Public Health England

Protecting and improving the nation's health

Making reasonable adjustments for people with learning disabilities in the management of constipation

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Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

The PHE Learning Disabilities Observatory

The Public Health England Learning Disabilities Observatory (PHELDO) provides high-quality data and information about the health and healthcare of people with learning disabilities. The information helps commissioners and providers of health and social care to understand the needs of people with learning disabilities, their families and carers, and, ultimately, to deliver better healthcare. PHELDO is a collaboration between PHE, the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion. The observatory is operated by PHE and is also known as Improving Health and Lives (IHaL).

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We would also like to thank the family carers who have shared their stories.

Contents

Easy-read summary

This report is about constipation.

People with learning disabilities are more likely to have constipation than other people.

They don’t always get the support they need to make this better.

If people don’t get their constipation treated then they may need to go to hospital as an emergency.

Some people may become very ill or die from constipation.

The law says public services should put ‘reasonable adjustments’ in place to help people with learning disabilities use the services. This means they need to change their services so they are easier to use.

This report lists all the information we have found about looking after people who get constipation.

We could not find very many easy-read resources.

This report has information about ways to stop people getting constipated. It also has information about how to treat constipation.

It is important to take a person-centred approach. It is also important to think about the whole person and all the things that might make a difference.

The pictures in this report are from Photosymbols: www.photosymbols.co.uk

Foreword

Richard's story

My brother Richard had Down's syndrome, psychosis and a mischievous sense of humour. He loved theme parks, theatre classes, watching 'Mr Bean' and tickling people's toes! Richard also had constipation from birth. There's nothing glamorous about 'poo' but my parents understood Richard's needs and did their best to make toileting fun! Laughter could be heard from the bathroom every night, as my parents helped Richard to relax and encouraged bowel movements.

When Richard left home, assessment reports by professionals said very clearly that his constipation would always need close monitoring and support and that constipation should always be considered as a potential cause, when his mental health deteriorated. Somehow, this knowledge was lost over the years.

Richard sadly died very suddenly in 2012 as a result of unmanaged constipation. He was only 33 years old. Over 10kg of faeces was removed from Richard's bowels before he died and his bowel was 18cm diameter at post-mortem. His psychiatrist and GP had both seen him that week but did not recognise the extent of faecal impaction. Richard's withdrawal and distress were attributed to his mental health and a mental health admission was arranged, when he actually needed urgent medical attention.

When Richard was finally admitted to hospital, his assessment and treatment were inadequate, the faecal impaction persisted and he aspirated gastric contents and died. It is difficult and harrowing to imagine how much pain and discomfort Richard must have been in, for quite some time.

Losing Richard has devastated his family, leaving a void that can never be filled. Our grief has been compounded by the extent to which we have had to fight for thorough investigations and sufficient recognition of the need to improve practice in this area. Shouldn't the death of an otherwise healthy 33-year-old with constipation raise serious alarm bells?

Another lady with learning disabilities died in Suffolk with constipation six months after Richard. I will always wonder whether a timely investigation and service improvements after Richard's death could have saved her.

The supports that Richard needed to manage his bowel care were actually quite basic. He was surrounded by support workers and professionals but his needs weren't met and he died unexpectedly with preventable and treatable symptoms. His constipation wasn't even mentioned in his hospital passport or Social Services' Community Care

Assessment! Families trust professionals and care providers to meet their family members' care needs, yet Richard's support workers had stopped using bowel charts and involving the district nurse, without letting us know.

Slight changes to practice by staff in various roles would have ensured good bowel management. It is hard to understand why this didn't happen but I suspect that it reflects a combination of 'poo aversion' (it isn't glamorous!), diffused responsibility towards physical health amongst professionals, diagnostic overshadowing, health inequalities and institutional discrimination, all of which are experienced too often by people with learning disabilities. Everybody thought somebody else would hold Richard's constipation in mind and, sadly, nobody did. The Serious Case Review report highlights how Richard's care provider, GP, psychiatrist, social workers and hospital staff could all have done more to help Richard.

As well as being Richard's sister, I am also a Senior Clinical Psychologist employed in a mental health service for people with learning disabilities. I am regularly shocked by the limited awareness of constipation risk and indeed of the health inequalities experienced more generally by people with learning disabilities, even amongst learning disability professionals. There is too often a diffusion of responsibility, wherein staff in various roles think 'physical health' is someone else's job. This needs to change! Individual practitioners have the potential to make big differences to the lives, the health and indeed the survival of people with learning disabilities, through small changes to their practice.

I hope that this report and Richard's story inspire support workers and professionals to adjust their practice, to speak up and advocate when others need to do the same and to implement timely practice changes when service limitations become apparent. Working proactively, flexibly and responsively with the 'whole person' should help to prevent further tragedies.

Emily Handley, sister of Richard

Introduction

Under the Equalities Act 2010,[1] public sector organisations have to make changes in their approach or provision to ensure that services are accessible to disabled people as well as everybody else. IHaL has a database of examples of reasonable adjustments made by health services (www.ihal.org.uk/adjustments/).

This report is the twelfth in a series of reports looking at reasonable adjustments in a specific service area. Appendix A gives a list of our previous reports. The aim of these reports is to share information, ideas and good practice in relation to the provision of reasonable adjustments.

We searched for policy and guidelines that relate to people with learning disabilities and the management of their constipation. We looked at websites to find resources that might help people with learning disabilities and constipation or those supporting them. We also put a request out through the UK Health and Learning Disability Network, a major email network for people interested in services and care for people with learning disabilities. This asked people to send us information about what they have done to improve constipation management for people with learning disabilities.

This report sets out what we found. It starts with a brief description of how many people have constipation, its causes and how it can affect people. It goes on to describe recent research findings about bowel management to avoid constipation and the management of constipation if it occurs. We also present a holistic approach to bowel care and management of constipation.

The report goes on to describe the online resources we found and where you can access them. This is followed by four descriptions of bowel management work by groups that sent them to us. There are two pathway descriptions from learning disability inpatient units, one from a transition service and a description of a regional group that has been set up to consider how to improve handling of this issue in one region of the country.

An appendix reproduces six personal examples we were sent. They show very acutely the extent to which this apparently simple issue can blight some people’s lives.

People with learning disabilities and constipation

Evidence and research

What is constipation?

Symptoms of constipation include difficulty in passing stools, infrequent bowel movements, hard and lumpy stools, stomach ache and cramps.[2] Many people experience constipation for a short time but it can also be a chronic condition. In extreme cases people may also exhibit vomiting, headaches and faecal overflow and people with epilepsy may experience an increase in seizures.[3] Constipation is more common in people with learning disabilities than in those without.[4]

There are three categories of constipation:

- primary – no underlying medical cause and largely associated with lifestyle factors
- secondary – caused by physiological conditions (such as cerebral palsy, diabetes mellitus)
- Iatrogenic – caused by side-effects of medications

Diagnosis of constipation is generally triggered by a description of the symptoms. Some people with learning disabilities may find it difficult to communicate their symptoms and this may lead to delay in diagnosis and treatment.[5] A systematic approach to monitoring bowel pattern and function can assist early identification of constipation in people with learning disabilities.[6,7] In some cases abdominal radiography may be necessary to confirm the diagnosis.[8]

How many people with learning disabilities have constipation?

The estimated prevalence rates of constipation vary. This is likely to be due to the use of differing research methods and definitions.[9,10] An unpublished study reported rates from 17% to 51% among adults with learning disabilities living in varying types of supported accommodation in the UK.[11] A European study of adults with learning disabilities living in institutions found that almost 70% of them had constipation compared to 15% in the general population.[12] This study found the same rates of constipation in children and adults and concluded that constipation is a problem from early in the life course of people with learning disabilities.

Anybody supporting people with learning disabilities should be aware that they are at a higher risk of having constipation. As they may be unable to communicate this, being aware of the signs and symptoms is essential.

What causes constipation?

People with learning disabilities mainly get constipated for the same reasons as other people. These include:

- inadequate diet and fluid intake
- reduced mobility and lack of exercise
- side effects of certain medications
- anxiety or depression

Given that people with learning disabilities are more likely to have poor diet and reduced physical mobility[14] it is unsurprising that they are prone to constipation. People with learning disabilities are much more likely to be prescribed medication that is associated with constipation.[12,15] Antipsychotic, antidepressant and anticonvulsant medication can all have a negative effect on bowel movement.

People with Down's syndrome or cerebral palsy have an increased risk of constipation. Other medical conditions that exacerbate constipation include hypothyroidism, depression and diabetes.[16] Recent primary care data has shown that people with learning disabilities have significantly higher rates of diabetes and hypothyroidism and slightly higher rates of depression.[1]

People with more severe learning disabilities are at an even higher risk of constipation. This may in part be related to complex health needs requiring a variety of pharmacological treatments that can contribute to constipation.[5] They are also more likely to be non-ambulant, which is another associated factor.[12] A causal connection with body shape distortion and/or abnormal muscle tone has also been suggested[12,17] although the evidence for this is much more anecdotal.

Environmental factors can increase the likelihood of constipation. Inappropriate toileting facilities or a lack of privacy or time to use them can cause constipation.[2] Disruption in someone's routine or changes to their care or environment can all negatively affect bowel habits.[3] Moreover, ignoring the urge to pass stools can cause constipation.[3] If people have not been potty trained when young and therefore do not respond to the urge to defecate they are more likely to have constipation.

[1] http://www.improvinghealthandlives.org.uk/projects/primarycaredata/details

Impact of constipation

Constipation may not be considered a particularly worrying health problem and treatment is usually effective if started promptly. If not treated promptly, constipation can lead to more complex problems. As a consequence of continual straining to try to pass stools people can experience rectal bleeding, which may be the result of anal fissures, haemorrhoids or rectal prolapse.[6]

Chronic, untreated constipation can be very serious. Symptoms can include:[3,5]

- abdominal pain
- cramps
- bloating
- loss of appetite
- nausea
- overflow diarrhoea
- faecal impaction
- faecal vomiting
- twisting of the bowel leading to ischaemia and septicaemia

In extreme cases, the symptoms of long-term constipation can lead to death. In 2014, the Safeguarding Adults Board in Suffolk commissioned two Serious Case Reviews (SCRs) into the deaths of two people with learning disabilities.[18,19] Their deaths occurred in the same hospital within a six-month period and were from complications related to faecal impaction.

The first SCR[18] looked at the events leading up to the death of Richard Handley.[2] Richard had lifelong problems with constipation and also had Down's syndrome and associated health challenges including hypothyroidism, psychiatric co-morbidity and communication difficulties. He was aged 33 when he died from complications arising from faecal impaction. The review found that despite his physical health problems the only regular health professional input was from psychiatry. The staff that supported him had received no training in monitoring bowel health.

The second SCR[19] was about 'Amy' who had epilepsy, cerebral palsy and known bowel problems. She died aged 52 of aspiration pneumonia related to faecal impaction. The review highlighted concerns that the significance of Amy's bowel problems was lost when she moved between providers and the new service then failed to monitor her bowel movements. Even when there was clear documented evidence that her breathing difficulties were associated with severe impaction this was overlooked by hospital staff. They treated the presenting symptoms and discharged her without appropriate investigation into the cause.

[2] Richard Handley was referred to as 'James' in the SCR. His family have requested that his real name is used in this report.

Symptoms of constipation can be overlooked, with resulting behaviours being attributed to the person's learning disability. There is a body of research demonstrating the link between chronic constipation and behavioural problems, including self-harm, in people with learning disabilities.[20-22] This is perhaps unsurprising given the extent and seriousness of some of the symptoms. It is important that physical problems (such as constipation) are considered if someone suddenly starts exhibiting challenging behaviour.

Chronic constipation can lead to a plethora of negative impacts on quality of life. In addition to the physical aspects described above, there are also psychological impacts. These include embarrassment, social isolation and anxiety.[6,23] Long-term constipation is also associated with urinary and faecal incontinence, which in turn can increase social anxiety.[24]

Although the primary negative impact of constipation relates to the individual, there is also a considerable cost in relation to healthcare services. The management of constipation is expensive in terms of professional resources and prescription costs. It has been shown that constipation management accounts for 10% of district nursing time.[25] Prescription costs of laxatives have been rising year by year. National statistics show that from 2004 to 2014 the use of laxatives increased by 40.1%, with the cost of laxative prescriptions in England in 2014 being £117.5million.[3]

Appendix B contains stories shared by family carers that illustrate some of the impacts of chronic constipation on people's lives.

[3] www.hscic.gov.uk/catalogue/PUB17644/pres-disp-com-eng-2004-14-rep.pdf

Bowel management to avoid constipation

Some of the literature suggests that learning disability is a cause of constipation.[3] Despite higher rates of constipation in people with learning disabilities, it is not a symptom of learning disability and it is a very treatable cause of suffering. There are a variety of pharmacological and non-pharmacological treatment options and there is a need for a holistic, person-centred approach to the management of constipation.[3,26,27]

Emly and Rochester[25] report the development of guidelines for the management of chronic constipation in the community. A multi-professional group worked on these and developed a care pathway to fit on a single side of A4 with the references on the reverse side. This can be downloaded at www.improvinghealthandlives.org.uk/adjustments/?adjustment=396.
The following section is primarily based on this guidance,[25] the NICE clinical knowledge summary on constipation[28] and a literature review of constipation in adults with severe learning disabilities.[3]

The approach recommended below is a holistic, personalised, multifaceted one. Although laxatives may have a role to play in the management of constipation other approaches and factors should be considered first. Carers often report feeling helpless when the person they care for has chronic constipation but there are practical steps they can take that will be useful alongside pharmacological intervention. It may be time-consuming but carers and paid supporters can help people with learning disabilities improve their bowel habits and this can lead to a reduction or cessation of laxatives.

A holistic approach requires multi-disciplinary input. This may include input from the following:

- family carers/paid supporters
- learning disability nurse
- GP
- physiotherapist
- occupation therapist
- dietitian

Diet and exercise

Constipation is mainly caused by a lack of fibre, dehydration and inactivity.[29] Therefore, a holistic approach is likely to require lifestyle changes for the individual around their food and drink intake and movement.

Current guidelines suggest that adults should be drinking about six glasses of fluid a day. Guidelines also suggest that a constipated person needs 50-60ml of fluid per day

for every kilogram that they weigh. People who breathe through their mouth, sweat a lot or dribble/drool a lot may need a higher intake.[29] Some foods such as soups and yoghurts may contribute to fluid intake.

People with learning disabilities living in supported communities tend to have poor diets with insufficient intake of fruit and vegetables.[30] There are simple dietary changes that can be made to increase fibre intake. It is recommended that any increase is made gradually. Sudden increases may result in bloating and flatulence. The diet should be balanced and contain whole grains, fruits, vegetables and pulses. This type of diet is in line with general advice on a healthy diet. Adults should aim to consume 18–30g fibre per day.

Guidance on a healthy diet and relevant easy-read resources can be found in our report *Making reasonable adjustments to obesity and weight management services for people with learning disabilities* at www.improvinghealthandlives.org.uk/gsf.php5?f=314268

Lack of exercise slows the natural movement of faeces in the bowel and can lead to constipation. There is clear evidence that adults with learning disabilities have low levels of activity in comparison to the general population. Those with higher levels of disability and those living in more restrictive environments are at an increased risk of sedentary lifestyles.[14] In relation to good bowel health, even just moving around is good exercise. A holistic approach to constipation should consider what physical activity the person can do to help get the abdominal muscles to work.[31]

Toileting

In order to encourage effective bowel movements it is important that a person is comfortable when using the toilet. Many factors affect someone's ability to relax and to open their bowels. Issues to consider in relation to the toileting environment are:

- bathroom is well-ventilated, warm and clean
- enough space
- adequate privacy
- lack of distractions

Research has demonstrated the most effective sitting position for defecation (see figure 1).[32] Physiotherapists or occupational therapists may be able to assist with providing appropriate toilet seating to encourage the optimum posture.

Figure 1: Optimum position to assist with complete emptying of the bowel

Reproduced by the kind permission of Ray Addison, Nurse Consultant in Bladder and Bowel Dysfunction.
Wendy Ness, Colorectal Nurse Specialist.

Produced as a service to the medical profession by Norgine Ltd.

If someone is unbalanced on the toilet seat they will not be able to relax their perineum and defecate. A footstool to help someone position their feet for balance may be useful as this can help them to push with their stomach muscles.

Bowel habit retraining may be helpful for some people. The person should be supported to sit on the toilet first thing in the morning after a warm drink (sometimes a lemony drink may help) or about 30 minutes after eating a meal. This should be done every day at the same time. Try to link the toileting plan with the usual time that the person opens their bowels. This may be in the morning, after lunch or after the evening meal. This may require some planning and time management. They should be encouraged to sit on the toilet for 10 minutes and if they open their bowels in this time they should be rewarded.

It is important that an individual can respond immediately to the sensation of needing to open their bowels. People with mobility problems should have help to get to the toilet when they need it.

Biofeedback is a behavioural therapy which can be used to treat people with bowel problems such as constipation if the usual treatment has not been effective.[33] Methods of biofeedback therapy can vary considerably, but the aim is for the patient to gain improved control over their bowel movements. There is some evidence that toileting programmes and behavioural approaches, including biofeedback, can improve symptoms of constipation but these studies were not specifically focused on people with learning disabilities.[34]

Physical health and medication review

It is important to check for health conditions that can cause constipation. Depression and thyroid deficiency are examples. These are usually very treatable but can come on slowly and unnoticed.

People with learning disabilities are more likely to be taking medication associated with the side effect of constipation.[14] People should be on the least amount of medication required to manage their condition. This is not true for many people with learning disabilities. Therefore, an essential aspect of constipation management should be a medication review. Any constipating medication should be adjusted if possible.

Abdominal massage

Abdominal massage can be as effective as laxatives in the treatment of constipation.[35] The advantage of the abdominal massage is there are no known side-effects. Additionally, it can help individuals regain normal bowel function. One case report of a trial of abdominal massage for a young man with cerebral palsy noted his increase in

self-esteem when he became in charge of opening his own bowels.[36] Following the trial, a three-stage training package was developed to train healthcare workers in the use of abdominal massage. Eighteen months after the training, the project was audited and staff knowledge of bowel care as well as confidence in delivering the abdominal massage was good. The staff members' initial concerns about the withdrawal of laxatives for the people they supported had proved unfounded.[37]

Leadership

Family carers and paid supporters have a key role in early recognition of constipation and prompt treatment. It is therefore essential that they have appropriate training and education around the issues. A case study of management of constipation in a young woman with learning disabilities identified the two-hour workshop they ran with the woman, her peers and her care staff as a crucial factor in successful treatment.[38]

Those supporting people with learning disabilities must be able to recognise signs and symptoms of constipation. Learning disability nurses are one of the professional groups that have a role to play in the management of constipation. They should be able to raise awareness of constipation, educate and advise on its management.[38] Research has shown that learning disability nurses have, in general, relatively good knowledge of constipation, but their knowledge around some of the risk factors, such as diabetes and medications, could improve.[38]

Easy-read information

Relevant information with pictures and simple language may be helpful for people with learning disabilities.[5] Such resources might address the causes of constipation as well as advice on how to manage it. The searches conducted for this report have shown that there is a dearth of easy-read resources about constipation and its management.

Monitoring

An essential aspect of a holistic management strategy is ongoing evaluation in order to gauge if the interventions are being successful. Ideally, a baseline measurement should be taken, and an objective measure such as a stool chart should be used on a daily basis to monitor the effectiveness of the bowel programme. It is important to identify what is working and what is not working. For example, in some cases increasing fibre intake can result in bloating but no improvement in bowel movements.[34] An effective management strategy will result in softer stools being passed more frequently and with less effort. There may be a need to take waist measurements to monitor bloating where there are real concerns.

Monitoring the problem is only useful if appropriate action is taken in response. There should be clear guidance on what action to take for an individual if concerns are identified.

Laxatives

Laxatives may be prescribed if lifestyle changes are not sufficient to manage the constipation or while waiting for them to have an effect. Long-term use of laxatives is not generally recommended. Some laxatives can be habit forming, which means the bowel may start to depend on them. This then compounds the problem. There is also some evidence of long-term use of stimulant laxatives having carcinogenic effects.[39]

Currently, guidance for laxative use in people with learning disabilities is the same as for the general population.

Laxatives do not always provide sustained relief of symptoms.[34] For many people with learning disabilities this will then lead to an additional type of laxative being prescribed. Ideally, the preferred treatment would be the lowest possible effective dose of one medication.

There is some evidence that for people with learning disabilities there can be an over reliance on laxatives.[2] If long-term use of laxatives is needed there should always be consideration of other non-pharmacological approaches. Sessions using muscular training, abdominal massage and diaphragmatic breathing combined with laxatives have been shown to be more effective for chronic constipation than the use of laxatives alone.[31]

Resources

The four tables that follow list all the information and resources we have found in relation to the management of constipation.

- Table 1 lists guidance about the management of constipation. This information is likely to be of use to commissioners, service managers and clinicians
- Table 2 lists resources for professionals/family members and carers. This includes leaflets, templates, web-pages and videos. These resources are not easy-read
- Table 3 lists the easy-read resources we have found. This is where you can find information to use with people with learning disabilities
- Table 4 lists all the relevant free apps we have found

Some resources may be available from more than one site, but we have only given one link. We have only included resources that are free to download, although some of the websites may also include resources you can buy.

Table 1: Guidance about the management of constipation

Theme	Description	Provider	Link
Constipation in children and young people: diagnosis and management	This 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	National Institute for Health and Care Excellence	https://www.nice.org.uk/guidance/cg99
Constipation	This is a clinical knowledge summary. This is aimed at primary care practitioners. There is a summary of the current evidence about constipation in relation to: • diagnosis • assessment • investigations • management	National Institute for Health and Care Excellence	http://cks.nice.org.uk/constipation
Management of Constipation in	This guidance presents evidence-based	The Guideline Development	http://health.gov.ie/wp-content/uploads/2015/11/Mgm

Theme	Description	Provider	Link
Adult Patients Receiving Palliative Care	recommendations about best practice and standardisation of assessment and care processes.	Group (a subgroup of the Health Service Executive/ Royal College of Physicians of Ireland National Clinical Programme for Palliative Care (Irish publication)	t-of-Constipation-Guideline.pdf
Practice guidelines for the management of constipation in adults	Evidence-based guidelines for use by healthcare providers in their assessment and treatment of constipation in adults.	Rehabilitation Nursing Foundation (US publication)	http://www.rehabnurse.org/pdf/BowelGuideforWEB.pdf

Table 2: Resources for professionals/family members and carers

Theme	Description	Provider	Link
Managing Bowels and Bladders for People with Profound and Multiple Learning Disabilities	An eight-page leaflet with guidance that addresses constipation as part of bowel management	PAMIS	http://pamis.org.uk/cms/files/continence_leaflet.pdf
Tip Sheet: Constipation	A short sheet with information for parents about the causes of childhood constipation and what to do about it.	Continence Foundation of Australia	http://www.continencevictoria.org.au/download/1496/
NHS Choices: Constipation	A series of web pages with information about constipation. The topics covered include symptoms, causes, diagnosis, treatment, complications and prevention.	NHS Choices	http://www.nhs.uk/Conditions/Constipation/Pages/Introduction.aspx
Bristol Stool Chart	A medical aid designed to classify faeces into seven groups. Helpful for keeping stool charts.	Lewis and Heaton, Bristol Royal Infirmary	http://www.sthk.nhs.uk/library/documents/stoolchart.pdf

Theme	Description	Provider	Link
Bristol Stool Chart	A version of the Bristol stool chart designed for children.	Based on Lewis and Heaton, Bristol Royal Infirmary	http://www.eric.org.uk/assets/Childrens%20Bristol%20Stool%20Form%20Scale%20April08%20.pdf
Tips on Increasing Fibre and Fluid in your Diet	This is aimed at parents of children. It advises on how to increase fluid and fibre intake. It gives specific suggestions for breakfasts, lunches, meals and snacks.	Royal College of Nursing	http://childhoodconstipation.com/Documents/Tips%20on%20Increasing%20Fibre%20and%20Fluid%20in%20you%20Diet.pdf
A Parent's Guide to Constipation in Children with Developmental Disabilities	A booklet about constipation in children, with information on how it can be managed in relation to diet, behaviour and medication. Recipe suggestions are included.	Shirley McMillan, Surrey Place Centre, Canada	www.improvinghealthandlives.org.uk/adjustments/?adjustment=390
Constipation and soiling	Webpages designed for parents to give advice about coping with constipation and soiling. There are factsheets, tips and an interactive constipation toilet tool (to help with recognition of the signs and symptoms of childhood constipation. There is also an interactive “Let’s talk about poo” game	ERIC – the children’s continence charity	http://www.eric.org.uk/Parents/information_constipation_parents

Table 3: Easy-read resources

Theme	Description	Provider	Link
What is constipation?	A short easy-read leaflet describing what constipation is and what you should do if you are constipated.	South Staffordshire and Shropshire Healthcare NHS Foundation Trust	www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/healthy-life-styles/diet/What_Is_Constipation.pdf
Preventing	An easy-read	Bristol PCT	www.apictureofhealth.southw

Theme	Description	Provider	Link
Constipation	information with advice about things to eat and drink to help prevent constipation. There is also some advice about how to stay active.		est.nhs.uk/wp-content/uploads/healthy-life-styles/diet/Preventing_Constipation.pdf

Table 4: Apps related to constipation management

Theme	Description	Provider	Link
Bristol Stool Scale	This App allows quick and easy rating of stool quality (using the Bristol Stool Scale). This information is recorded and can be shared with a health professional. It also presents information about each type of stool along with links to more information online.	Web Garden Limited	Available in Apple i-store: https://itunes.apple.com/us/app/bristol-stool-scale/id466239623?ls=1&mt=8
Tummy Trends: Constipation and Irritable Bowel Syndrome Tracker	Tummy Trends is a personal guide designed to track symptoms associated with constipation and irritable bowel syndrome. 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.	Takeda Pharmaceuticals	Available in Apple i-store: https://itunes.apple.com/us/app/tummy-trends-constipation/id513358882?mt=8
Stool Checker	This App is designed for people to keep a record of their bowel movements. It is designed to be very easy to use.	CUBIC Co.,Ltd.	Available in Apple i-store: https://itunes.apple.com/us/app/stool-checker-simple-convenient/id542571748?mt=8
Poop Diary	"Poop Diary" is an application that allows easy recording of every bowel movement, including time, colour, amount, and shape information. In addition, it can send a reminder if there	PInC	Available in Google Play Store: https://play.google.com/store/apps/details?id=com.pinc.poop&hl=en

Theme	Description	Provider	Link
	has been no bowel movement for a period of time.		
CDHF Gi BodyGuard	Allows people with a digestive disorder to record and track factors relevant to their intestinal health. This includes • stool frequency and consistency • presence and type of blood in stool • symptoms • pain location and severity	Canadian Digestive Health Foundation	Available in Apple i-store: https://itunes.apple.com/nz/app/gi-bodyguard/id445162991?mt=8 Available in Google Play Store: https://play.google.com/store/apps/details?id=com.cdhf.gibodyguard
Pooplog	An App 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/photo. There is an optional function to log a pain/discomfort level from 0-10.	Kefsco	Available in Google Play Store: https://play.google.com/store/apps/details?id=com.kefsco.pooplog2&hl=en_GB

Examples of bowel management work

Detailed below are examples of services that are actively working to address the bowel management needs of people with learning disabilities.

Tees, Esk and Wear Valleys NHS Foundation Trust

The adult learning disabilities services in Tees, Esk and Wear Valleys NHS Foundation Trust have developed a Clinical Link Pathway for bowel management. This is designed to be used in conjunction with a Person Centred Pathway of Care. It can be linked to other pathways, such as nutrition.

The pathway is designed for use with adults with learning disabilities who are at risk of constipation. It begins with a part one screening assessment on entry to in-patient services. It can be used at any time if there is a clinical, carer or service concern around constipation.

The pathway starts with a quick, initial assessment. If there are two or more indicators of constipation, a more detailed assessment is undertaken. This considers:

- physical health problems
- bowel history/habits
- bowel investigations/surgery
- medication
- diet and fluid intake
- physical ability
- physical activity

Following the full assessment, a multi-disciplinary team meeting is held to determine appropriate algorithms/interventions. The team considers appropriate referrals for physical interventions, including:

- increase in physical activity
- review of fluid and food intake
- continence advice
- need for relevant aids and appliances
- abdominal massage

If underlying anxieties are deemed to be a relevant factor, there is a referral to psychology. These interventions should then be reviewed in line with trust guidance or significant change in presentation or care package.

The pathway includes links to relevant documents such as algorithms, monitoring charts and an easy-read information leaflet. The pathway and accompanying documents can be downloaded at www.improvinghealthandlives.org.uk/adjustments/?adjustment=397

The local learning disability liaison nurse team are monitoring hospital admissions for people with learning disabilities.

From April 2014 to March 2015, 18 people with learning disabilities were admitted to hospital due to constipation. In these cases, the learning disability liaison nurse worked with the doctors on the ward to ensure appropriate action was taken. This may have included a referral to district nurses for enemas or suppositories. The nurse also conducted a follow-up home visit to the care provider. At this visit, it was explained that they were referring to a community nurse who would then initiate the bowel pathway. This was confirmed in a letter which was sent to the patient, the care provider, the GP and the care co-ordinator. The community nurse then took the lead in the assessment and management of the constipation.

Danshell Wast Hills Autism Service

Wast Hills is an independent hospital providing specialist support and services for adults on the autistic spectrum with associated complex needs. Everybody who has a planned admission will have a pre-admission assessment. This has a section on bowel function that enquires whether:

- the person is continent
- the person has any known bowel conditions
- the person suffers from constipation
- their usual routine for opening their bowels

Everyone admitted to Wast Hills has the following documentation in place:

- healthcare promotion plan
- health action plan
- hospital passport
- communication passport, completed by a speech and language therapist with input from named nurses and key workers. This includes an assessment using the Disability Distress Assessment Tool (DisDAT), fluid intake charts and nutritional assessments

If the nursing assessment indicates any bowel problems, the individual will also have a specific care plan for bowel function. This is reviewed on a daily basis by the nurse in charge. This plan includes:

- monitoring of bowel function
- use of the Bristol stool chart
- progress notes

- a personalised protocol with instructions for when PRN medication (such as laxatives) are to be used

The nursing assessment form and a chart for monitoring bowel function can be downloaded at www.improvinghealthandlives.org.uk/adjustments/?adjustment=395

The protocol is written by the named nurse following guidance and instruction from the consultant psychiatrist and the GP. It is essential that this is personalised as people have different patterns of bowel movements. There is also an awareness that people with epilepsy may have an increase in seizures when they are constipated.
There is a list of all medications that an individual is prescribed in their individual folder. This includes the possible side effects and prompts the team to be mindful of the risk of constipation due to new medication. Charts are used to record the efficiency of any PRN medication, including laxatives. They document when the medication was given and if it has worked at regular time intervals. The charts are reviewed by the consultant psychiatrist.

As part of this holistic approach, everyone has a meaningful activities plan and participation in these activities is monitored. The chef can provide individualised meals, so this can include extra fibre, for example. The occupational therapist provides input around toilet adaptations to ensure that someone is securely balanced when on the toilet and seated in the optimum position for defecation.
Everyone is reviewed on a four-weekly basis by the multi-disciplinary team. Family members are invited to these meetings and able to look at records such as bowel and epilepsy charts.
For further information, contact Wast Hills Autism Service, Kings Norton, Birmingham, 0121 458 2263.

Scope - Orchard Manor Transition Service

Orchard Manor offers a transition to adulthood residential service for young disabled adults aged 18 to 25 with complex physical and learning disabilities. The young adults supported by this service have high support needs, including profound and multiple physical disabilities, sensory impairments and significant learning disabilities. Rates of constipation are high. This is due to a number of factors, including medication side effects, diet and restriction of mobility or illness. Constipation is managed through a variety of methods including medication, diet, exercise or massage.

Staff run relaxation sessions, which include bowel massage (where assessed as appropriate). They are trained to provide bowel massage by the service physiotherapist who also assesses which individuals will benefit from the support. The session is run in a structured way, with massage starting with a head massage and working down the body to set pieces of music. Carrying out the massage with the same routine and same music helps people to feel more at ease, and being supported by familiar people also

helps. The massage includes firm stroking, light stroking, kneading and ends up with stroking, again following the route of the intestines.

Staff have found that within an hour of receiving a bowel massage the individual is likely to open their bowels. It is important to note that even if a person has a large bowel movement after massage, that does not always mean that the bowel is empty and there is no wind or restrictions. However, the team members have seen significant results. One young woman they support has very hard abdominal musculature, which makes it difficult to judge if she has faecal material in her gut. She also suffers from severe constipation. She is nil by mouth and has a jejunostomy (JEJ) feeding tube in place. Bowel massage has shown good effects for her. She has always opened her bowels after the massage and her distress in relation to her constipation is notably reduced. One young man becomes very distressed and can display self-injurious behaviours when constipated. Massage has worked very well for him even though he can struggle with touch that does not meet his particular sensory needs. Through the massage sessions he has come to know and anticipate the set routine and recognises which piece of music accompanies each massage. This helps him to remain settled and calm. When moving onto a bowel massage, he lies on his back and is happy to have his abdomen touched. A bowel massage is carried out regardless of whether he is constipated (with his agreement), as this helps to relieve any trapped wind, keeps his bowel functioning normally and maintains his familiarity with the structure of the session.

Some difficulties have been encountered. For example, it is difficult to give a bowel massage to someone who has a jejunostomy (JEJ) because the tube can restrict how the massage is given and how much pressure can be applied. Posture can also be an issue, as many of the recipients do not have a neutral alignment of their spine, or have scoliosis, so organs may not be where they should. In such cases, it is often possible to carry out partial bowel massage to get bowel movement started and assist as much as possible.
For further information, contact Ciara McGurk at ciara.mcgurk@scope.org.uk

Central Midlands and East Learning Disability Network Constipation Working group

Following an IHaL event about reducing emergency admissions to hospital for people with learning disabilities, the Regional Learning Disability Network Officer for Central Midlands and East DCO Team decided it was important to undertake some local work around constipation.

She contacted people in the region about setting up a constipation working group and got a lot of positive responses. Following this, she organised a first meeting of the group. The majority of people attending were nurses and physios. There was a discussion about trying to improve representation on the group from people with learning disabilities, family carers, social care and commissioning.

At the first meeting, terms of reference for the group were agreed. It was decided that the group would meet every three or four months with email communication between meetings. The group started to think about using social media to get more people involved. Sub-groups will be set up to take forward specific pieces of work.

The aims of the group are to:

- develop simple messages about the impact of constipation
- talk to colleagues about the need for better awareness about constipation
- raise awareness of different interventions such as postural care, bowel management and massage
- raise awareness of resources for use in the management of constipation
- develop a 'risk of constipation' tool to support families, people with learning disabilities, health and social care staff to assess the risk of constipation for an individual with the aim of prevention and effective management

Contact Louisa Whait at Louisa.Whait@leicester.gov.uk
Twitter: #telllouaboutpoo

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Appendix A

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Appendix B

Introduction

As stated in the introduction, a striking and unusual part of our experience in producing this guidance was the number of stories of personal experiences we received. We sent out our normal request, through a widely circulating email network, asking for information about what people had done to improve constipation management in people with learning disabilities. While we received a few responses giving information as requested, we were sent a lot more accounts of experiences.

We are reproducing a few of these here. This is not because we think they describe good care. Some are evidently the opposite. We believe their relevance is to underscore for care professionals and care commissioners how important an issue good bowel management can be.

NK's story

"My story is about how constipation or irritable bowel syndrome (IBS) has affected my son, G. I have had excellent treatment from the same local NHS trust services that my son uses, but his treatment has not been of the same quality at all. I was referred immediately for physiotherapy treatment, with a plan of action, whereas his IBS treatment did not seem to follow any pathway or real investigation.

Several years ago, G began to have spells of severe anxiety leading to behaviours that were extremely worrying. He was treated with increased medication but no other interventions were tried, which I found very puzzling, as several GPs have since said that exercise is a good treatment for anxiety, as well as constipation. G had to leave college and was at home all the time, which I don't think was good for his mental wellbeing and this didn't help his IBS or constipation. I set up a daily structure of easy workouts using familiar DVDs and video tapes, with hour-long walks every other evening, meaningful learning activities every day to keep his mind active and a fortnightly evening activity club to see old school friends.

Things continued to go downhill and after appealing to a director of services for help, G was offered a few months of support from a learning disabilities day service. There was good teamwork between his family, learning disability nurses and support staff. We all made sure that he had daily physical and cognitive activities and at this time his constipation or IBS was not a huge problem.

However, the biggest challenge to overall care happened once G moved to actually living away from home. He had no keyworker with overall responsibility and occasional conversations happened with health facilitation nurses and individual learning disability nurses. I felt his physical health was unmonitored by the support staff. I spoke to three different GPs as he moved placements, a psychiatrist and a learning disability nurse about constipation and we agreed diet and exercise plans were key. Implementing plans with care staff in three different settings has been a colossal failure, simply because of lack of communication. I believe treatment for constipation can be fairly simple if people follow a plan.

For G, I believe the lack of management of his constipation added to regular self-harm which led to permanent sight loss. I heard that he was on the toilet in his care home often for over an hour, and sometimes for up to three hours at a time. Staff have told me this is his personal choice, but I see it as neglect. He never does this during visits home. His sight-loss has severely damaged his quality of life and now has led to limited mobility, which in turn worsens his constipation.

I feel increasingly concerned that because so many people with learning disabilities suffer from constipation that it might be seen as 'normal' for them to suffer, or even as part of the disability itself. I believe that management of IBS and constipation is about holistic solutions exactly as it would be for any of us. The most common treatment I see staff turn to is more medication, such as regular Lactulose. What I notice particularly is that exercise plans get far less attention.

The main barriers to proper treatment are to do with lack of monitoring, and good person-centred care.. G moved between three different homes and information was not passed between them, as homes don’t share their files as a person moves on. This reduces any real person-centred care or ownership of people's own health records and is an issue that needs to be properly addressed by social care.

I know from research on challenging behaviour that physical health problems need to be treated first. My approach to managing G’s constipation was to write a health action plan about how to manage it; a plan that would stay with him and not with his providers. It would include clear individualised advice, such as IBS-friendly foods that he might eat, quantities to eat and drink, and most importantly exercise plans.

This plan will only work if someone takes overall responsibility for monitoring all his symptoms and completing food logs, stool charts and noting his physical exercise and any patterns around time spent on the toilet. I think that families must be able to formally work with paid staff. We are the people that know G best and we can help staff to understand how G responds and how best to engage and communicate with him. Any health problems can only managed by working together as ‘partners in care’. I know we are still at a starting point.”

Mandie's story

"My daughter has had constipation all her life. She has been on various types of medication every day of her life to try to help. In the last few years, things have been much worse.

First the bad: she had brain surgery in 2002 and the rehabilitation of six weeks was the first time she had spent more than four days away from us. Unfortunately, although we tried to set up everything for her stay, on her return her constipation was horrendous. This resulted in a hospital admission. Things have never been good since with many hospital admissions and the discovery of a volvulus of her bowel. We were told there was nothing they could do to help her as her bowel was not in a good way. She also has slow gastric emptying and peristalsis making the transit of food in her digestive system very slow.

However, now for the good: a protocol was put in place using Movicol with a gradual increase and then a preventative flush once a month. This seemed to work for a few years with occasional emergencies. Then, things started to get worse again.

She was in and out of hospital with a twisted bowel again and again. It was at this point that we met a surgeon who was the first to say, "I can do surgery and help her". This was a huge surprise for us, having been told before that nothing could be done. She was placed under the specialist team from the bowel ward, with the team supervising her care in the community. They introduced enemas for her every three days for the next seven months, until she was well enough for surgery. She has now had surgery to remove the volvulus and that seems to be healing well.

Her constipation is still being treated with the gradual increase in the Movicol from her normal three a day. She is still being kept on the books of the specialist team from the bowel ward. They want her admitted to their ward for any emergency admission (even if it is not for bowel/digestion issues) as they feel they now know her, her support workers and us.

Following a complaint about one hospital stay she now has a hospital admission plan, with details of who to call, what her reasonable adjustments are and where she should be admitted. One of the bowel team is her link worker."

Karen's story

"My teenage son has profound learning disabilities. He is nonverbal, extremely uncommunicative, very very autistic in some ways but very much not so in others. He has shown extremely challenging behaviour, which is very much unlike what I think of

as his usual self. For years we did charts and diaries and reports, trying to find triggers for his uncharacteristic violent episodes, and it wasn't until he finally had an abdominal x-ray that we found he was impacted and we were referred to gastroenterology. At this stage we found out that the very fact that my son pooed huge amounts and often was actually a warning sign that he was impacted and constipated. This was the very thing that had suggested to me that he was not constipated! I now know this was a red flag.

The things we gained specifically from seeing gastroenterology were:

- a Bristol stool chart (several, in fact!) and instructions on what we were trying to achieve with it, how I should 'read' his poos
- an understanding of what his huge bowel movements meant
- a prescription for stimulant laxative in addition to the softener (Movicol) that we were already using. Until this was added in, the Movicol was actually making things worse

It is a bumpy ride to improvement - the laxatives themselves have side effects that are almost as bad as the constipation. It is absolutely clear that if we can manage this, he will be without pain and without the behaviour that tips him from the complicated into the dangerous and challenging category. Needless to say, that is a huge issue, as when he is dangerous we lose support, our family life descends into oblivion, and I start thinking that I can no longer care for him at home. But when he is well, when he is back to what I now know is 'normal', he is his old self – loving and calm, if very complicated.

We know what the problem is, but haven't yet solved it and I am not sure if we ever will, fully. I am terrified that only my constant, consistent, vigilance will keep him functioning for the rest of his life. I fill in pages and pages of poo and behaviour and laxative diaries but when he is at school or with respite, there are gaps in the records, which isn't good.

His care is too much for one person (I am struggling) but needs a single oversight especially in terms of his very subtle but very important constipation. One thing I do know is that the line between complicated and very, very challenging behaviour (to the point of being unmanageable) is constipation. From my experience the prevalence of constipation issues is not well known to parents, carers, and even paediatricians. It wasn't until we got to gastroenterology that we got specific and much needed advice on what to look out for.”

Ian’s story

“My son and I have had a long, long battle with his chronic constipation so I am relieved and thrilled that IHaL is producing this report.

In the last few years, I have tried and tried to get Adam effective, ongoing monitoring for his condition, which has resulted in damage to his colon. Three years have passed since his emergency treatment and I still haven’t managed to get anyone interested in

monitoring him regularly. His care home staff do a brilliant job but rely on the NHS to look after his medical arrangements.

I understand that chronic constipation is not by itself recognised as a condition deserving of funding. Therefore, the regular support of a consultant or even a specialist nurse is not available, unlike Crohn's, for example. Last year I asked the area health facilitation nurse to help us and she couldn't get anyone interested either, apart from arranging three ad hoc appointments with a continence nurse. Adam is on regular laxatives and he eats a healthy diet. The health action plan from the GP practice is useless; it lists constipation as an issue but under 'management plan' it simply says 'Movicol'. In reality, he actually requires daily laxatives administered by care staff in accordance with a protocol issued by the appropriate continence clinic. He doesn't even get a proper annual health check because he finds it very hard to co-operate, but we haven't been offered any help.

Adam is often in discomfort confirmed by groin pressing. He can't tell us what is wrong or how he feels because of his learning disability, so we have to go on instinct and luck. Staff do an amazing job tweaking laxatives depending upon his bowel motions. Adam is doubly incontinent. Currently, Adam is passing brown water rather than solids, so his key worker thinks he might have a blockage again and is talking to the GP. This is heartbreaking. I wish there was a recognised, ongoing oversight and treatment methodology so I could advocate for him effectively."

Ian worked with the Challenging Behaviour Foundation to tell his and Adam's story. You can read more about it at www.challengingbehaviour.org.uk/cbf-articles/your-stories/consent-to-treatment.html

Sharon's story

"My adult son has Angleman's syndrome and severe learning disabilities and complex needs. I now think he has probably suffered from constipation all his life. When he was living at home we monitored his bowel movements and if needed he was given Lactulose as a softener.

He now lives in a residential care home and they feel that he should be opening his bowels every day. As he doesn't, he is given Laxido in a drink in the mornings. He has never opened his bowels every day and so I feel that they shouldn't be aiming for this. Moreover, the advice about Laxido says that prolonged use is not usually recommended.

When he comes home to visit I don't give him the Laxido and there isn't a problem with him opening his bowels. Therefore, I think that the difficulty he has may be

psychological or related to the environment he is in. Rather than just giving him medication I think the care home should be taking a more holistic approach.

He often needs to sit on the toilet for a while. When he is at home I will sit in the bathroom with him. I am worried he may fall if I leave him alone. While he is sat on the toilet we interact and may have a sing-song together. I think that when he is on the toilet in his care home he may not feel relaxed enough to open his bowels.

When he is constipated his behaviour can change and he might be a bit more grumpy or aggressive. I have also noticed that if he hasn't opened his bowels for a while then there are signs that he finds it painful when he tries to do so.

I think there is a need for a more person-centred approach to help him feel relaxed enough to open his bowels when he is at his care home. I hope then that there wouldn't be a need to give him the Laxido every day."

Lyn's story

"I have been able to witness over many decades at first hand, the underestimated, and certainly under reported, impact of constipation and its close association to increases in challenging behaviour. The usual dietary guidance in terms of fluid intake and roughage is sometimes given, but in my experience not always followed up in eating support plans. The links between the incidence of challenging behaviour and constipation are often not included in ABC charting and recording.

What has failed to inform decisions on bowel management for this vulnerable group of people over the years has been the low risk attributed to poor and inadequate management of bowel movements. The behaviours that ensue are often then treated by further increases in psychotropic medication, which, of course, increases constipation.

Thankfully, in the case of our own son, our GP, enlightened on the subject because of a sibling with severe physical disability, supported us with the prescribing of a routine daily suppository, in order to circumvent the cycle of faecal build up, pain, refusal to eat, screaming etc.

Our son remains at his most comfortable and content with this regime. His Cerebellar Ataxia was always going to prevent full bowel control in any case, so he has only gained in terms of the best possible outcome. Definitely a Best Interest Decision, with an informed risk assessment that has worked well for him.

This does not mean that attention to diet and fluid intake is ignored, and this need is always a focus of his eating plan and dietary needs.

I can only report positively on how this need has been managed for our son. Not without battles and debates over the years to arrive at this point. I can only share this in the hope that the risks to others might be informed and better managed by this good practice.”