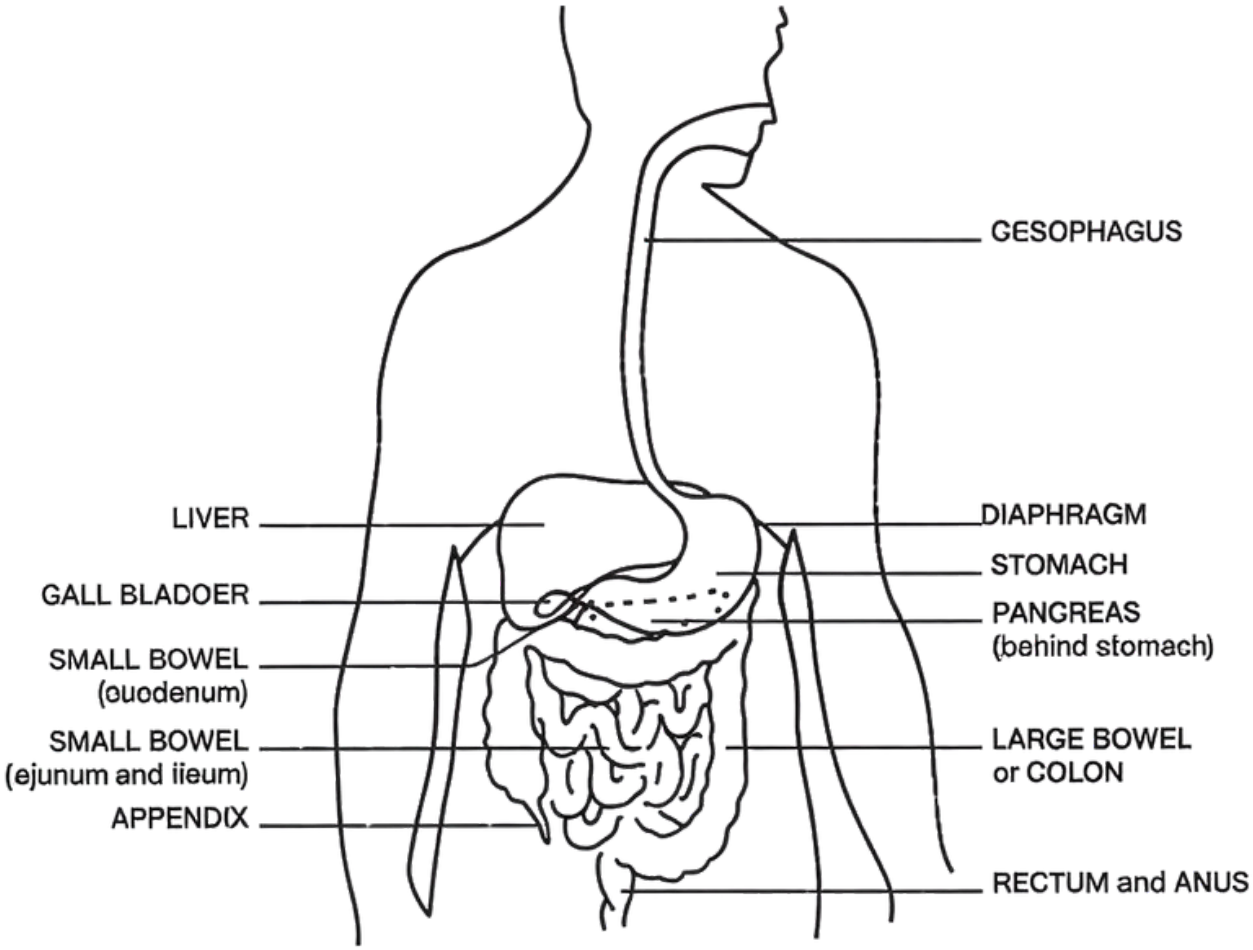
DOWN'S SYNDROME ASSOCIATION

The Down Syndrome Medical Interest Group

Gastrointestinal Conditions in Adults

June 2026



A Down's Syndrome Association publication

Introduction

The gastrointestinal tract covers all parts of the body involved in the processing of food. It includes the mouth, the oesophagus (food pipe), stomach, small intestines (duodenum, jejunum, ileum), the large intestines (colon, rectum) and the anus. The liver and pancreas are attached to the gastrointestinal tract and produce enzymes which help with the digestion of food.



There are some gastrointestinal conditions that are more common in people who have Down syndrome. Some will have obvious symptoms such as diarrhoea, vomiting, marked weight loss, severe abdominal pain. Others may have subtle symptoms that can be easily missed and perhaps put down to behavioural or psychological problems.

Subtle symptoms may be overlooked as the person experiencing them is unable to, or finds it difficult to, explain what they are feeling.

For many people who have Down syndrome, a change in their behaviour may be the first sign that something is wrong.

If a person who have Down syndrome seems to have a problem relating to the gastrointestinal tract, it is important that they are checked out thoroughly by their GP.

As with any medical condition that occurs, we should never allow symptoms to be explained away by the fact that the person has Down syndrome.

You should expect health professionals to take your concerns seriously.

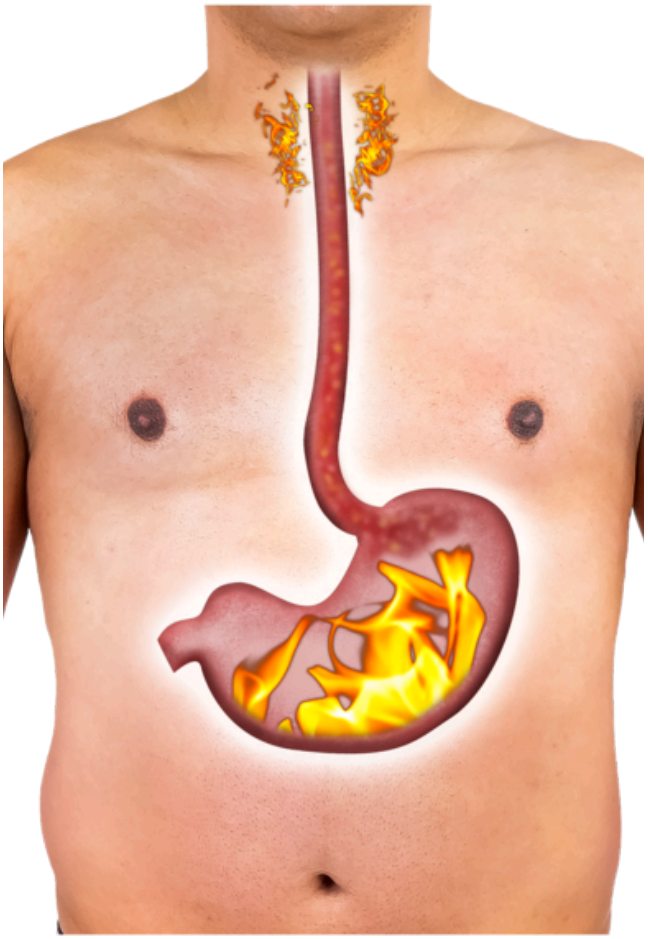
Gastroesophageal Reflux Disease (GORD)

This is a recurrent condition where stomach acid flows backwards and up towards the throat. It appears to be more common in people who have Down syndrome of all ages, although it often goes undiagnosed. Some of the more common causes of GORD in teenagers and adults include obesity, over-eating and sleep apnoea. However, it isn't always possible to identify a cause.

The most obvious symptom of GORD is heartburn, which is a burning sensation or a pain in the chest after eating.

Common Signs and Symptoms Include:

- **regurgitation of food**
- **abdominal pain**
- **hoarseness**
- **cough**
- **sore throat**
- **aspiration**
- **irritability**
- **aggression**
- **loss of enamel on the teeth**
- **difficulty swallowing**
- **bad breath.**



There are some simple measures (as directed by the GP) which may help with GORD such as sitting up after meals, not overeating, wearing looser clothing and sleeping with the upper body slightly raised.

Avoiding certain foods and drinks may also help (e.g. acidic fruits/juices, caffeine, chocolate, fatty foods and onion).

Seek advice from the GP if you are concerned about GORD. The GP may prescribe medication to reduce acid levels in the stomach (antacids).

They may also prescribe medication to stop the backflow of food (e.g. Gaviscon), or to help food pass through the stomach.

Coeliac Disease

In this condition, there is a sensitivity to gluten which is a protein found in wheat, rye and barley. Exposure to gluten causes inflammation which damages the lining of the small intestine. The damage reduces the intestine's ability to absorb vitamins, minerals and calories. Over time this leads to reduced absorption of nutrients in food.

Coeliac disease is more common in people who have Down syndrome than in the general population. It can occur at any age, even in people who have never had any symptoms before.



The most common symptoms of coeliac disease are weight loss and diarrhoea because of poor absorption. However, it can also be associated with many other additional symptoms:

- constipation
- indigestion
- stomach aches
- passing wind and bloating
- feeling tired, lack of energy or motivation (because the body is having difficulty taking in nutrients from food)
- unexplained anaemia or vitamin deficiency.



The process of diagnosing coeliac disease starts with an assessment of a person's symptoms and a physical examination. If coeliac disease is suspected, the doctor will arrange for a blood sample to be taken. The blood sample will test for the antibodies that are usually present in coeliac disease. The doctor may also suggest a short trial of cutting out certain gluten-containing foods from the person's diet to see if this helps.

If antibodies are present, the doctor will make a referral for further testing. This will usually be to a gastroenterologist. They may arrange more blood tests or perform an endoscopy. An endoscopy involves a flexible tube with a small video camera (endoscope) being fed through the mouth and down into the small bowel where a sample of bowel wall will be taken for analysis. A local anaesthetic or sedative is often used to help the patient relax. A biopsy is the only way to be certain that a person has coeliac disease.
It is possible to have coeliac disease and not have the antibodies in your blood. If symptoms continue, the doctor may still make a referral anyway.

There is no formal coeliac disease screening programme in the UK for people who have Down syndrome. If there is any evidence (even if it appears relatively minor) to suggest that a person may have the condition, their doctor should be asked to carry out tests.
Coeliac disease should be discussed as part of an Annual Health Check. Everyone who has Down syndrome over the age of 14 years is entitled to a free Annual Health Check with their GP.

Once the diagnosis has been made, the person who have Down syndrome will need a gluten-free diet. Even a small amount of gluten can cause the symptoms already discussed. This means wheat, barley and rye should be avoided. It is important that a gluten-free diet is balanced and healthy. Your GP can give help and advice about managing with a new gluten free diet. You may be referred to a dietician for support and advice.



Some people may need to take vitamins and minerals while the body repairs itself.

Most people, with support, cope very well with sticking to a gluten-free diet. To stick to the diet, the person needs to learn about the foods and other non-food substances (e.g. some medications, lipsticks, stamps), that may contain gluten. Most people will need help and support with this to varying degrees.

Visual supports can be useful to help teach about the new diet. These could include a resource around recognising gluten-free foods and packaging labels. There is an internationally recognised 'Crossed Grain' Symbol that is found on packaging for gluten-free foods. It may be useful to think about how to give your son/daughter the means of explaining that they have Coeliac Disease. This may be through teaching them the words they need to know and/or giving them a way to let strangers know about their Coeliac Disease (e.g. a laminated card with gluten free written on it to present to a waiter or shop assistant).
There has been much discussion about whether all children who have Down syndrome should be screened for coeliac disease, and different countries follow different recommendations. Currently the recommendation in the UK is that practitioners should have a high awareness of this as a possible problem in children and adults who have Down syndrome and have a low threshold for testing.

Irritable Bowel Syndrome (IBS)

IBS is a common condition that affects the digestive system. Symptoms can be similar to those of coeliac disease (e.g. abdominal pain, diarrhoea, wind, constipation, cramps, bloating). There is no single cause, but symptoms do appear to get worse when people are under psychological / emotional distress. In people with IBS, there are differences in the way in which the intestine is working. Food and waste products don't seem to move through the intestine in the usual way. Food may be moving through the intestine either faster or slower than is normal, leading to spasms of the intestine.



There is no test for IBS, but the GP may carry out tests to rule out other causes for the symptoms the person is experiencing. IBS is usually a lifelong condition and there is no cure. There is no single diet or medication that suits everyone. However, there are measures (as directed by the GP) that can be taken to alleviate some of its symptoms:

- Reassurance and sometimes medications to reduce anxiety.
- Increased fibre in the diet.
- Medication to control diarrhoea if this is the main symptom the person is experiencing.
- Medication to reduce spasms and cramping pains.
- Avoidance of large meals, caffeine and fatty foods.

Food Sensitivity

As already mentioned earlier in this resource, sensitivity to gluten (coeliac disease) is more common in people who have Down syndrome. The inability to digest lactose, a sugar found in cow's milk, may also be more common in people who have Down syndrome.

Symptoms of lactose intolerance include:

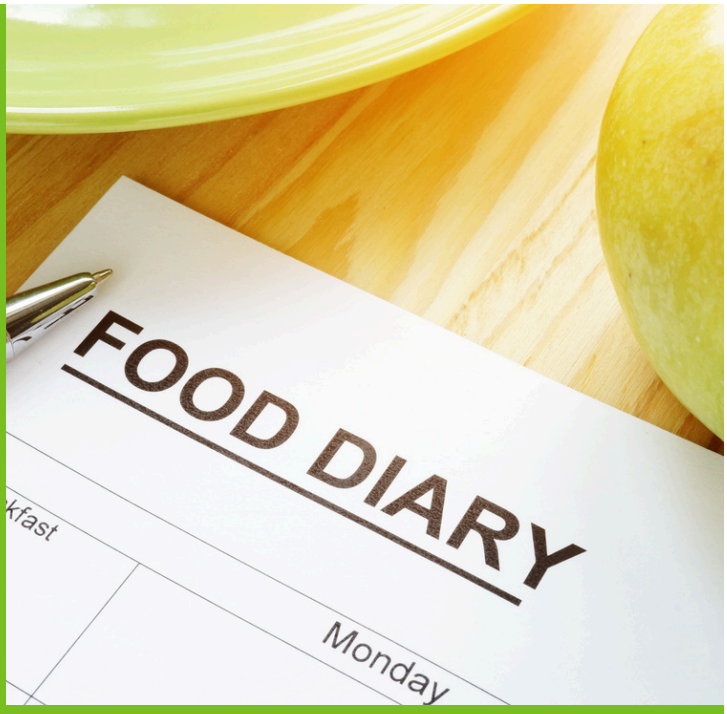
- swollen abdomen
- irritability
- abdominal pain
- anaemia
- tiredness
- malaise
- diarrhoea
- bloating
- cramping.



Diagnosis of lactose intolerance, where there is sufficient information, may be based on a person's history and by the person excluding lactose from their diet.

An alternative method can be to take a non-invasive lactose breath hydrogen test.

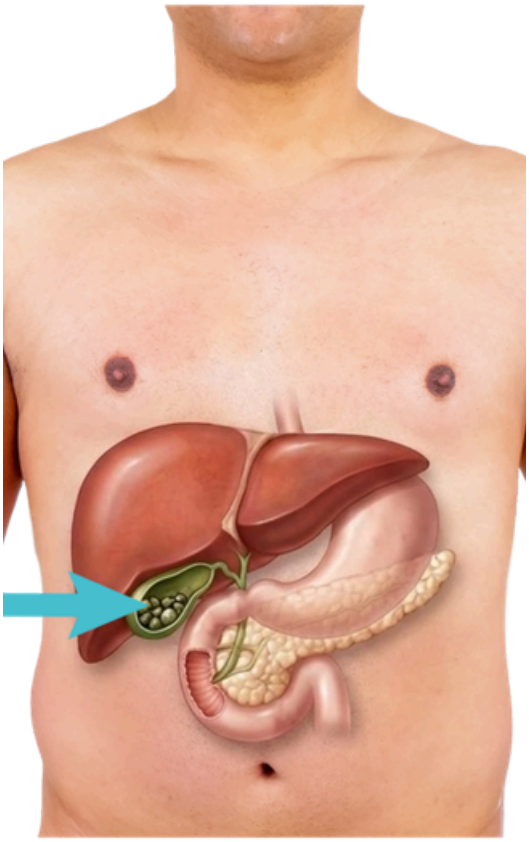
Once a diagnosis of lactose intolerance is made, the person should avoid foods that contain lactose. Lactase supplements (the enzyme lacking in lactose intolerance) is available in liquid , powder and pill forms. The person with lactulose intolerance may need vitamin D and Calcium supplements. Advice and support should be sought from your GP and, if appropriate, a dietician. Some people will have both lactose and gluten intolerance.



Apart from the two exceptions covered here, there don't appear to be any other particular foods or patterns of foods that are problematic for people who have Down syndrome. If a person is suffering gastrointestinal symptoms such as cramps, bloating or diarrhoea and other causes have been ruled out, it is worth considering food intolerance.

It can be helpful to keep a food diary containing details of what a person eats and drinks and at what times, along with details of any symptoms they experience. This will be helpful in identifying any food or drink that is problematic.

Gallstones



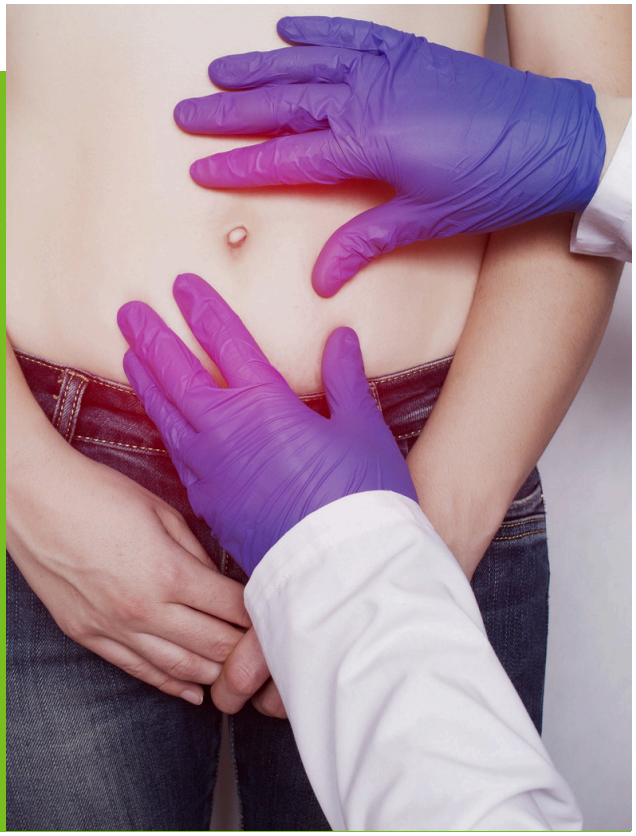
The gall bladder is a small organ, just below the liver, that stores and concentrates bile from the liver. When we eat, the gall bladder releases bile into the small intestine via the bile duct. Bile helps us to digest fats, but it can also harden into gallstones.

Gallstones are more common in people who have Down syndrome. The chance of developing gallstones increases with age and for those who are overweight or obese.

Many people will have gallstones but only a small number of people will develop symptoms. However, if a gallstone blocks the bile duct it can lead to sudden and severe abdominal pain. Other symptoms may include nausea, vomiting, diarrhoea, bloating and indigestion. These symptoms may occur after eating fatty foods.

Treatment depends on the severity of the symptoms. If the symptoms are more severe and occur regularly, surgery to remove the gallbladder may be recommended.

Hernias



Hernias are more common in people who have Down syndrome. A hernia is a lump caused by an internal part of the body pushing through a weakness in a muscle or tissue wall. Hernias are sometimes uncomfortable, but many people do not have any symptoms. Diagnosis is usually made via a physical examination; sometimes a scan may be necessary.

The common areas for hernias in people who have Down syndrome seem to be in the groin, at the belly button, in the abdominal area and at the site of previous abdominal surgery. Once a diagnosis has been made, the doctor will discuss whether surgery to repair the hernia is necessary.

Constipation



Constipation refers to bowel movements that are infrequent or hard to pass. Constipation happens to people who have Down syndrome of all ages. This may be due to lower muscle tone, reduced mobility, poor hydration, side effects of medication and diet. Constipation can also occur because of coeliac disease or thyroid disease, both of which are more common in people who have Down syndrome.

We sometimes hear of young adults, who have recently left home, developing this problem. Where parents may have previously kept an eye on the family's diet; new-found independence may mean the person eating less healthy food and taking less exercise.

Symptoms include abdominal pain, flatulence, bloating, small hard stools that are difficult to pass, bleeding from the anus and over-flow diarrhoea. Constipation can lead to people, who have previously been continent, having stool and urine incontinence. Everyone's bowel habits are different. Any change in normal bowel habits for the person you support might indicate there is a problem.

Sometimes behaviour changes may be a sign that the person you support is having a problem with constipation. A person may be showing anxiety around going to the toilet and/or avoiding going to the toilet altogether.



Eating more fruit and vegetables, drinking more water and exercise can help. Seek advice from your pharmacist/chemist. They might suggest a fibre supplement, mild laxative or a stool softener.

If constipation persists and symptoms worsen, the person whom you support should be checked out by their GP. They may arrange for a blood test and/or x-ray examination of the abdomen to rule out other causes for the constipation.

Diarrhoea

Diarrhoea refers to frequently passed loose stools. Diarrhoea may occur as a result of constipation, coeliac disease, irritable bowel syndrome (IBS) and food sensitivity, but there are many other causes.

Other symptoms include stomach cramps/pain, weight loss, distress and blood in the stools. If there is bleeding, seek medical attention promptly.

Diarrhoea usually clears up without treatment after a few days.

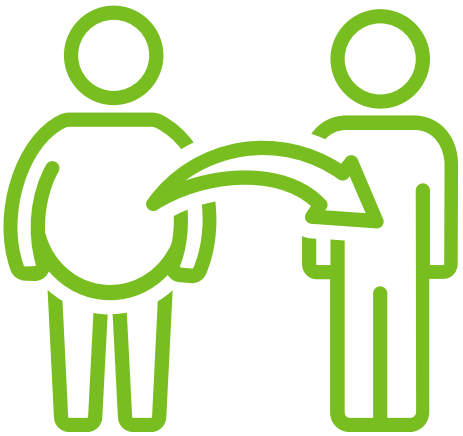
Everyone's bowel habits are different. Any change in normal bowel habits might indicate there is a problem. A person may be showing anxiety around going to the toilet, avoiding going to the toilet altogether or obsessively going to the toilet. If the diarrhoea persists after a few days, is frequent and/or severe and/or accompanied by other symptoms (e.g. blood in the diarrhoea), prompt medical review is required.



Weight Loss

There are many reasons why someone might experience unexplained weight loss. It may be due to the person not eating enough or refusing to eat at all. Some people have cut down on their eating, stopped eating foods with certain textures or stopped eating altogether because of bad experiences where they choked on something and/or because they experienced physical pain when eating. People may experience pain when eating for a variety of reasons including physical conditions such as ulcers in the mouth, sore throats, reflux, abdominal pain or dental pain. In these situations, some people who have Down syndrome go on to develop obsessions about not eating. Refusal to eat can become a learned behaviour, a compulsion, or part of symptoms related to anxiety and depression. Depression can also be a trigger for changes in eating habits, including loss of appetite.

There may be instances where a person's eating habits haven't changed but they are still losing weight. Autoimmune disorders are common in people who have Down syndrome.



As already covered in this resource, coeliac disease can lead to weight loss as it reduces the intestine's ability to absorb vitamins, minerals and calories.

Other auto-immune disorders (e.g. hypothyroidism, diabetes) may result in weight loss even where the person still has a good appetite.

Where unexplained weight loss is present, it is important for the GP (in the first instance) to look at the whole person, their physical and mental health, and their circumstances whilst trying to establish the cause(s) for the weight loss.



Sometimes treating the underlying health condition may help the person to return to their normal eating habits. But some people may continue to refuse to eat even after an underlying physical health problem has been treated.

Where this is the case, treatments may include counselling, referral to a speech and language therapist for help to regain swallowing skills, tailored support from those around the person, and anti-depressant/anti-anxiety medications.

Your local Community Learning Disability Team (CLDT) may be a useful source of support and information.

Obesity



Obesity is a more severe form of being overweight. It is best defined as an increase in body weight beyond that which is necessary for one's height, because of excess body fat. Obesity is often associated with a diet which is high in fats and sugars combined with an inactive lifestyle.

There may be an assumption that obesity is both inevitable and normal for people who have Down syndrome. There are certainly many people who have Down syndrome who defy this stereotype. Obesity is not inevitable for people who have Down syndrome.

However, there may be factors that people who have Down syndrome have to overcome that are not faced by the wider population such as a lower metabolic rate, physical impairments, and chronic health conditions. Certain medications may cause weight gain.

It is best to get advice from your GP about losing weight and before you start any exercise programme.

Your local Community Learning Disability Team (CLDT) may be a useful source of support and information.

Tips for Weight Management

'It's easier to try and avoid her gaining weight than it would be for her to lose weight. My daughter would eat constantly if allowed; she seems to have no switch that tells her when she is full. I keep her active, she swims at least twice a week and she spends huge amounts of time on her swing and trampoline. But obviously as a family we all try to eat sensibly; sitting down for a homemade meal around the table is great for everyone'

'Lots of exercise and small portions – same as the rest of us really'

There are no special approaches or interventions for people who have Down syndrome where weight is concerned. As with the general population, prevention is easier than cure. One of the issues raised regularly via our Helpline is one of weight gain when adults leave home and move into more independent living placements.

Weight management is not purely about dieting and losing weight, but balancing time, food and activity levels. Focusing on the positives, rather than a punitive approach. What can be done rather than what shouldn't be done is the approach that stands the better chance of success.

As in the general population, people who have Down syndrome benefit from being offered healthy choices to enable them to feel that they have some control. Visual cues around what is healthy versus unhealthy can be useful (e.g. grouping foods in a traffic light system). Some adults are very good at knowing when they have had enough 'red' or unhealthy food and stick rigidly to their eating plan. We do see issues where people living independently go wild with unhealthy food shopping as they take advantage of newfound freedom.

Children and adults should be involved in planning meals, shopping for ingredients and in preparing meals. A person who have Down syndrome will learn from family, friends and supporters so it's important to model the behaviours that you are helping the person to adopt.

Helping people to recognise when they are full and modelling good portion sizes (e.g. one cup of cereal for breakfast) are skills that everyone needs to be taught. Starting early in life is the ideal but it's never too late to start. Buying smaller plates and bowls can be a way of making sure that portion sizes are healthy. Regular set mealtimes with family and/or housemates can help reinforce ideas about healthy eating.



Exercise



Exercise is an important part of a healthy lifestyle. It does not have to mean going to the gym or taking part in team sports.

Walking, dancing, drama and online fitness programmes can all be good alternatives. Fun, social activities can provide the benefits of exercise without feeling like hard work. Regular walks with family or friends can help a great deal.

Activities such as dancing or drama groups can be strong motivators for people who have Down syndrome.

Many adults also enjoy online exercise videos, especially those featuring a favourite actor or TV personality, or workout games on a console.

There are no quick fixes for weight management. Small lifestyle changes, applied consistently over time, work better than rapid diets. Peer mentoring, groups, food diaries and visual timetables with goals can all be useful. There is also a resource about weight in the health and wellbeing section of our website.

Vomiting

Vomiting is the body's way of trying to rid the stomach of something that is harmful. It can also happen if there is something that is irritating to the gut. You can feel the need to vomit (nausea) or try to vomit (retching) without passing any contents of the stomach/gut.

There are many possible causes including reflux, food poisoning, infections, side effects of medications ulcers and emotional upset. This is not a complete list of possible causes.

If vomiting is persistent and/or severe and/or accompanied by other symptoms (e.g. abdominal pain, blood in the vomit) the person for whom you care should be checked out by their GP.

Summary



The gastrointestinal issues covered in this resource are the ones more commonly seen in people who have Down syndrome.

However, these are not the only ones that may develop. Some symptoms may be subtle; therefore, it is important to be vigilant for any behaviour changes in the person as a change in behaviour may be the first indication that something is wrong.

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