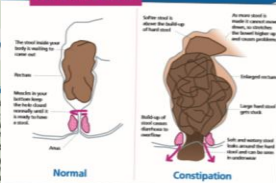
Resources & Tools



Constipation can be dangerous in people with a learning disability - Get the diagnosis right

Poo matters

Information for health professionals



Possible presentations of constipation

Soiled underwear (leakage)

Hard stool

Infrequent stool

Build up of lots of stool - three flush poo



It is important to correctly identify constipation in people with a learning disability

Some people with a learning disability are more at risk of constipation than the general population. Reviews into the deaths of people with a learning disability have shown us that too many people are still dying from constipation.

Any changes in behaviour - think constipation

It may be the only way a person with a learning disability can communicate something is wrong. Look for physical causes, including constipation before diagnosing a mental health condition.

History

- Take a detailed history including frequency and consistency of stool.
- Ask about childhood constipation - a key risk factor for the development of megacolon/rectum*.

Additional symptoms

- Abdominal pain, bloating, distension, loss of appetite, loss of weight.
- Rectal bleeding and pain when defaecating. Anal fissures are associated with chronic constipation.
- Blears when the wind stops - it can be a sign of significant obstruction.

Examination

Distended abdomen.
Rectal examination maybe misleading as the constipation often involves the colon and does not reach the rectum. Check for anal fissures.
Abdominal radiology can confirm the diagnosis, but needs to be used judiciously.

Ask about pharmacological factors

- Prescribed drugs causing constipation include opiates, anti-psychotics, anti-depressants, anti-epileptics, anti-emetics and anti-parkinsons.
- Are prescribed laxatives been taken regularly?
- Is the dose sufficient? Consider a stimulant alongside softeners/laxatives.

Lifestyle factors

Lack of exercise, diet low in fibre and fresh food, and low fluid intake predispose to constipation.

Make sure people with a learning disability or their family or carers know the symptoms of constipation

#TakeActionSaveLives



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 outgrow 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 CP whether abdominal massage might be helpful

Laxatives are medicines to help a person have 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

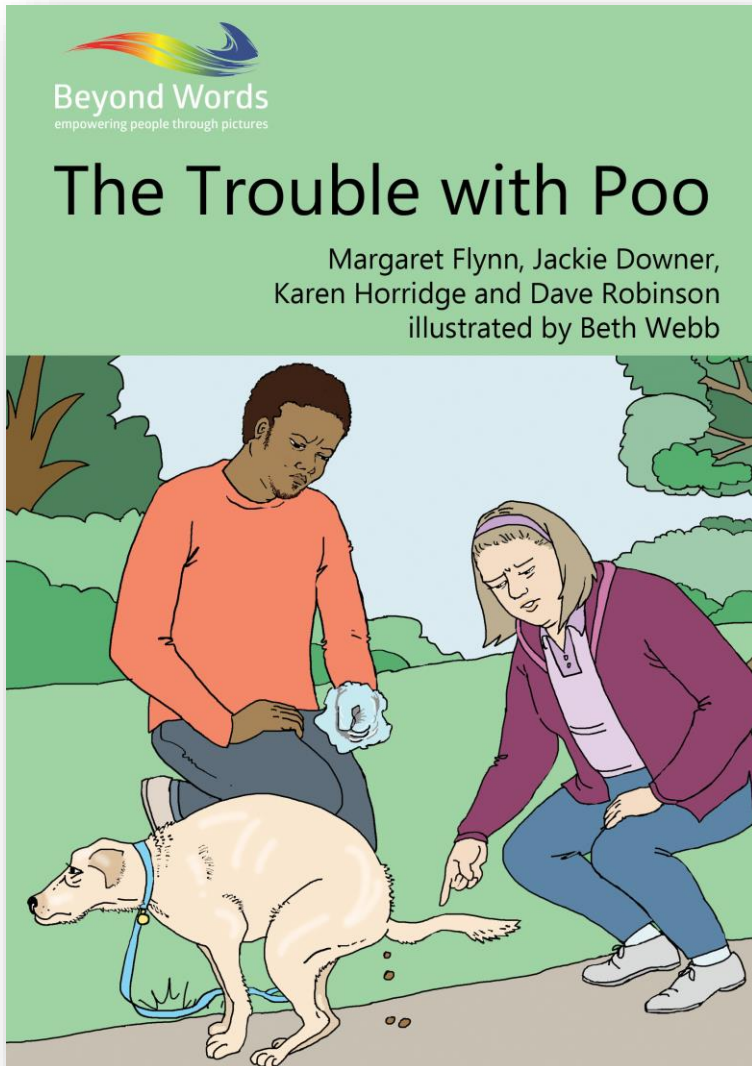
Call 999 or go to A&E if: Stomach ache comes on very suddenly or is severe

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

Resources & Tools



Other resources: Guidance about the management of constipation

- NICE have published [a clinical knowledge summary about constipation aimed at primary care practitioners](#) with the current evidence about diagnosis, assessment, investigations and management
- Further [NICE guidance](#) provides strategies based on the best available evidence to support early identification, positive diagnosis and timely, effective management of constipation in children and young people
- [Management of constipation in adult patients receiving palliative care](#) makes evidence-based recommendations about best practice and standards of assessment and care processes

Resources for professionals, family members and carers:

- [Bowel management: constipation - clinical link pathway \(CLIP\)](#) is a pathway designed to be used at any time with any adult where constipation is a concern; the appendices include embedded documents to be used as part of the pathway
- [Managing bowels and bladders for people with profound and multiple learning disabilities](#)
- [Tip sheet: constipation](#) is a short sheet with information for parents about the causes of childhood constipation and what to do about it
- [The NHS website](#) has a series of web pages with information about constipation including symptoms, causes, diagnosis, treatment, complications and prevention
- [Bristol Stool Chart](#) is a medical aid designed to classify faeces into 7 groups which is helpful for keeping stool charts; there is also a [version for children](#)
- [Tips on increasing fibre and fluid in your diet](#) gives specific suggestions for breakfasts, lunches, meals and snacks
- [A parent's guide to constipation in children with developmental disabilities](#) has information on how constipation can be managed in relation to diet, behaviour and medication; recipe suggestions are included
- [ERIC, a children's bowel and bladder charity](#) have web pages designed for parents to give advice about coping with constipation and soiling. There are factsheets, tips and links to resources.

Easy read resources:

- [What is constipation?](#) is a short, easy-read leaflet describing what constipation is and what you should do if you are constipated
- [Preventing constipation](#) gives information about things to eat and drink to help prevent constipation with advice on how to stay active

Smartphone apps related to constipation management:

- Bristol Stool Chart app allows quick and easy rating of stool quality (using the Bristol Stool Scale); it is available on [Apple](#) and [Android](#) - this information is recorded and can be shared with a health professional, with information about each type of stool along with links to more information online
- [Tummy Trends](#) is a personal guide designed to track symptoms associated with constipation and irritable bowel syndrome, available on Apple; it is designed to allow someone to easily enter symptoms, keep track of meals, and select factors that may affect them - the entries can be reviewed at any time or viewed in a graph
- [Stool Checker](#) is for people to keep a record of their bowel movements easily
- 'Poop Diary' allows easy recording of every bowel movement, including time, colour, amount, and shape information; it can also send a reminder if there has been no bowel movement for a period of time
- [Poop Log](#) to track bowel movements using the Bristol Stool Scale; it is possible to record the type of bowel movement, volume, and time and to attach a note or photo and there is an optional function to log a pain or discomfort level from 0 to 10

Our Role's and Responsibilities



General Practitioner (GP)



Community Learning Disability Team (CLDT)



MacIntyre Staff



Family & Circle of Support

Any other Business

Any
Questions
?



Any other Business



Thank
You!



MacIntyre

Providing support...your way

Sarah Ormston,

Health, Dementia & Wellbeing Manager at MacIntyre

Sheila Handley,

Mother of Richard Handley

Ruksana Fauzel-Abbas,

Specialist Physiotherapist at Guy's & St Thomas
NHS Foundation Trust

T: 01908 230100

E: health.team@macintyrecharity.org

www.macintyrecharity.org



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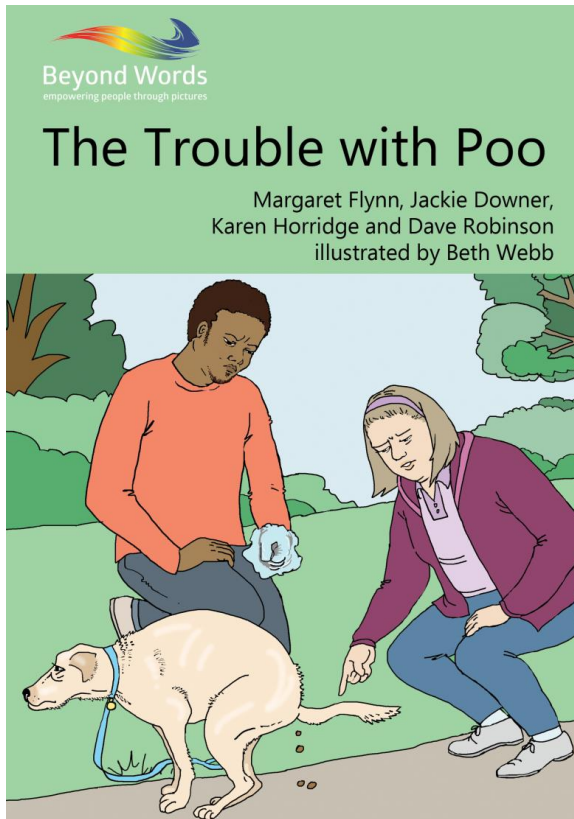
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20 October 2021:

Evaluating frailty risks in people with learning disabilities,

Ade Eriolu, Strategic Liaison Nurse Secondary and Tertiary Care



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