NHS
Greater Glasgow and Clyde

Learning Disability Services

Prevention and Management of Constipation Guideline

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Authors: Bowel Management Group	Professor Sally Ann Cooper OBE MD FRCPsych Professor of Learning Disabilities & Honorary Consultant Psychiatrist Jennifer Crockett Professional Lead for Physiotherapy Learning Disability Services Allison O'Donnell Practice Development Nurse Specialist Learning Disability Services(Group Chair) Lynsey O'Hagan Community Learning Disability Nurse East Renfrewshire Christine Pacitti Clinical Pharmacist Mental Health & Learning Disability Melissa Rice Learning Disability Dietician
Approval Group	Learning Disability Clinical Governance Group
Version	1

This guideline is based on examination of current evidence and best practice. However it is necessary to note that clinical judgement should be exercised on the appropriateness of any guideline, influenced by individual patient characteristics.

It is good practice to record any reason for not following the guideline (Including patient or carer decisions) and ensuring this is communicated to all relevant others involved in care.

Contents

1 Introduction

Constipation is common in people with learning disabilities. It needs to be taken seriously and requires proactive management, as, in addition to causing pain, it can result in serious health conditions and death (Evenhuis, 1997; Flynn & Eley, 2015a; Flynn & Eley, 2015b). If a person with constipation receives the right treatment and support, death due to constipation can be avoided.

In the NHS Greater Glasgow and Clyde area, the Learning Disabilities Primary Care Liaison Team have conducted health checks with many adults with learning disabilities. From the first 1,023 health checks they discovered that constipation was experienced by 34% of the adults with learning disabilities, and was the third most common condition (just behind visual impairment and epilepsy). The prevalence of constipation increased the more severe the person's learning disabilities, but was not related to age.

A recent systematic review identified 31 studies that reported on constipation or laxative use by people with learning disabilities (Robertson et al. 2017). They reported the prevalence of constipation to be 50% or more in 14 of the studies, and 33% or more in 21 of the studies. They reported that constipation was more common in the people with learning disabilities who also had cerebral palsy, profound learning disabilities, and/or immobility. Other conditions that might increase risk for constipation include neurological and spinal cord conditions, spinal bifida, multiple sclerosis, Parkinson's disease, depression, anxiety, hypothyroidism, diabetes, irritable bowel syndrome, Crohn's disease, ulcerative colitis, anal pathology e.g. anal fissures or haemorrhoids, colon cancer, Hirschsprung disease, complications of surgery, obesity and underweight, and poor general health, along with poor nutrition, low fluid intake, and low physical activity. Many drugs can cause constipation, often due to anticholinergic side effects, including drugs commonly prescribed for people with learning disabilities such as antipsychotics (especially clozapine), procyclidine, some antidepressants, tolterodine. Indeed, people with learning disabilities are often in receipt of several constipating drugs.

Staff are sometimes unaware of the serious consequences of constipation. Communication needs of people with learning disabilities, and the intimate nature of the problem may compound this. Additionally, faecal impaction can cause faecal overflow, which may be incorrectly assumed to be diarrhoea. Constipation can cause problem behaviours, agitation, abdominal cramps, rectal prolapse, diverticula of the colon, severe haemorrhoids, and megacolon. Impaction can lead to obstruction, bowel ischaemia, breathing problems, vomiting, aspiration, and death. A study of 70 people with learning disabilities found that 57% had chronic constipation, and four of them died from constipation over a 10 year period (Evenhuis, 1997).

Given the importance of preventing the health and death consequences of constipation, NHS Greater Glasgow and Clyde's learning disabilities service convened a working group to review existing constipation resources, and design a bowel management pathway. This is the outcome of the work undertaken.

1.1 References

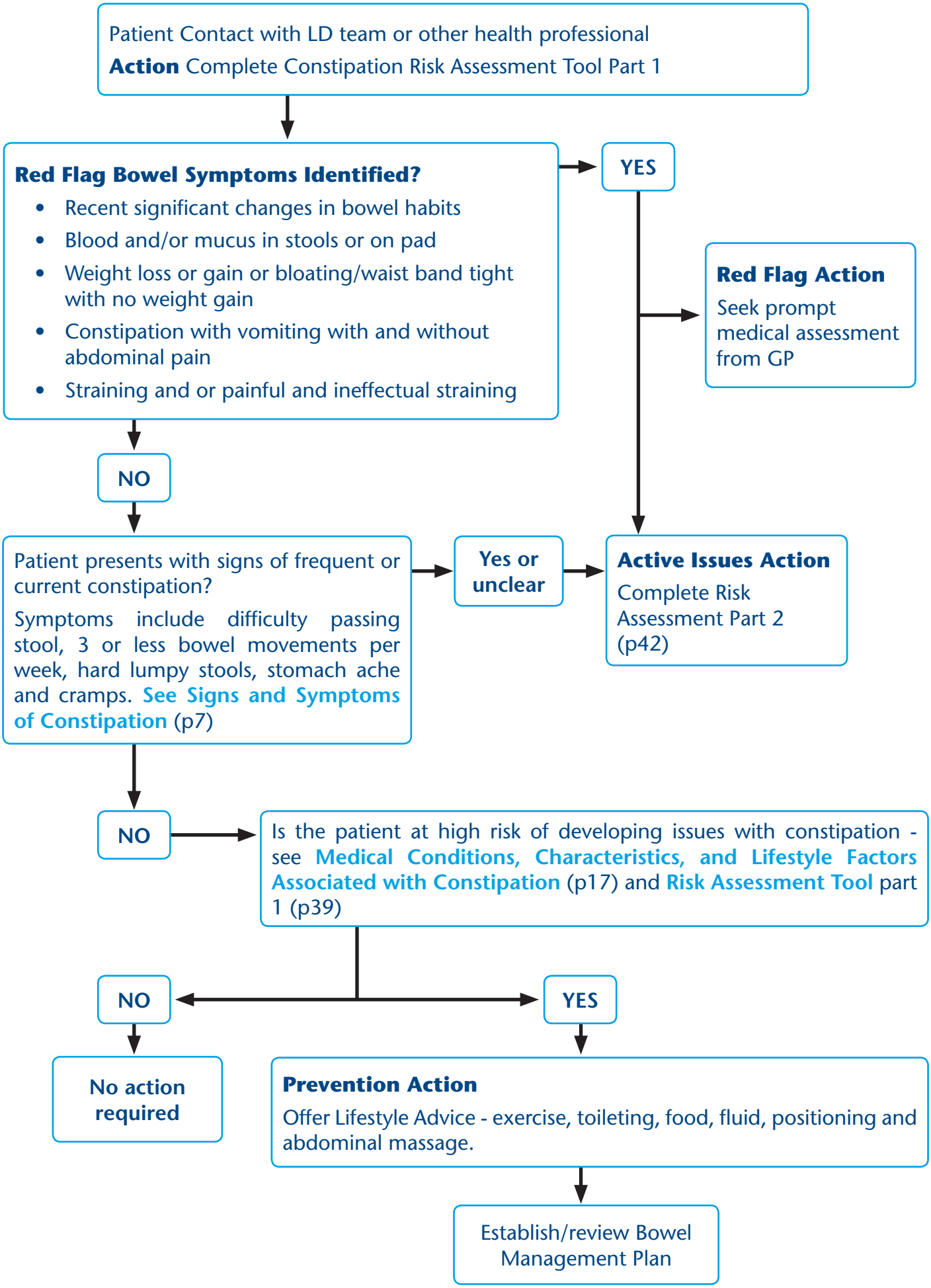
Flynn, M., & Eley, R. (2015a) A serious case review: Amy. Suffolk County Council. **www.suffolkas.org/assets/Safeguarding-Adult-Reviews/SCR-Case-Amy-091015.pdf**

Flynn, M., & Eley, R. (2015a) A serious case review: James. Suffolk County Council. **www.suffolkas.org/assets/Safeguarding-Adult-Reviews/SCR-Case-James-091015.pdf**

Evenhuis HM. (1997) Medical aspects of aging in a population with intellectual disability: III. Mobility, internal conditions and cancer. Journal of Intellectual Disability Research 1997; 41: 8–18

Robertson, J.M., Baines, S.M.J., Emerson, E.B., Hatton, C.R. (2017) Prevalence of constipation in people with intellectual disabilities: a systematic review. Journal of Intellectual and Developmental Disability. **dx.doi.org/10.3109/13668250.2017.1310829**

2. Management and Treatment of Constipation Flowchart



3. What is Constipation?

Constipation is the infrequent passing of stools - that is, less than three stools per week, or sometimes straining to pass stool, or passing hard, dry, or bullet shaped stools.

Most people will experience constipation at some point in their life and it is often considered as a discomfort as opposed to a more serious health problem. However undiagnosed and untreated constipation can have serious consequences and implications for health, and people with learning disabilities have become very ill or died from complications of severe constipation.

Constipation can be a complex problem. Chronic constipation can result in the development of haemorrhoids, diverticulitis, straining and perforation of the colon. Chronic constipation has also been linked with cancer of the rectum and colon. Preventative measures include good nutrition, adequate hydration, and exercise and physical activity.

3.1 Signs and Symptoms of constipation

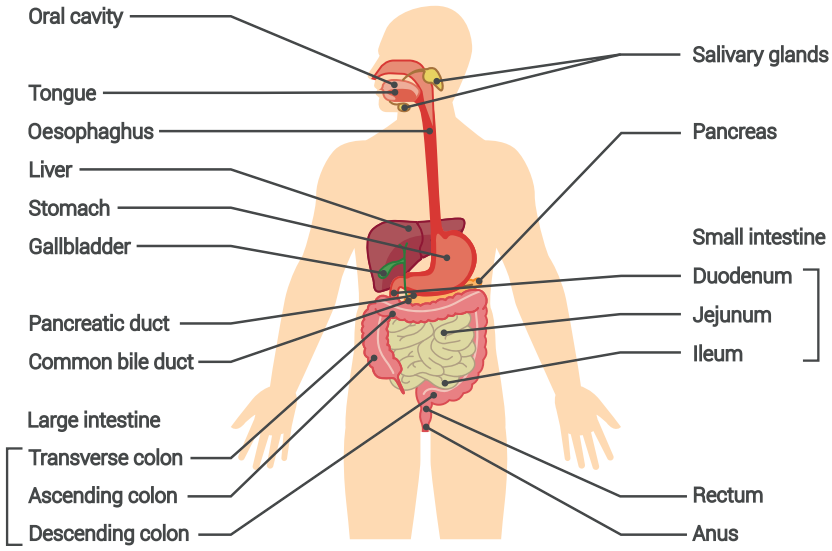
- The infrequent passing of stools- that is less than three stools per week, or sometimes straining to pass stool, or passing hard, dry or bullet shaped stools. (Type 1 or Type 2 stool as identified from The Bristol Stool Chart or Stool Types for People who Use Pads)
- Blood or mucus in stool
- Urgency to open bowels
- Incontinence of faeces
- Loss of appetite
- Pain or discomfort in abdomen
- Lethargy/ lack of energy or enthusiasm
- Faecal leakage (overflow) often mistaken for diarrhoea. Consider stool Type 7 as identified from The Bristol Stool Chart or Stool Chart for People who Use Pads
- A change in behaviour or mental health presentation
- A change in seizure pattern including frequency
- Faecal staining on underwear or continence pad
- Blood staining on underwear or continence pad
- Observe toilet for signs of constipation after use such as stool type, unusual foul smells, and blood in toilet
- Does the person strain or sound as though they are straining when using the toilet?
- Do they spend a long time on the toilet or visit it excessively?
- Do they avoid or put off going to the toilet?
- Do they have bad breath despite having good oral hygiene and good dental health?
- Do they insert a finger into the anus to perhaps remove faeces?
- Do they have a swollen or distended abdomen? Is their waist band too tight?
- Do they pass wind excessively?
- Signs of faecal impaction may include a change in pattern of bowel movements e.g. Type 1 or Type 2 stool – no bowel movement – Type 7 stool

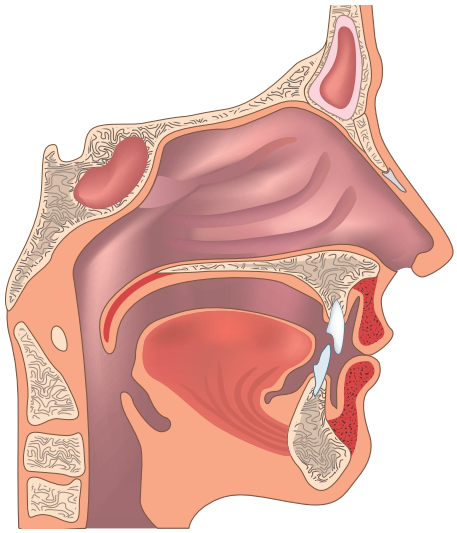
4. Understanding Constipation - The Digestive System

The digestive system is a group of organs working together to convert food into energy and basic nutrients to feed the entire body allowing it to function, grow and repair itself. Food passes through a long tube inside the body known as the gastrointestinal tract (GI tract). The GI tract is made up of the oral cavity, pharynx, oesophagus, stomach, small intestines, and large intestines, with other organs having supportive functions.

The Process of Digestion

1. Ingestion of food
2. Secretion of fluids and digestive enzymes
3. Mixing and movement of food and wastes through the body
4. Digestion of food into smaller pieces
5. Absorption of nutrients
6. Excretion of wastes



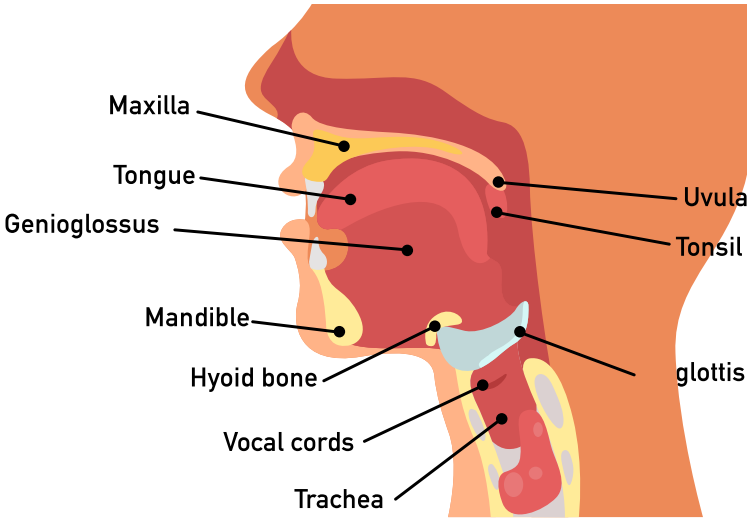


The Mouth

Food begins its journey through the digestive system in the mouth, also known as the oral cavity. Inside the mouth are many accessory organs that aid in the digestion of food—the tongue, teeth, and salivary glands. Teeth chop food into small pieces, which are moistened by saliva before the tongue and other muscles push the food into the pharynx (throat).

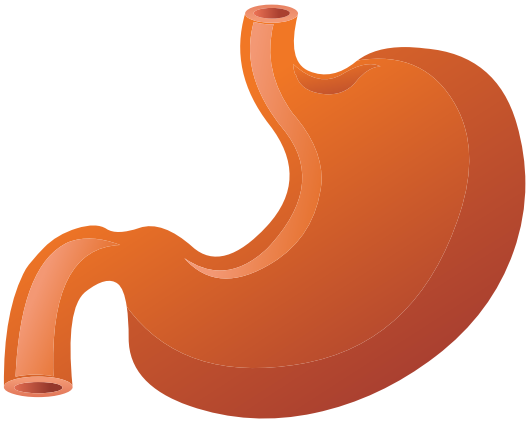
The Oesophagus

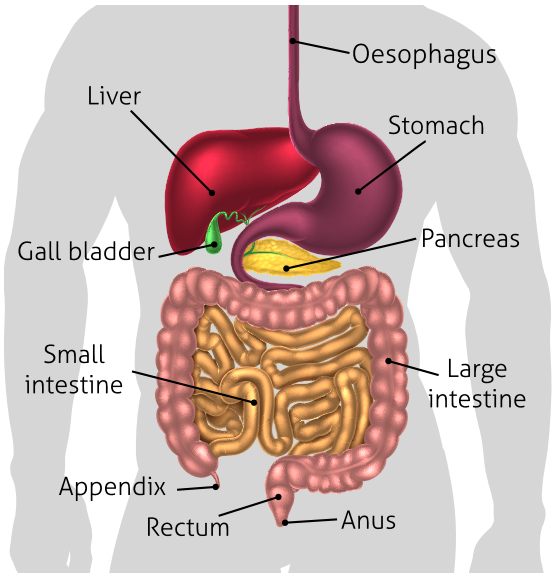
The oesophagus is a muscular tube connecting the pharynx to the stomach that is part of the upper GI tract. It carries swallowed masses of chewed food along its length. At the inferior end of the oesophagus is a muscular ring called the lower oesophageal sphincter. The function of this sphincter is to close of the end of the oesophagus and trap food in the stomach.



The Stomach

The stomach acts as a storage tank for food so that the body has time to digest large meals properly. The stomach also contains hydrochloric acid and digestive enzymes that continue the digestion of food that began in the mouth.



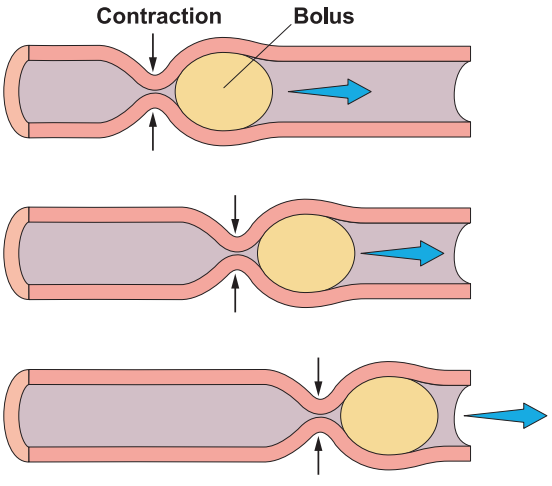


The Small Intestine

The small intestine is a long, thin tube about 1 inch in diameter and about 10 feet long that is part of the lower GI tract. It is located just inferior to the stomach and takes up most of the space in the abdominal cavity. The entire small intestine is coiled like a hose and the inside surface is full of many ridges and folds. These folds are used to maximise the digestion of food and absorption of nutrients. Water, nutrients and electrolytes continue to be absorbed and by the time food leaves the small intestine, around 90% of all nutrients have been extracted from the food that entered it.

Peristalsis

Peristalsis moves the food in small quantities along the intestines. As the bolus of food moves forward, it stimulates the muscle behind to contract, and the muscle in front to relax, thereby sweeping it forward. Peristalsis occurs several times a day and is triggered by both food entering the stomach and by the individual moving around. This occurs predominantly after breakfast. Neurogenic conditions may decrease peristaltic activity. When there are excess iron levels in the body, the body increases peristalsis which leads to rapid defecation. When there is iron deficiency the body, the body works hard to increase absorption. It slows down peristalsis, which means the stool is expelled slower resulting in constipation.



The Large Intestine (Colon)

The large intestine is a long, thick tube about 2 ½ inches in diameter and about 5 feet long. It is located inferior to the stomach and wraps around the superior and lateral border of the small intestine. The large intestine absorbs water and contains bacteria that aid in the breaking down of wastes to extract some small amounts of nutrients. Hard, dry stools are the result of the large intestine absorbing too much water.

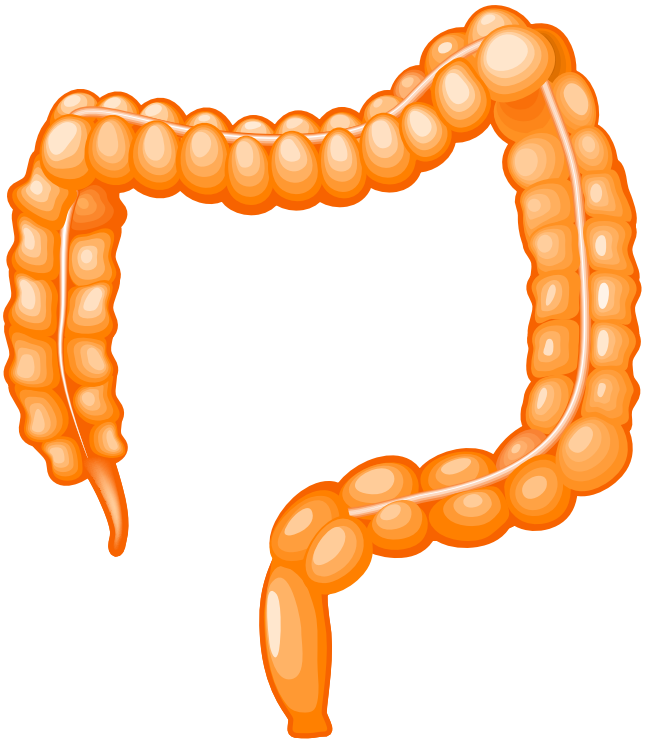
Faeces in the large intestine are moved by strong peristaltic waves from the ascending colon through the transverse colon down the descending colon and into the rectum to exit the body. By the time the stool reaches the rectum, most of the water has been absorbed, making the stool solid. When the colon's muscle contractions are slow or sluggish, the stool moves through the colon too slowly, resulting in too much water being absorbed.

Filling of the rectum produces the desire to empty the bowel, which may be responded to or, if inconvenient, may be voluntarily suppressed and the faeces may then be returned to the colon.

Mass Peristalsis:

Strong waves at infrequent intervals

Start at upper end of ascending colon



They empty the transverse colon and sweep faeces into the descending and pelvic colons and into the rectum for evacuation

5. Causes and Prevention of Constipation

Constipation is caused by issues of stool consistency (hard painful stools) and issues of defecatory behaviour (infrequency, difficulty in evacuation, straining during passing of stool). There is often an overlap of issues:

- Lifestyle factors such as:
  - » Eating a diet not including enough in fibre
  - » Dehydration - Not drinking enough fluids or drinking fluids that can cause dehydration such as alcohol. Other causes of dehydration common in some people with learning disabilities include excessive salivation or drooling and / or some thickening agents used in the management of dysphagia
  - » Poor mobility, or not exercising enough
- Some medications
- Medical conditions associated with constipation
- Social, psychological, and environmental factors

5.1 Eating and Drinking

People with learning disabilities are at increased risk of having a poor diet, and eating inadequate quantities of fruit and vegetables. Fibre intake, from sources such as fruit and vegetables, is essential as it adds bulk to the stool and makes it easier for it to pass through the intestine. Fibre intake can also be increased by some cereals, and switching to wholemeal and wholegrain products. Changes to the diet to include more fibre should be gradual to prevent abdominal discomfort and flatulence. Irregular mealtimes can also lead to constipation.

Maintaining the correct fluid level is essential in promoting and achieving good digestive health. The digestive system transports fluids in the body so both constipation and diarrhoea can have a negative impact on fluid balance and needs to be monitored closely.

Note that some gum based thickeners can cause diarrhoea in some clients.

Encourage individuals to drink enough fluid, preferably water (approx 8-10 cups although this will depend on the persons weight). Alcohol should be cut back as it can dehydrate. Salty foods should also be avoided. Food that contains fluids such as yogurt, fruit, vegetables, ice cream, custards, and soups may help.

Thickening drinks may cause clients to drink less, so contributing to dehydration.

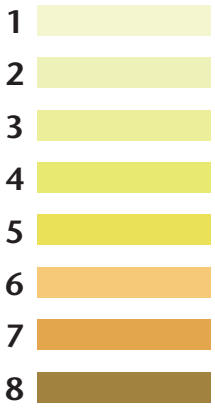
Hydration status should be assessed before laxative use as they can make dehydration worse.

People who have difficulties with dysphagia often have additional difficulties maintaining hydration. This is often difficult for people with profound and multiple learning disabilities, and those who are physically unwell.

A texture modified diet may affect constipation by altering the fibre intake.

Dehydration also increases the risk of urinary tract infection and cancer of the bladder.

5.2 Pee Chart



Your target is to make sure that your pee is the same colour as numbers **1-3**

4 and 5
suggest dehydration

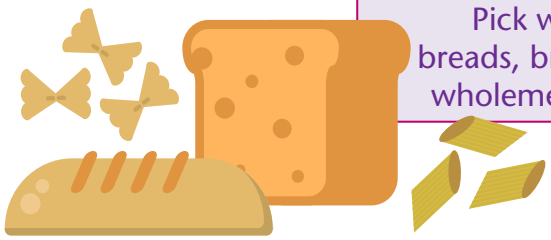
6, 7 and 8
suggest severe dehydration

Eating and Drinking to help keep things moving

Eat foods high in fibre

High fibre cereal or porridge look for options with wholewheat, bran, oats and nuts

Go brown!
Pick wholemeal breads, brown rice, wholemeal pastas.



Vegetables
Beans, lentils or chickpeas

Fruit - or occasional small glass of fruit juice such as prune juice

When adding in more foods high in fibre to your diet try to do it slowly as sudden changes can cause further bowel issues. Make 1 change every 2-3 days and stick with them. Examples of changes are:

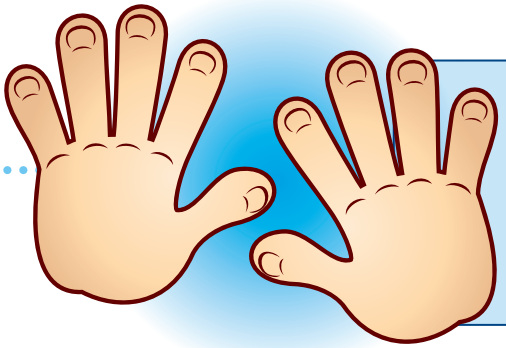
- Add in a piece of fruit as a snack.
- Switching to a higher fibre cereal such porridge rather than rice crispies
- Add in a portion of vegetables with your dinner
- Switching to brown bread
- Add salad to your sandwiches
- Switching from diluting juice to fresh fruit juice with breakfast
- Have vegetable soup with lunch

People on a high fibre diet who still suffer with constipation may benefit from referral to a dietitian particularly if they also have a diagnosis of IBS

Drinks

1 cup = approx **200mls**

Aim to drink at least **6-8** drinks a day



Increase it to **10** drinks a day if you are currently constipated, if you get constipated a lot or if you feel thirsty.

Water, milk, juices, tea or coffee all count

The best way to check you are getting enough water is to check the colour of your urine – it should be a pale straw colour. If it is darker than this you should try to drink a little more.

Thickened Drinks

If your doctor has prescribed thickener* to use in your drinks you may be getting quite a lot of fibre from these as well as the food you eat.

People using any variety of thickener may need to drink more to stay well even though it can be hard for them to take more.

Speak to your GP, Speech and Language Therapist or Dietitian if you are struggling with constipation and using thickeners.

* Applies to gum based thickeners such as Nutilis Clear particularly for people using larger doses.

5.4 Exercise to Ease Constipation

How Can Exercise Help Constipation?

Exercise helps constipation by decreasing the time it takes food to move through the large intestine, thus limiting the amount of water absorbed from the stool into the body. Hard, dry stools are harder to pass. In addition, aerobic exercise accelerates your breathing and heart rate. This helps to stimulate the natural contraction of intestinal muscles. Intestinal muscles that contract efficiently help move stools out quickly.

When Is the Best Time to Exercise?

People should wait an hour after a big meal before engaging in any rigorous physical activity. After eating, blood flow increases to the stomach and intestines to help the body digest the food. However, exercising right after eating causes the blood to flow toward the heart and muscles instead. Since the strength of the gut's muscle contractions directly relate to the quantity of blood flowing in the area, less blood in the GI tract means weaker intestinal contractions, fewer digestive enzymes, and the food waste moving sluggishly through the intestine. This can lead to bloating, excess gas, and constipation. So after a big meal, people should give their body a chance to digest it before starting to exercise.

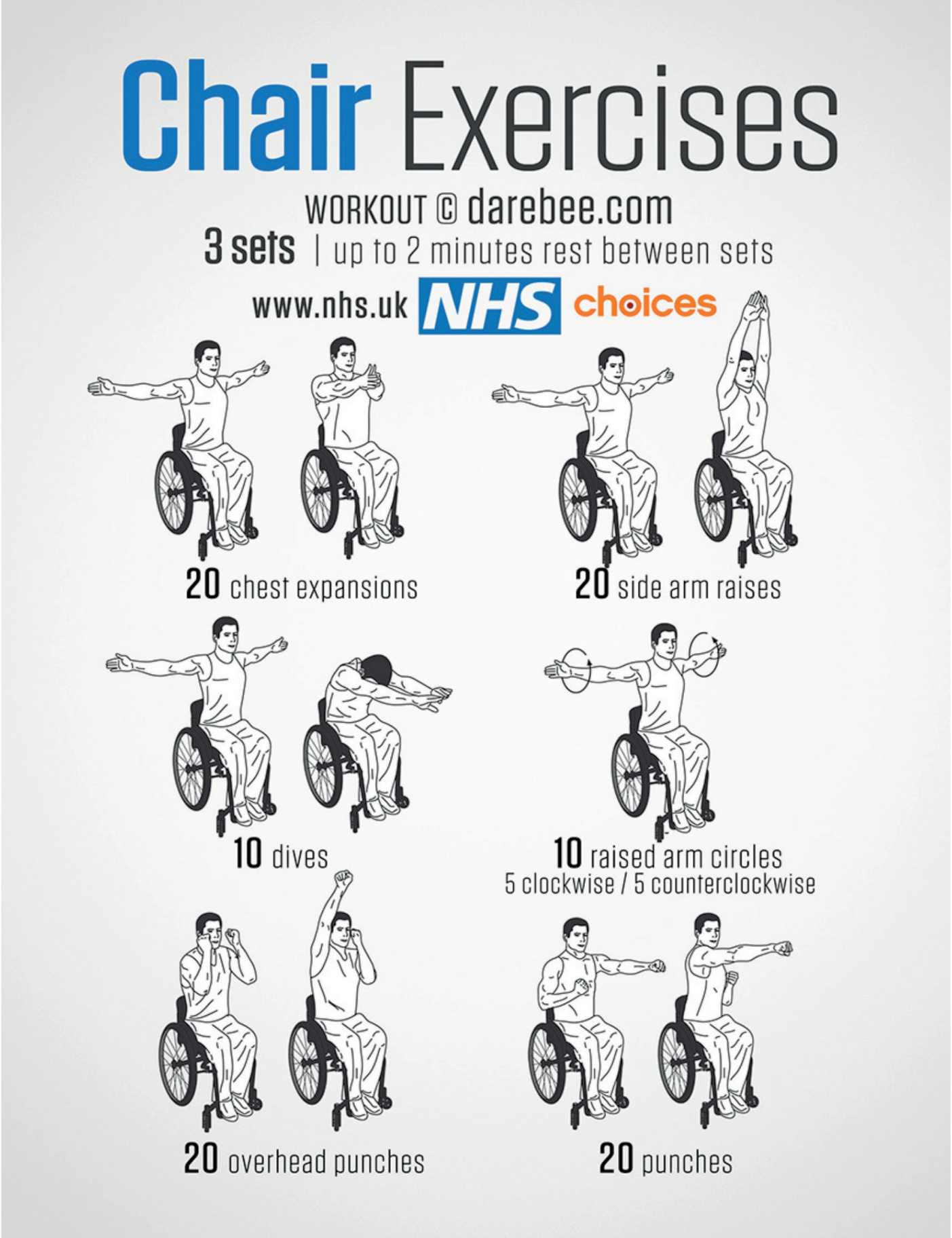
What Are the Best Exercises for Constipation?

Simply getting up and moving can help constipation. A regular walking regimen - even 10 to 15 minutes several times a day - can help the body and digestive system function optimally. People who are already fit might opt for aerobic exercise: walking briskly, jogging, swimming, or dancing, for example. All these exercises can help keep the digestive tract healthy. Stretching may also help alleviate constipation, and daily activities such as household chores or gardening can be helpful.

What kind of exercise is suitable for wheelchair users?

People who are in a wheelchair or find it difficult to walk or stand can still benefit from exercise to ease constipation. Exercises can be performed in a chair that can increase heart rate and breathing. Using small weights can increase the effort required for the exercise and this can increase heart rate and breathing. An example of chair exercises is given below. Taking time out of the chair to stretch out and do movements such as rolling, hip and knee bending will be helpful. For people who find it difficult to move on their own, their carer can help with these exercises.

5.5 Chair Exercises



5.6 Medication

On the next page is an alphabetical list of commonly prescribed medications that may increase the risk of constipation. This is not a comprehensive list of every drug that may increase the risk of constipation. If you are concerned about a medication and the risk of constipation please speak to the GP, community pharmacist, or learning disabilities nurse. If the medication has been prescribed for a long time it is less likely to cause constipation as a new side effect.

There is also an increased risk of constipation for patients with 5 or more prescribed medications (polypharmacy).

Many medicines used by people with learning disabilities have anticholinergic effects. Acetylcholine is the most common neurotransmitter in the brain. Medicines with anti-cholinergic effects reduce the activity of acetylcholine in the brain. The anti-cholinergic effect of an individual medicine may be small, but the anti-cholinergic effects of multiple medicines may be additive, constituting "anticholinergic burden". The degree of anti-cholinergic effect varies greatly between drugs. The anti-cholinergic effect may be intrinsic to the therapeutic effect of the medicine or an unintended side effect. The most common effects of anti-cholinergic drugs are constipation, dry mouth, and blurred vision, confusion, impaired cognition and effects on balance, gait and mobility. Medications with anti-cholinergic effects are in italics.

Antipsychotic drugs are marked with an asterisk*. Constipation is a common and potentially serious side effect of antipsychotics, particularly Clozapine. When taking Clozapine, there may be a reduced urge to pass stools so individual patients may not be accurately reporting or displaying symptoms associated with constipation.

Drugs associated with constipation

Alendronic acid	Gabapentin	Pregabalin
Amiloride	Gemfibrizol	*Procyclidine*
Amitryptiline	Gliclazide	*Promethazine*
Atomoxetine	*Hydroxyzine*	*Quetiapine**
Carbamazepine	*Hyoscine*	*Risperidone**
Cetirizine	Lacosamide	*Solifenacin*
*Chlorpromazine**	Lansoprazole	*Tolterodine*
Clarithromycin	*Lofepramine*	Topiramate
Clomipramine	Loratadine	Tramadol
Clonidine	Maalox/Maalox plus	*Trazodone*
Chlorphenamine	Mucogel	*Trospium*
*Clozapine**	*Olanzapine**	Venlafaxine
Co-amilozide	Omeprazole	Verapamil
Codeine	Oxcarbazepine	*Zuclopenthixol**
Duloxetine	Oxybutynin	
Fexofenadine	Phenytoin	

It is recommended that GP's review prescribed medication that may be associated with constipation.

5.7 Medical Conditions, Characteristics, and Lifestyle Factors Associated with Constipation

The following increase the risk of constipation:

Profound and multiple learning disabilities	Depression
Cerebral palsy	Anxiety
Elderly population	Hypothyroidism
Life Style Factors such as: • Lack of exercise/ poor mobility • Poor diet with not enough fibre • Dehydration: not drinking enough fluids, or drinking fluids that cause dehydration such as alcohol, or excessive salivation / drooling	Diabetes
Social and psychological factors such as environment, abuse, ignoring the urge to go	Hypocalcaemia
Reliance on others for support	Parkinson's disease
Certain medications	Multiple sclerosis
Mobility impairing conditions	Stroke
Anal Fissures	Other neurological conditions e.g. spina bifida
Haemorrhoids	Rheumatoid arthritis
Hirschsprung Disease	Low muscle tone
Bowel disease such as Crohn's Disease, ulcerative colitis	Muscular dystrophy
Irritable bowel syndrome	Pain
Colon cancer	Underweight
Bowel surgery	Obesity
Complications of pelvic or abdominal surgery	Anaemia
PEG feeding	
Swallowing difficulties	

5.8 Toileting

Defecating is a private thing. Privacy is important as it reduces stress, helping the person relax and feel more comfortable for defecation. Toileting should be as stress free as possible to minimise the risk of constipation. Support with negative experiences must be considered along with interventions such as life style changes and prescribing.

Remember that increased anxiety, change in behaviour or mental health deterioration may indicate distress around constipation or toileting.

Timed toileting programmes are an effective way of supporting self-management irrespective of level of learning disabilities.

When planning a toileting routine remember that most people open their bowels:

- In the morning after breakfast or caffeinated coffee (this is due to the gastro colic reflex)
- 30 minutes after eating a meal
- 30 minutes after taking a laxative

A warm bath may help to relax muscles before attempting to defecate and should also be considered as part of a toileting routine. Successful training of the bowel requires routine. Facilitating regular time may help the bowel from emptying irregularly.

5.9 Positioning

Squatting is the best position to open the bowels. This can be assisted by providing a footstool which raises the person's feet off the floor and allows them to lean forward resting their elbows on their upper leg. This allows the rectum to be straight, promotes the use of abdominal muscles and allows gravity to assist supporting defecation. This is also known as the high Fowlers position.

If the individual is unable to achieve or maintain this position they should lie on their left side with their knees flexed to support the natural anatomy of the anal canal and rectum when defecating, if possible. Flexing the knees reduces discomfort.

Correct position for opening your bowels

Step one

Knees higher than hips

Step two

Lean forwards and put elbows on your knees

Step three

Bulge out your abdomen
Straighten your spine

Correct position

Knees higher than hips
Lean forwards and put elbows on your knees
Bulge out your abdomen
Straighten your spine

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Wendy Ness, Colorectal Nurse Specialist.

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6. Abdominal Massage

6.1 What is Abdominal Massage?

- Abdominal massage is a non-invasive massage technique for the treatment of constipation
- It is a clockwise massage technique over the stomach area that takes 10-20 minutes

6.2 Abdominal Massage Can:

- Reduce the need for long-term laxative medication
- Help to relieve flatulence (wind) and / or constipation
- Reduce the incidents of hospital admission due to bowel impaction and associated health problems

6.3 Who Can Give It?

- Anyone who undertakes the appropriate training can give abdominal massage. This could be a partner/carer or person with learning disabilities

6.4 Who Would Benefit?

- Most people suffering from chronic constipation
- People with stomach cramps due to wind
- People who continue to have some problems with emptying their bowels in spite of having regular enemas
- People who take regular laxatives to have their bowels open

6.5 How Do We Know It Works?

- Research has shown that the use of abdominal massage as part of a wider bowel management programme can improve bowel function. This may reduce the amount of laxatives required and / or the need for enemas and suppositories

6.6 Abdominal Massage is Not For:

People with:

- A history of malignant bowel obstruction or abdominal growth
- A history of inflammatory disease of the intestine e.g. Crohn's disease
- Spastic colon, experienced in irritable bowel syndrome (not to be confused with spasticity of the abdominal wall)
- Unstable spinal injury
- Recent scaring or abdominal surgery
- Skin lesions
- Pregnancy
- Any abdominal hernia – hiatus, umbilical, or inguinal: care should be exercised

GP consent must be completed prior to commencing abdominal massage.

6.7 Total Bowel Management

Other areas to be considered prior to/in conjunction with abdominal massage:

- Diet and fluid intake
- Mobility
- Exercise
- Medication
- Physical difficulties in using the toilet
- Behavioural problems

6.8 Training and Learning Resources

- LD physiotherapy and nursing staff will be offered training in abdominal massage over 2 separate half day sessions. This will ensure they have the required competencies to deliver individual training to care staff of people with learning disabilities
- A training pack for the abdominal massage training to carers will be devised to ensure training consistency
- A minimum of 2/3 trainers per team is required to ensure service delivery
- A 10 minute DVD and an A4 pamphlet with photos of the massage strokes will be commissioned to provide additional resources to consolidate their training
- Once competent the LD trainers will deliver the abdominal massage training to care staff/s for the individual client over 3 separate sessions:
  - Session 1: Theory and practical demonstration on care staff
  - Session 2: Practical demonstration on the client
  - Session 3: Trainer will observe massage technique by carer on the client
- The carer training pack will be sent to the carer prior to session 1
- The DVD and pamphlet will also be given to care staff as an additional learning resource

6.9 Ongoing Monitoring of the Abdominal Massage

- Bowel charts and massage recording charts will be implemented for the client receiving the massage. These will act as outcome measures for monitoring the effectiveness of the massage technique
- Food and fluid charts may also be appropriate
- Refresher sessions to care staff can be offered if required
- The use of DisDAT will be encouraged to ensure care staffs are applying the appropriate technique

7. Medication to Support the Treatment of Constipation

The least invasive method of treatment should always be considered in the first instance. This should involve a review of lifestyle factors, and appropriate advice given on lifestyle factors including diet and exercise.

The GP or medical staff should advise on the use of long term laxatives as opposed to over the counter remedies, and this should help determine a care plan. The care plan should be reviewed regularly by the multi-disciplinary team (MDT).

The pharmacist can advise on over the counter remedies on a short term basis, perhaps over a holiday period. However if symptoms persist or worsen (red flag indicators) medical advice should be sought.

Some laxatives can be habit forming and result in the muscles and nerves of the colon functioning inadequately in producing the urge to defecate. Some people with learning disabilities have a long history of laxative use and this can slow down colonic motility. The colon can become atonic and distended and doesn't respond normally to the presence of the stool. Life style changes should always be considered in preventing and to manage constipation. A holistic approach involving the MDT should provide input when implementing a bowel management plan.

Prescription of stimulant laxatives are recommended on a short term basis. Osmotic laxatives can be given longer term and may take a day or two to have effect. Some people with learning disabilities rely on laxatives in the long term, and this should be reviewed regularly with the GP and the MDT.

7.1 Types of Laxatives

Osmotic laxative	Also known as a faecal softener. Increases the amount of fluid in the bowel to soften the stool and promote stimulation to want to go to the toilet. It is essential that the individual has adequate fluid intake to make them work and avoid intestinal obstruction	Examples - Lactulose, Laxido
Bulk forming laxative	Of value if the diet is deficient in fibre; in people with small hard stools. Adequate fluid intake must be maintained to avoid intestinal obstruction. Wheat bran taken with food or fruit juice is an effective bulk-forming preparation	Examples -Ispaghula husk, Methylcellulose, Sterculia
Stimulant laxative	May be prescribed to help the individual pass the stool once bulk-forming and osmotic laxatives have softened the stool. These encourage the bowel muscles to push harder than normal and generally work within 6-12 hours	Examples - Senna, Bisacodyl, Sodium picosulphate
Suppositories	As above but work faster (20-60 minutes)	Examples - Senna, Bisacodyl, Sodium picosulphate
Enemas	Work like osmotic laxatives / faecal softener and work quickly	

Faecal impaction is treated with high doses of osmotic laxatives followed by a stimulant laxative. Suppositories and enemas are also used to treat faecal impaction.

7.2 Information Regarding Prescribing Guidelines

Refer to NHSGG&C Therapeutics Handbook for current formulary drug choices for managing constipation. www.ggcprescribing.org.uk

Learning Disability
Treatment Protocol for Administration of As Required Medications

NHS Greater Glasgow and Clyde

Name:		**CHI:**	
Please tick indication for medication	a. Pain Relief ☐	**CLDN**	0141 577 3967
		NHS 24	111
	b. Bowel Management ☐	**GP**	
		Consultant Other	
	c. Behaviour Management ☐		
	d. Other – (describe):		

Medication prescribed for indication a/b/c or d

Name of Drug	Formulation	Strength	Dose	Route
Laxido	Powder reconstituted with water	N/A	See below	Oral
MAXIMUM DOSE IN 24 HOURS:				

1. When should Laxido be administered?

- ..... is administered 2 sachets of Laxido every day
- This should mean that ..... will open his bowels every day with a type 3, 4 or 5 on the Bristol stool chart
- If ..... bowels become loose i.e. a type 6 or 7 on the Bristol stool chart then Laxido will be reduced to 1 sachet a day
- If ..... bowels continue to be loose then Laxido will be withheld and contact the GP for advice
- If ..... is moving his bowels but it is a type 1 or 2 on the Bristol stool chart then this means he is constipated

2. What to do after Laxido 2 sachets have been administered?

Continue to monitor ....., offer reassurance and record any bowel movements accurately

3. When can a repeat be administered? (see guidance note Section 3)

- If ..... does not have a bowel movement for 24 hours or is passing a type 1 or 2 on the Bristol stool chart then administer 3 sachets of Laxido daily for 2 days
- If ..... does not have a bowel movement or continues to pass a type 1 or 2 on the Bristol stool chart then administer 4 sachets of Laxido daily for 2 days
- When ..... has a bowel movement and/or does not appear constipated return to 2 sachets of Laxido daily

4. When do you seek further advice? (what for and who from))

- If after following the above administration plan ..... has not had a bowel movement or continues to appear constipated then seek medical advice
- If at any time ..... is showing signs of distress due to abdominal pain or distension, nausea and vomiting or poor appetite then seek medical advice

This treatment is approved by (prescriber/ GP/Consultant) **Signed:** **Date** **Regular review timescale**	GP Practice stamp (if relevant): 1 year – due November 2017

Carer Note: This protocol does not have an automatic expiry date – it remains valid until discontinued by a healthcare professional. Please request a review annually.
Nurse/Doctor Note: The treatment protocol should be reviewed annually for efficacy.

Name		**Name**	
Designation		**Designation**	
Date		**Date**	
Signed		**Signed**	

Guidance Notes for Treatment Protocol for Administration of As Required Medication.

This protocol is designed to be used for a range of medication treatments which are prescribed 'as required' to people with learning disability/reduced capacity. This will be where the individual to be treated has a reduced ability to communicate and may lack capacity to recognise when medication may be of benefit, and to enable such treatments to be delivered safely and appropriately by carers. The focus of this guidance is on the specific issues relating to delivering treatments in this population, not the treatments themselves. All patients who lack capacity should have an AWI section 47 certificate in place which authorises such treatments. Where medication may be being covertly administered please refer to NHSGG&C Covert Medication Policy.

Section

1. Provide clear indications for individual treatment, use behavioural markers where verbal expression is absent. Assessment tools such as Disability Distress Assessment Tool (DisDAT) can help identify non verbal expression of physical and psychological communication for the individual. The Community Learning Disability Team (CLDT) may be able to help with this type of assessment.
   - **Pain** - age can be a less reliable indication of body weight in this population – ensure a recent weight is available.
   - **Bowels** - descriptions using the Bristol stool chart may help carers to identify when to treat as directed. Individual bowel management plan may be in place.
   - **Behaviour** - cause and presentation of individual behaviours targeted for treatment will vary e.g. anxiety/ aggression etc and must be specified where possible in conjunction with any de-escalation/ reactive behavioural management plan. CLDT can further advise on reactive management plan.
2. Include advice for carers including what to expect as an outcome from treatment e.g. following administration of analgesia there should be decreasing markers of distress/pain (as identified in section1.) within 30 minutes of treatment administration. Also describe what to do if the treatment fails e.g. call for medical advice. Encourage carers to note and record the actual effects to feed back on behalf of the patient.
3. Make the indications for any subsequent dose clear. Specify the timing of repeat doses and include symptom persistence if appropriate. If a repeat dose is inappropriate please write this on the protocol, do not leave blank.
4. For each individual clearly indicate the timescale and/or describe perseverance of symptom for seeking medical advice/ support. Specify what the advice is, for example:

Pain - If pain symptoms escalate; temperature remains elevated or continues to rise call for urgent advice from either GP or NHS24. Arrange GP appointment if pain relief has been administered for three days with no worsening but no improvement.

Bowels - arrange GP appointment if unsatisfactory bowel movement, abdominal pain/distension or diarrhoea, as may be overflow.

Behaviour Management - If behaviours continue to escalate following medication being administered or where there is lasting distress after the treatment cycle specified for the individual has been completed. Call appropriate support service for the individual e.g. may be out of hours LD nursing service, NHS24, specific on call senior in support service. Regular timescale for review for change/discontinue/continue should be stipulated on the protocol by the prescriber.

8. Assessment

Assessment of constipation includes a detailed history:

- Evidence from diary or stool charts is required
- Diet and fluid intake diary
- Changes to diet
- Changes to mobility
- Consideration of factors causing constipation

In terms of assessment it is important to identify what the normal frequency of bowel movements is for the individual. However it is important to consider the definition of constipation and consider appropriate interventions even if the norm for that individual is to open his/her bowels once a week on a regular basis. If the individual is passing hard, dry stools, or is sometimes straining to pass stools, or passes stools less than three times a week they have the characteristics of constipation, and interventions should be considered.

"Normal" for the individual does not necessarily mean that they are not experiencing constipation and appropriate interventions should be considered.

Monitoring of bowels should be carried out on a daily basis when constipation is considered. A stool chart should be implemented and appropriate interventions put in place and evaluated and reviewed regularly with the MDT.

The goal is:

- Soft, formed stools at least three times per week.
- Preventing, or identifying and managing discomfort and distress associated with constipation
- Identifying measures that prevent or treat constipation
- Self-management or carer understanding of measures that will prevent and/or manage constipation

Bristol Stool Chart, and Stool Types for People who Use Pads is at appendix 1.

8.1 Involvement of MDT

Recurrent constipation should be reviewed by the GP, who may carry out a physical examination followed as appropriate by appropriate laboratory and radiological investigations. The physical examination may involve feeling the abdomen or a more invasive examination such as rectal exam. This may cause discomfort or distress and the person may require person centred support with this and reasonable adjustments should always be considered.

Chronic constipation may be assessed by a gastroenterologist. Further investigations such as colonoscopy or the use of radiological coloured markers, and X-rays may be considered.

All people supporting people with learning disabilities should know that constipation is more common in this group. A holistic, partnership approach is required and the multidisciplinary team should be included:

- Family carers / paid carers
- Learning disabilities nurse
- GP
- Psychiatrist
- Physiotherapist
- Occupational Therapist
- Dietician
- Pharmacist

8.2 Communication, including Pain and Distress

All people supporting people with learning disabilities should also know that individuals may be unable to communicate issues with constipation and therefore there is a responsibility for support and care staff to be aware of the signs and symptoms of constipation to prevent diagnostic overshadowing.

Someone with good verbal communication may be able to self report that they have opened their bowels and describe discomfort they experience when using the toilet. Others may not despite having good verbal communication skills. Additionally they may not be comfortable talking about toileting and may not highlight any problems they are having. To assess it may be necessary to observe the toilet after use.

Communicating pain can be challenging and we should never assume that an individual has the skills to verbally do this. Recognising and managing pain can also be a challenge and there is a risk of diagnostic overshadowing.

As well as constipation, other conditions such as haemorrhoids, anal fissures, or other anal/ rectal conditions can cause distress and pain. Anticipating the pain associated with this can cause individuals to ignore the urge to defecate which will over time result in a dilated rectum that no longer responds to the presence of the stool. The longer the stool stays in the rectum the drier and harder it becomes and the more difficult it will be to pass.

Consider whether pain relief is required in the form of pain killers prior to going to toilet, or local anaesthetic ointment, or muscle relaxant to ease pain and relax muscles around anus. Treatment of haemorrhoids and anal fissures should be implemented.

Non pharmacological interventions which will reduce distress such as a warm bath, massage including abdominal massage, should also be considered in the bowel management plan. Abdominal massage helps move the stool through the colon when the person's mobility is compromised. It is additionally a pleasant and relaxing intervention.

A recorded base line of content and distress behaviours should be considered. DisDAT can help identify distress cues in people who have severely limited communication. It is designed to describe a person's usual content cues, thus enabling distress cues to be identified more clearly and managed (Appendix 3).

9. Complications of Constipation

- **Faecal impaction** can occur when hard, dry stool causes obstruction in the rectum meaning it cannot be passed. This can also lead to bowel ischemia, breathing problems, vomiting, aspiration, and death.

  Signs of faecal impaction may include:

  » Swelling around rectum

  » Bleeding

  » Faecal Incontinence of soft or liquid stools seen as staining on underwear or pad. Note: this can give the false impression that the person is passing stools as normal

  » Blood on underwear or pad could also be an indicator

  Urgent medical advice should be sought

- **Haemorrhoids (piles)** may occur when attempting to pass a constipated stool. These are caused by swollen blood vessels, and cause pain and bleeding.

  Signs of haemorrhoids may include:

  » Swelling around anus

  » Anal Fissures

  » Bleeding

  » Pain

  » Itch – the client may scratch or touch anus

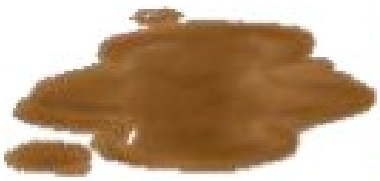
  Medical advice should be sought

- **Change in behaviours and/ or mental health deterioration**
- **Pain – abdominal cramps; pain from haemorrhoids or anal fissures**
- **Diverticula of colon**
- **Mega colon**
- **Death**

Link workers from within Learning Disabilities Services will be identified to deliver training opportunities around constipation for carers.

Appendix 1. Stool Charts

The Bristol Stool Chart

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on its surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges (passed easily)
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces. **Entirely Liquid**

Stool Types for People who Use Pads

We recommend that this chart is always printed in colour

	**Type 1 –** Separate hard lumps, difficult to pass, may be evidence of straining. These will not flatten if sat on but will retain some shape and may leave indentation on the skin.
	**Type 2 –** Similar to type 1 but will be more clumped together. Difficult to pass and may be evidence of straining. Will not flatten if sat on and may be indentation on the skin.
	**Type 3 –** Will be easier to pass, more sausage shaped but with cracks on the surface. Will flatten slightly if sat on but will retain most of its shape. Faeces will look harder in appearance than type 4.
	**Type 4 –** Is soft and smooth, passed easily however will be formed faeces when passing. If sat on it will flatten easily leaving no indentation on the skin but there will be some shape. If urine passed at the same time it may take on a slightly wet appearance but will be evidence of formed soft faeces.
	**Type 5 –** Soft faeces will be passed easily with minimal formed shape and will be spread over the pad if sat on leaving no shape. If urine passed it may have an appearance of being softer and more like type 6.
	**Type 6 –** Will be very soft/liquid faeces and may soak into the pad. There will be evidence of some formed faeces.
	**Type 7 –** Type 7 will be entirely liquid which will give the appearance of brown staining only on the pad

Guidance Notes:

Type 1 and 2 may be very similar in appearance however both give an indication of constipation and should be acted upon. You may see the person straining at times when they are opening their bowels and this is because the faeces are hard and difficult to pass.

Type 3 and 4 are considered to be normal and should be much easier to pass with type 4 being ideal as it should glide out easily. In a pad these will be much softer and will be flattened if sat on however there will be some obvious shape retained and it won't just look like a blob in the pad. There will be no evidence of straining with these types and you may not know the person has moved their bowels immediately.

Type 5, 6 and 7 are much harder to distinguish between especially if urine has been passed at the same time. This will make the faeces wet in appearance and can make it look more liquid than it is. With type 5 there will be evidence of more formed faeces although it will be very soft and squashed into the pad. With type 6 there will be less of this and will be evidence of brown staining in the pad. With type 7 it is entirely liquid; the person may have no control over it and it will look like brown staining on the pad as it will be soaked into the pad. This can be an indication that the person has a stomach upset but can also be an indication of faecal impaction. If this continues for more than 48 hours then medical advice must be sought.

Bowel Movement Chart

Name: _____ **CHI:** _____ **Date Commenced:** _____

Date	Time	Comments **i.e: volume, blood, mucus** S - small M - Medium L - large	**Type 1** Separate hard lumps like nuts (hard to pass)	**Type 2** Sausage shaped but lumpy	**Type 3** Like a sausage but with cracks on surface	**Type 4** Like a sausage or snake, smooth and soft	**Type 5** Soft blobs with clear-cut edges (passed easily)	**Type 6** Fluffy pieces with ragged edges, a mushy stool	**Type 7** Watery, no solid pieces (entirely liquid)	**Staff Initials**
										

Appendix 2. Bowel Chart

A Guide to completing the Comments section

Write a comment if you see anything unusual, don't worry about how you describe it just write what you see.

Examples could include:

- Comment if you have been unable to observe toileting for any reason.
- Anything unusual about colour e.g.yellowy, green or black
- Signs of mucus or blood in stool
- Straining while on the toilet
- Signs of feeling an urgent need to go to the toilet
- Stomach rumbling a lot
- Stomach pain
- Smearing but no stool to comment on
- Lots of wind
- Straining/ bloated tummy but only
- passing small amounts of Type 7
  (this can be a sign of constipation with something call overflow diarrhoea)
- Bloating
- Upset by going to the toilet
- Seen as independent toileter /flusher
- Unusually foul smells
- Long time spent in toilet
- Excessive toilet visiting

Appendix 3. The DisDAT

v15

Disability Distress Assessment Tool

Client's name:	
DoB:	**Gender:**
Unit/ward:	**NHS No:**

Your name: **Date completed:**

Names of others who helped complete this form:

DisDAT is

Intended to help identify distress cues in people who because of cognitive impairment or physical illness have severely limited communication.

Designed to describe a person's usual content cues, thus enabling distress cues to be identified more clearly.

NOT a scoring tool. It documents what many staff have done instinctively for many years thus providing a record against which subtle changes can be compared. This information can be transferred with the client or patient to any environment.

Only the first step. Once distress has been identified the usual clinical decisions have to be made by professionals.

Meant to help you and your client or patient. It gives you more confidence in the observation skills you already have which in turn will help you improve the care of your client or patient.

INSTRUCTIONS FOR USING DisDAT ARE ON THE BACK PAGE

SUMMARY OF SIGNS AND BEHAVIOURS

Appearance when CONTENT

Face Eyes

Tongue/jaw

Skin

Appearance when DISTRESSED

Face Eyes

Tongue/jaw

Skin

Vocal signs when CONTENT

Sounds

Speech

Vocal signs when DISTRESSED

Sounds

Speech

Habits and mannerisms when CONTENT

Habits

Mannerisms

Comfortable distance

Habits and mannerisms when DISTRESSED

Habits

Mannerisms

Comfortable distance

Posture & observations when CONTENT

Posture

Observations

Posture & observations when DISTRESSED

Posture

Observations

Known triggers of distress (write here any actions or situations that usually cause or worsen distress)

Disability Distress Assessment Tool

Please take some time to think about and observe your client's appearance and behaviours when they are both content and distressed, and describe these cues in the spaces given. We have listed words in each section to help you to describe your client or patient. You can circle the word or words that best describe the signs and behaviours when your client or patient is content and when they are distressed. Document the cues in each category and, if possible, give a fuller description in the spaces given. Your descriptions will provide you with a clearer picture of your client's 'language' of distress.

COMMUNICATION LEVEL *

This person is unable to show likes or dislikes	☐	Level 0
This person is able to show that they like or don't like something	☐	Level 1
This person is able to show that they want more, or have had enough of something	☐	Level 2
This person is able to show anticipation for their like or dislike of something	☐	Level 3
This person is able to communicate detail, qualify, specify and/or indicate opinions	☐	Level 4

* This is adapted from the Kidderminster Curriculum for Children and Adults with Profound Multiple Learning Difficulty (Jones, 1994, National Portage Association).

FACIAL SIGNS

Appearance

Information / instructions	Appearance when content	Appearance when distressed
(Ring) the words that best describe the facial appearance	Passive Laugh Smile Frown Grimace Startled Frightened Other:	Passive Laugh Smile Frown Grimace Startled Frightened Other:

Jaw movement

Information / instructions	Movement when content	Movement when distressed
(Ring) the words that best describe the jaw movement	Relaxed Drooping Grinding Biting Rigid Other:	Relaxed Drooping Grinding Biting Rigid Other:

Appearance of eyes

Information / instructions	Appearance when content	Appearance when distressed
(Ring) the words that best describe the appearance	Good eye contact Little eye contact Avoiding eye contact Closed eyes Staring Sleepy eyes 'Smiling' Winking Vacant Tears Dilated pupils Other:	Good eye contact Little eye contact Avoiding eye contact Closed eyes Staring Sleepy eyes 'Smiling' Winking Vacant Tears Dilated pupils Other:

SKIN APPEARANCE

Information / instructions	Appearance when content	Appearance when distressed
(Ring) the words that best describe the appearance	Normal Pale Flushed Sweaty Clammy Other:	Normal Pale Flushed Sweaty Clammy Other:

VOCAL SOUNDS (NB. The sounds that a person makes are not always linked to their feelings)

Information / instructions	Sounds when content	Sounds when distressed
Ring the words that best describe the sounds *Write down* commonly used sounds (write it as it sounds; 'tizz', 'eeiow', 'tetetetete'): …… …… ……	**Volume**: high medium low **Pitch**: high medium low **Duration:** short intermittent long **Description of sound / vocalisation**: Cry out Wail Scream laugh Groan / moan shout Gurgle Other:	**Volume:** high medium low **Pitch:** high medium low **Duration**: short intermittent long **Description of sound / vocalisation**: Cry out Wail Scream laugh Groan / moan shout Gurgle Other:

SPEECH

Information / instructions	Words when content	Words when distressed
Write down commonly used words and phrases. If no words are spoken, write NONE		
Ring the words which best describe the speech	Clear Stutters Slurred Unclear Muttering Fast Slow Loud Soft Whisper Other:	Clear Stutters Slurred Unclear Muttering Fast Slow Loud Soft Whisper Other:

HABITS & MANNERISMS

Information / instructions	Habits and mannerisms when content	Habits and mannerisms when distressed
Write down the habits or mannerisms, eg. "Rocks when sitting"		
Write down any special comforters, possessions or toys this person prefers.		
Please Ring the statements which best describe how comfortable this person is with other people being physically close by	Close with strangers Close only if known No one allowed close Withdraws if touched	Close with strangers Close only if known No one allowed close Withdraws if touched

BODY POSTURE

Information / instructions	Posture when content	Posture when distressed
Ring the words that best describe how this person sits and stands.	Normal Rigid Floppy Jerky Slumped Restless Tense Still Able to adjust position Leans to side Poor head control Way of walking: Normal / Abnormal Other:	Normal Rigid Floppy Jerky Slumped Restless Tense Still Able to adjust position Leans to side Poor head control Way of walking: Normal / Abnormal Other:

BODY OBSERVATIONS

Information / instructions	Observations when content	Observations when distressed
Describe the pulse, breathing, sleep, appetite and usual eating pattern, eg. eats very quickly, takes a long time with main course, eats puddings quickly, "picky".	Pulse: Breathing: Sleep: Appetite: Eating pattern:	Pulse: Breathing: Sleep: Appetite Eating pattern:

Information and Instructions

When to use DisDAT

When the team believes the client is NOT distressed

The use of DisDAT is optional, but it can be used as a
- baseline assessment document
- transfer document for other teams

When the team believes the client IS distressed

If DisDAT has already been completed it can be used to compare the present signs and behaviours with previous observations documented on DisDAT. It then serves as a baseline to monitor change.

If DisDAT has not been completed:

a) When the client is well known DisDAT can be used to document previous content signs and behaviours and compare these with the current observations

b) When the client or the distress is new to the team, DisDAT can be used document the present signs and behaviours to act a baseline to monitor change.

How to use DisDAT

1. **Observe the client** when content and when distressed- document this on the inside pages. *Anyone* who cares for the patient can do this.
2. **Observe the context** in which distress is occurring.
3. **Use the clinical decision distress checklist** on this page to assess the possible cause.
4. **Treat or manage** the likeliest cause of the distress.
5. **The monitoring sheet** is a separate sheet, which may help if you want to see how the distress changes over time.
6. **The goal** is a reduction the number or severity of distress signs and behaviours.

Remember

- Most information comes from the whole team in partnership with the family.
- The assessment form need not be completed all at once and may take a period of time.
- Reassessment is essential as the needs of the client or patient may change due to improvement or deterioration.
- Distress can be emotional, physical or psychological. What is a minor issue for one person can be major to another.
- If signs are recognised early then suitable interventions can be put in place to avoid a crisis.

Clinical decision distress checklist

Use this to help decide the cause of the distress

Is the new sign or behaviour?

- Repeated rapidly?

Consider pleuritic pain (in time with breathing)
Consider colic (comes and goes every few minutes)
Consider: repetitive movement due to boredom or fear.

- Associated with breathing?

Consider: infection, COPD, pleural effusion, tumour

- Worsened or precipitated by movement?

Consider: movement-related pains

- Related to eating?

Consider: food refusal through illness, fear or depression
Consider: food refusal because of swallowing problems
Consider: upper GI problems (oral hygiene, peptic ulcer, dyspepsia) or abdominal problems.

- Related to a specific situation?

Consider: frightening or painful situations.

- Associated with vomiting?

Consider: causes of nausea and vomiting.

- Associated with elimination (urine or faecal)?

Consider: urinary problems (infection, retention)
Consider: GI problems (diarrhoea, constipation)

- Present in a normally comfortable position or situation?

Consider: anxiety, depression, pains at rest (eg. colic, neuralgia), infection, nausea.

If you require any help or further information regarding DisDAT please contact:
Lynn Gibson 01670 394 260
Dorothy Matthews 01670 394 808
Dr. Claud Regnard 0191 285 0063 or e-mail on claudregnard@stoswaldsuk.org

Northgate & Prudhoe NHS Trust Palliative Care Team
and St. Oswald's Hospice

Further reading

Regnard C, Matthews D, Gibson L, Clarke C, Watson B. Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing,* 2003, 9(3): 173-6.

**Distress may be hidden,
but it is never silent**

V3

Disability Distress Assessment Tool (Monitoring Tool)

Edinburgh University (Matt Hayes), Northgate Palliative Care Team and St. Oswald's Hospice

Client's name:	DoB:	Page No:	Please affix patient
Unit/ward:	Gender:	NHS No:	addressograph here

Please complete at any times when you are concerned that the patient is distressed
This individual's signs and behaviours of contentment / distress are detailed on the first page of the DisDAT assessment sheet

Date	Time	Is Patient Content/ Distressed	Please record observations of severity and duration of distress in these columns		Action Taken	Outcome
			Signs of Distress	Context of Distress		

Appendix 4. Constipation Risk Assessment Tool Part 1

Can be carried out by any members of the health team

Personal Details Name Date of Birth CHI Consent/ AWI/ Guardianship

Red Flag Symptoms:		
Are any of the following present?	**Yes**	**No**
Recent significant changes in bowel habits		
Blood and / or mucus in stools or pad		
Weight loss or weight gain, or bloating/ tight waist band with no weight gain		
Constipation with vomiting, with or without abdominal pain		
Constipation and loss of appetite		
Straining, or painful and ineffectual straining		
Changes in frequency of seizure activity		
Signs of faecal impaction, and the individual does not have an existing current Bowel Management Plan		

Yes to any of these questions - Seek prompt medical advice

Outcome

Bowel Habits / History		
Frequency of opening bowels Per day/ per week / per month Is this different from your usual pattern? **Reported Stool Types** Bristol Stool Chart / Stool Types for People who Use Pads (appendix 1)		
Onset of bowel problems - days / weeks / months / years / lifelong		
Is there a current issue or history of constipation?	**Yes**	**No**
Detail		
Bowel Chart given to collaborate history or assess (See Appendix 2)	**Yes**	**No**
Toileting programme Is the individual undertaking a toileting programme?	**Yes**	**No**
Detail		
Are there any additional signs or symptoms associated with constipation?		
If constipation medication is indicated refer to GP / medical staff for bowel management advice **Refer to Learning Disability Nurse as a priority in community setting. Nurse should then complete Constipation Risk Assessment Part 2 and identify other members of MDT who should support the bowel management plan**	**Detail and Date of referrals**	

High Risk Groups		
No current issues but should be considered to be at a high risk of developing constipation	Yes	No
High Risk Groups include : • Associated medical problems • Prescribed medication associated with constipation • Life style factors		
No history or current issue with constipation or other bowel problems, nor considered to be in a high risk group	Yes	No
Advice leaflet given – Eating and Drinking to Help Keep Things Moving	Yes	No
Advice leaflet given – Exercise to Ease Constipation	Yes	No

Print name

Signature Date

Designation

Appendix 5. Constipation Risk Assessment Tool Part 2

To be carried out by a Learning Disability Nurse

Personal Details Name Date of Birth CHI Consent/ AWI/ Guardianship					
Signs and Symptoms of Constipation					
	Yes	**No**	**Don't Know**	**Detail**	**Actions required**
Type 1 or Type 2 stool identified from The Bristol Stool Chart or Stool Type Chart for People who Use Pads **(See Appendix 1 for Stool Charts and Appendix 2 for stool recording charts)**					
Urgency					
Straining					
Incontinence of faeces					
Loss of appetite					
Pain or discomfort in abdomen					

	Yes	No	Don't Know	Detail	Actions required
Lethargy/ lack of energy or enthusiasm					
Faecal leakage (overflow) often mistaken for diarrhoea. Consider stool type 7 identified from The Bristol Stool Chart or Stool Type Chart for People who Use Pads (See Appendices 1 & 2)					
Consider signs of faecal impaction such as pattern of bowel movements e.g. Type 1 or 2 stool - no bowel movements - Type 7 stool					
A change in behaviour					
A change in seizure pattern					
Any additional signs associated with constipation					

History					
Investigations, surgery and identified bowel disease. Such as :	**Yes**	**No**	**Don't Know**	**Date of investigation**	**Actions Required**
Abdominal X-Ray					
Barium enema					
Sigmoidoscopy					
Colonoscopy					
Anal Ultrasound					
Chest X-Ray					
Other					
Outcomes					

History - Previous Bowel Surgery	Yes	No	Don't Know	Date of investigation	Actions Required
Outcomes					

History - Bowel Disease	Yes	No	Don't Know	Date of investigation	Actions Required

Existing Bowel Management Plan In Place?	Yes	No	Don't Know	Date of investigation	Actions Required

Aged between 50 and 74 years - Regularly participates in the National Bowel Screening Programme?	Yes	No	Don't Know	Date of investigation	Actions Required

Life Style Factors: Mobility and Nutrition and Fluid Intake					
Mobility	**Yes**	**No**	**Don't Know**	**Date of investigation**	**Actions Required**
Life Style Factors: Mobility and Nutrition and Fluid Intake					
Requires assistance / aids					
Independent wheelchair user					
Immobile / restricted to wheelchair / chair					
Information provided to individual / carer. Leaflet - Exercise to Ease Constipation					
Is referral to Occupational Therapy or Physiotherapy required?					
Outcome: Referral to: Date of Referral:					

Nutrition and Fluid Intake	**Record**	**Date**
	Height	
	Weight	
	BMI	
	MUST Screen Score	

Mobility	Yes	No	Don't Know	Detail	Actions Required
Is the individual considered to be underweight or over weight?					
Does the person have a healthy diet and fluid intake? Refer to Eating and Drinking to Keep Things Moving Leaflet					
Difficulty with swallowing and chewing?					
Dysphagia / modified diet and / or fluids e.g. PEG or other (specify)					
Fluid balance chart required?					
Does the individual have excessive salivation or drooling?					
Does the individual drink excessive amounts of alcohol?					

Mobility	Yes	No	Don't Know	Details	Actions Required
History of urinary tract infections (UTI)?					
Active with dietetics?					
Active with speech and language therapy (SLT)?					
Referrals required to SLT or dietetics?					
Outcome: Referral To: Date of Referral:					

Communication					
Detail individuals means of communication:					
	Yes	**No**	**Don't Know**	**Detail**	**Actions Required**
Is a communication passport required?					
Is a Bowel Management Plan highlighted in the communication passport? Detail - where is it available? To be completed / timescale					
Is DisDAT in place to support the recognition of distress? Detail- where available?					
Prompt required in care plan to check toilet (or agreed alternative) if individual toilets independently?					
Consent Considered					

Medication

Record all current medication and highlight all medication identified as high risk medication

Name of Medication	Dose and Frequency	Rational for Use
Over the Counter Medication	**Dose and Frequency**	**Rational for Use**

Social Considerations	Yes	No	Don't Know	Detail	Actions Required
Social isolation due to constipation or incontinence?					
Is there privacy?					
Is the toilet adapted to meet individual's needs?					
Has the individual a new routine which could be impacting on their previous toileting routine?					
Is the individual ignoring the urge to go to the toilet because they are engrossed in another activity?					
Is referral to GP /Continence advisor / OT required?					
Outcome: Referral to: Date of Referral:					

Toileting Facilities, Physical Environment and Routine	Yes	No	Don't Know	Detail	Actions Required
Can the individual adopt a squatting position to promote defecation?					
Has the individual seen OT, physiotherapist or continence advisor for assessment of functional ability and posture difficulties?					
Toileting programme Is the individual undertaking a toileting programme?					
Can the individual use the toilet independently?					
Can the individual use the toilet independently but requires support with personal hygiene?					
• Uses toilet with aids - rails / frames • Uses commode / bedpan • Uses raised toilet seat • Other					

	Yes	No	Don't Know	Detail	Actions Required
Requires support with transfers only?					
Requires support with transfers and personal hygiene?					
Uses foot stool to maintain squatting position?					
Uses prescribed continence aids? Specify					
Uses purchased continence aids? Specify					

	Yes	No	Don't Know	Detail	Actions Required
Does the individual have difficulty fully emptying the bowel and / or bladder?					
Are there any current issues around access to toilet? Specify					
Are there any environmental issues such as poor ventilation (odour), privacy, or comfort?					
Can the individual change position independently?					
Does the individual require assistance to change position? Specify					

	Yes	No	Don't Know	Detail	Actions Required
What is the individual's usual routine for the toilet e.g. time they usually go, how long they take, signs that indicate they need the toilet?					
Has there been a recent change to their daily routine that may disrupt the regular use of the toilet or stop them going when they want to e.g. time they leave for day services?					
Do they have any specific toilet habits such as taking a newspaper with them or listening to music? Specify					

	Yes	No	Don't Know	Detail	Actions Required
Is referral to OT, physiotherapy, or psychology required?					
Outcome : Referral Too: Date of Referral:					

Physical Considerations	Yes	No	Don't Know	Detail	Actions Required
Is the individual able to use the most optimal position for emptying bowels?					
Does the individual require the regular administration of suppositories or enemas?					

	Yes	No	Don't Know	Detail	Actions Required
Is the individual in pain attempting to open their bowels?					
Does the individual have haemorrhoids / piles?					
Does the individual have an anal fissure?					
Is abdominal massage used as alternative non-invasive intervention regularly					
Is referral to GP or continence advisor required?					
Outcome : Referral Too: Date of Referral:					

Psychological Considerations	Yes	No	Don't Know	Detail	Actions Required
Is there any suggestion of distress behaviour?					
Has there been a change to the individual's normal behaviour, perhaps manifesting as an increase in challenging behaviour?					
Is there any sense of embarrassment around constipation or toileting?					
Has a toileting programme been considered to promote independence?					
Has there been a negative experience in a toileting environment?					
Is there an increase in anxiety around toileting?					
Are there obsessional behaviours exhibited around toileting?					

	Yes	No	Don't Know	Detail	Actions Required
Is there current relevant involvement with psychology					
Is referral to GP or Psychology required?					
Outcome : Referral Too: Date of Referral:					

Print name

Signature Date

Designation

Appendix 6. Bowel Management Plan

Assessment	Rational	Intervention	Rational
Assess the usual pattern of elimination, including frequency and consistency of stool	To determine if individual is at risk of constipation or at risk of developing constipation	At baseline - complete Risk Assessment Pt 1, and use Bowel Record Charts in conjunction with the Bristol Stool Chart and / or the Stool Chart for People who Use Pads	Constipation is often wrongly viewed as a discomfort rather than a serious health problem. Undiagnosed and untreated constipation can have serious health consequences
Assess the individual's dietary habits, eating habits, eating schedule, and fluid intake	Appropriate diet and fluid intake stimulates gastric distension which is necessary for gastrointestinal activity. Irregular mealtimes, type of food, amount of fluids and interruption of usual schedule can lead to constipation. People with dysphagia often have additional difficulties maintaining hydration. This is often difficult for people with profound and multiple learning disabilities and those who are physically unwell	Complete Risk Assessment Pt 2 Encourage a diet high in fibre. Aim for at least 5 handful sized portions of fruit and vegetables a day. See Eating and Drinking to Help Keep Things Moving. Encourage the client to take in fluid; 6-8 drinks a day if no medical contraindication. Maintaining the correct fluid level is essential in promoting and achieving good health Hydration status should be assessed before laxative use	To determine risk factors Fibre adds bulk to the stool and makes defecation easier because it passes through the intestine essentially unchanged Sufficient fluid is needed to keep faecal matter soft. The digestive system transports fluids so both constipation and diarrhoea can negatively impact on fluid balance, requiring monitoring Laxative use can make dehydration worse. Additionally, dehydration increases the risk of UTI's and cancer of the bladder
Assess the client's activity level	Sedentary lifestyle such as sitting all day, lack of exercise, prolonged bed rest and inactivity contribute to constipation	Promote some physical activity and exercise. See Exercise to Ease Constipation	Movement promotes peristalsis. It decreases the time food takes to move through the large intestine, limiting the amount of water absorbed from the stool into the body. Hard, dry stools are hard to pass. Aerobic exercise accelerates breathing and heart rate which helps to stimulate the natural contraction of intestinal muscles. Intestinal muscles that contract efficiently help move stools out quickly. Abdominal exercises strengthen muscles that facilitate defecation

Assess and identify medication usage that may lead to constipation	A lot of drugs can slow down peristalsis. Antipsychotics, opioids, antacids, anti-epileptics, antidepressants, anticholinergics, anti-hypertensive, general anaesthetics, hypnotics, and iron and calcium supplements can cause constipation	Where possible have a GP review prescribed medication that can cause constipation. The GP, or medical staff, should advise on the use of long term laxatives as opposed to over the counter remedies	Many medicines used by people with learning disabilities have anticholinergic effects with cumulative risk of 'anticholinergic burden'. Constipation risk is increased for people taking 5+ medications
Assess toileting facilities	An assessment of functional ability, postural difficulties and environmental aids and adaptations will promote privacy, dignity, and encourage independence	Defecating is a private thing. Some clients may find it difficult if they are anxious or stressed. Additional aids and adaptations may be needed to the toilet area. Squatting is the best position to open the bowels. See Correct Position for Opening Your Bowels. Some individuals may be unable to achieve this. Consider assessment from OT and Physiotherapy	The toilet should ensure privacy and reduce any levels of stress the individual may be experiencing
Assess and identify if the individual is distressed when toileting	Haemorrhoids, anal fissures, or other painful disorders can cause the individual to ignore the urge to defecate, which over time results in a dilated rectum that no longer responds to the presence of stool. Additionally, consider other distressors around toileting such as environment, abuse, previous negative experiences, lack of independence, and embarrassment	The DisDAT Tool can help identify the language of the individuals distress Consider the following to minimise rectal discomfort: • Warm bath • Haemorrhoid preparations Is pain relief required prior to toileting e.g. pain killers / local anaesthetic ointment / lubricant / muscle relaxant Positioning. Unless contraindicated, encourage the client to use the bathroom. For bedridden patients, assist the client assume a high-Fowler's position with knees flexed	Toileting should be as stress free as possible to minimise the risk of constipation The warmth relaxes muscles before defecation attempt These over-the-counter preparations shrink swollen, painful haemorrhoids To ease pain and relax muscles around anus A sitting position with knees flexed straightens the rectum, enhances the use of abdominal muscles, and facilitates defecation

Consider the degree to which the patient responds to the urge to defecate	Ignoring the urge to defecate eventually leads to chronic constipation because the rectum no longer senses or responds to the presence of stool. The longer the stool stays in the rectum, the drier and harder it becomes. This makes the stool difficult to pass	Encourage a regular period for elimination	Timed toileting programmes are an effective way of supporting self-management irrespective of level of learning disabilities Most people defecate first thing in the morning or within 30 minutes of eating a meal, drinking coffee or taking a laxative, as a result of the gastrocolic reflex

Assess and identify associated medical conditions and factors	Some medical conditions, characteristics, and other factors are known to decrease peristaltic activity. There is a significantly higher incidence of constipation in people with learning disabilities	Consider and agree the frequency of review if any high risk groups are identified. See Risk Assessment Pt 2 Discuss with a dietician about dietary sources of fibre to prevent constipation The least invasive method of treatment should always be considered first. Consider: • A balanced high fibre diet that comprises adequate fibre, fresh fruits, vegetables, and grains • 8-10 drinks a day • A regular period for elimination and adequate time for defection • Regular exercise and activity • The environment and individual distressors • Explain medication use to support the treatment of constipation • Abdominal Massage, a non invasive massage therapy for the treatment of constipation	A person with enough knowledge will recommend sources of fibre consistent with the client's usual eating habits. Those unaccustomed to a high-fibre diet may experience abdominal discomfort and flatulence; a progressive increase in fibre intake is recommended Aim for at least 5 handful sized portions of fruit and vegetables a day. See 'Eating and Drinking to Help Keep Things Moving'. Increased hydration promotes a softer faecal mass Successful bowel training relies on routine. Facilitating regular time prevents the bowel from emptying sporadically Exercises strengthen abdominal muscles and stimulate peristalsis Allows the individual to relax, which can promote defecation The individual and their care provider will need to understand the use of prescribed medication to fully engage in the care plan. Stimulant laxatives should only be prescribed on a short term basis. Osmotic laxatives can be given longer term and may take a day or two to work Abdominal massage as part of a wider bowel management programme can improve bowel function. This may reduce the amount of medication required

Assess the impact of communication	Communication is the key to good assessment	Communication passports; DisDAT	Sharing of important information including bowel management plan. Supports non verbal communication
Education for self-management and / or for carer support	All people supporting people with learning disabilities should know they have a high risk of constipation, and be able to support individuals with the management of constipation	Link workers from Community Learning Disability Teams will work with individual nurses to provide education sessions to carers	Education and learning will enhance and improve the identification, treatment, and management of care in relation to constipation

Problem

- Constipation

Goal

- Soft, formed stools at least three times per week
- Preventing, or identifying and managing discomfort and distress associated with constipation
- Identifying measures that prevent or treat constipation
- Self-management or carer understanding of measures that will prevent and /or manage constipation

Intervention and Rational	**Outcome**	**Date**	**Review Date**

Appendix 7. Some Accessible Information

- **Making reasonable adjustments for people with learning disabilities in the management of constipation. Public Health England**
- https://www.ndti.org.uk/uploads/files/Constipation_RA_report_final.pdf

- **Self Care Forum**
- http://www.easy-read-online.co.uk/media/50962/constipation-lo-res-_v3pages.pdf

- **Preventing Constipation. Bristol Primary Care Trust**
- https://www.easyreadhealthwales.org.uk/media/47536/preventing-constipation.pdf

- **What is Constipation? South Staffordshire and Shropshire Healthcare**
- https://www.easyreadhealthwales.org.uk/media/47662/what-is-constipation.pdf

Notes

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