



**Down's Syndrome
Association**

A Registered Charity No. 1061474

Health Series



Gastrointestinal issues in children



The
Down Syndrome
Medical Interest
Group

A Down's Syndrome Association publication

Our resources and Information Team are here to help

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The Down's Syndrome Medical Interest Group (DSMIG)

This resource has been produced in collaboration with the Down's Syndrome Medical Interest Group (DSMIG).

DSMIG was launched in 1996 and is a registered charity. It is a network of healthcare professionals – mainly doctors – from the UK and Republic of Ireland whose aim is to share and disseminate information about the medical aspects of Down syndrome and to promote interest in the specialist management of the syndrome.

The gastrointestinal tract comprises the parts of the body involved in taking in food, processing it to make use of the nutrients and disposing of the solid waste. It includes the mouth, the oesophagus, stomach, small intestines or bowel (duodenum, jejunum, ileum), the large intestines (colon, rectum) and the anus – see diagram. The liver and pancreas are attached to the gastrointestinal tract and produce enzymes which help with the digestion of food. Problems with the gastrointestinal tract can either be due to abnormal structure i.e. the organs are formed differently from usual, or may be because part of the tract is not functioning properly.

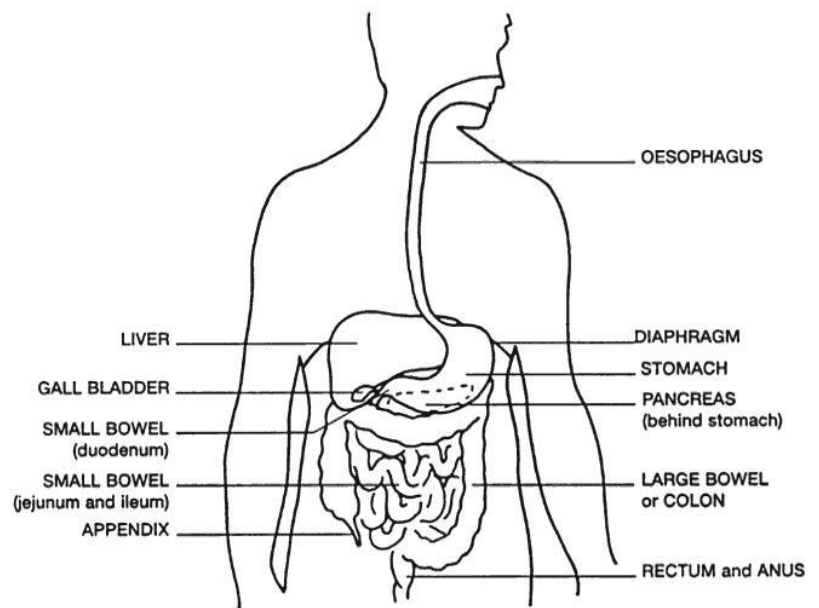
Children with Down's syndrome are more likely to have problems in both of these areas in comparison to the rest of the population. Some of these are serious and are likely to cause immediate difficulties in the new-born period. Others may not be so dramatic, but nevertheless cause considerable concern. In some of the conditions, problems will develop slowly and may not be picked up by parents or health professionals for some time.

Gastrointestinal difficulties are a common cause of illness in all children. Common symptoms are vomiting, diarrhoea or constipation, and common conditions they occur in include Gastroesophageal reflux disease and gastroenteritis (an infection affecting the stomach and intestines).

Children with Down's syndrome may have any of the same issues that occur in other children, but may also be more likely to have certain problems as discussed below.

If a child with Down's syndrome does seem to have a problem relating to the gastrointestinal tract, it is important that they have a medical assessment which takes into account both the common conditions that may affect any child as well as those that particularly affect children with Down's syndrome.

In this resource it's impossible to cover all areas of gastrointestinal problems, so we have focussed on issues that parents have identified as possible areas of interest or concern.



Structural problems

The gut is like a long tube connecting from the mouth to the anus with many different twists and turns on the way. It works to ensure that we can absorb all the right nutrients from our food, and eliminate the waste that we don't need in the bowel movement.

Although children with Down's syndrome are more likely to have certain unusual differences in the formation of their gut which are specifically associated with their condition, these problems usually appear acutely, early in life and sometimes are even spotted before birth, while the baby is being scanned in the mother's womb.

The tube connecting the mouth to the stomach (gullet or oesophagus) can fail to develop properly or the exit to the stomach may be narrowed or closed. If there is a problem at the upper end, in the oesophagus/gullet or stomach, then this may even be diagnosed from a scan, or will be a problem early on, as the baby will not be able to swallow milk, or may swallow and vomit after feeds. Because health professionals are aware of this greater incidence of this type of problem, all children are checked at birth and observed closely to see that they can suck and swallow normally. Sometimes if there is doubt a small flexible tube can be passed into the baby's gullet to check that if there are any blockages. Less frequently blockages occur lower down the gut. If there is a narrowing further down the gut it may result in the baby not passing a bowel movement soon after birth and again this is one of the regular checks recorded for all children. Rarely, babies with Down's syndrome have unusual development of their anus and lower bowel and again this is checked routinely in all new-born babies.

Symptoms of gastrointestinal disorders

Vomiting and diarrhoea

Like most children, particularly in the preschool years, mild problems with gut upsets, vomiting and/or diarrhoea are common for children with Down's syndrome. Research suggests that decreased resistance to infection makes children with Down's syndrome

more susceptible to some infections, particularly chest infections, but this is **not** shown to be the case for gut infections and with the same type of care available for any child, your child with Down's syndrome should recover well if you ensure they keep their fluid intake up to compensate for fluid loss. (Signs that the child is becoming dehydrated might include dryness around the lips and tongue, sunken eyes, not wetting their nappy or not going to the toilet if older.) The child should stay off nursery or school, and wash hands after going to the toilet, so that others within the school/nursery or family don't catch it as well! Generally, such infections are caused by viruses, are transmitted by contact, and do not require any drug treatment from your doctor, but if you are worried it's always a good idea to check with a health professional.

Sometimes children with Down's syndrome have a problem with persistent diarrhoea, loose, frequent bowel movements, sometimes with small bits of whole food such as sweet corn or bits of carrot recognisable in the 'poo', without any symptoms of being unwell. They have no fever or tummy pain, and continue to grow normally. This condition which occurs in children with and without Down's syndrome is called 'toddler diarrhoea', but in children with Down's syndrome it sometimes persists later in the pre-school years. It makes toilet training difficult, but is not harmful to the child in any way and does not require treatment and usually resolves as the child gets older. Some parents will report that their child's diarrhoea is worse with certain food substances e.g. fruit juices or certain vegetables, and then the condition will improve with reduction of those items in the diet. It is not the case that the child is allergic to these foods and they should continue to be taken in reduced amounts. Sometimes knowing foods that make the gut move more quickly can be helpful if the child subsequently becomes constipated.

Constipation

Another condition which is common in children with Down's syndrome is constipation. This is particularly a problem for those children with lower muscle tone, and those who take less exercise. Not drinking enough through the day also contributes, as does a diet that is low in fibre content. Most parents can help their children by making sure they drink at least 1 to 1½ litres a day, have a healthy diet with fibre like bran and vegetables and take exercise. Sometimes a replacement for natural fibre in the diet such as Movicol will be prescribed by the doctor, and this can be taken over many years if needed to keep the child's bowel regular. Other safe medications such as Lactulose may also be suggested. Very occasionally thyroid disorder (which is again common for children with Down's syndrome) may be a cause of constipation, but more usually it is due to diet. Fortunately, these days most children with Down's syndrome will have their thyroid function routinely checked and doctors will know to recheck it if they develop constipation.

Pain

Children often complain of tummy ache. In many cases it is nothing to do with the gastrointestinal tract but is a general symptom of being unwell, or it may be the child's way of explaining a pain elsewhere in the body. It may also be a symptom of anxiety. Most tummy aches disappear after a few hours and a few cuddles!

It is often caused by constipation and may be relieved by the child having a bowel movement. Advice should be sought from a doctor if it persists, is associated with other

symptoms such as vomiting, or if severe. Pain may also be related to the oesophagus (heartburn or indigestion). This is likely to be due to gastro-oesophageal reflux (discussed below). Reflux is most likely to occur in babies who are unable to tell us they are in pain, so it is always worth thinking about in a baby who seems in discomfort, especially after feeds.

Poor weight gain

This can be a symptom of many childhood disorders. It is often associated with gastrointestinal problems.

The other symptoms above may not be very serious, but should always be considered more seriously if associated with poor weight gain, or weight loss. Children with Down's syndrome do grow slowly when compared with other children.

There are growth charts available specifically for children with Down's syndrome. Like all children, there is considerable variation in size and weight, so a child's actual weight is not as important as the rate of weight gain or the comparison with previous weight or height measurements for that child.

Gastro-oesophageal reflux

In order to digest our food, we all produce enzymes and an acidic environment in the stomach. If this acidic stomach content refluxes back up the gullet it can cause irritation and then become painful. If you have had indigestion yourself, you will know how that feels. In babies and children with Down's syndrome they can become irritable and upset and vomit with feeds. Sometimes it will cause them distress and discomfort during the night. If the irritation is severe they may even show some specks of blood in their vomit. If the baby is in pain and vomiting and particularly is losing weight, parents need to seek help quickly, but it is more usual that the discomfort and early vomiting will lead to this problem being spotted and treated before any weight loss is seen.

The reason children with Down's syndrome are more susceptible to this condition is because of their low muscle tone. This affects the control of the muscles in the tummy, making reflux more likely. Additionally, because children are likely to take longer to acquire a sitting and standing position they are more at risk of reflux. Reflux is very common, and parents should anticipate this and follow simple steps to try to help the baby remain in a more upright position after feeds and through the day.

Sometimes the use of special equipment to help the baby sit in an upright supported position can be very helpful. This has double benefits as it also allows your infant to be more aware of what is going on around them rather than seeing the world from a horizontal position on the floor. Occupational therapists or physiotherapists will be able to help source supportive seating, some of which is commercially available. If your child is continuing to have problems, there are two main approaches to treatment which can be used alone or together. The first is a medicine that coats the area where the reflux is happening and soothes and protects the lining of the gullet. The second type of medication reduces the amount of acid produced in the stomach so that even if the reflux continues the irritation is diminished. Both types of oral medicine are well

tolerated and easy to take. As the child becomes more upright and mobile, the tendency for stomach contents to reflux decreases greatly.

Hirschprung's disease

As noted earlier, unusual problems with the development of the gut can occur in children with Down's syndrome. There is a rare problem with the nerve control of the muscles in the lower part of the gut which can cause constipation. This is a condition called Hirschsprung's disease. Although more common in children with Down's syndrome it is still quite rare and the practice guidelines for the health surveillance of children with Down's syndrome ensure that health practitioners are aware that this should be considered in children with Down's syndrome who are constipated. The diagnosis can only be made by specialist examination of a biopsy from the child's gut. This is usually done under anaesthesia.

Malabsorption and coeliac disease

One of the other areas of concern for parents relates to possible overreaction to food proteins in the gut. The most common concern relates to reactions to gluten, a wheat protein that can stimulate an inappropriate adverse reaction in the gut. This results in damage to the surface of the gut where nutrients are absorbed and particularly leads to the under absorption of iron and then vitamin B12 which results in the child becoming anaemic. The child's growth may also start to slow and they may complain of wind and tummy pains, develop diarrhoea, or occasionally, become constipated. There has been much discussion about whether all children with Down's syndrome should be screened for coeliac disease, and different countries follow different recommendations. To screen for the disorder requires the child to have a blood test and then to confirm the diagnosis, a small local biopsy of the lining of their gut wall, while taking gluten in their diet. Currently the recommendation in the UK, is that practitioners should have a high awareness of this as a possible problem in children and adults with Down's syndrome, but that tests should only be done if the health practitioner feels that this is a real possibility. Recent research suggests that a simple blood test within the first year can identify those who may be at risk or not at risk of being sensitive to gluten.

If diagnosed with coeliac disorder, children are treated in the usual way with gluten free diets and respond well. Interestingly children and adults with Down's syndrome seem to be less likely to get long term complications of coeliac disease, even if they do not rigidly follow their diet.

Food intolerance

It is not clear that any other food allergies are more common in children with Down's syndrome and nutritionally they appear to absorb all nutrients and vitamins adequately. A study carried out in the UK to look at whether vitamin supplementation was helpful showed no positive benefits to the group taking the vitamin supplements. A healthy diet is what we all need.

Information on that study can be read here : <https://www.downs-syndrome.org.uk/download-package/vitamins-minerals-research/>

Conclusion

So, in conclusion, as for all children a healthy diet with attention to water and fibre intake is important, as is exercise and maintaining a healthy weight. Just like all children, those with Down's syndrome can contract mild viral infections resulting in diarrhoea and/or vomiting. Simple things like teaching your child about good hand washing, particularly after going to the toilet, can be really useful and protective for them. Reflux is common and related to the child's posture. Parents can take steps to minimise the amount of reflux and effective treatment is available.

Weight loss, unless related to a prescribed calorie controlled diet, is not normal. Parents should seek medical advice if their child's growth slows or their weight starts to fall. We all need to be aware that children with Down's syndrome will have problems expressing their symptoms and parents are invaluable in ensuring that health practitioners understand and appropriately interpret the child's symptoms.

Annual health checks for people with Down's syndrome (aged 14 years plus)

In the past people with learning disabilities have not had equal access to healthcare compared to the general population. This, amongst other reasons, has given rise to poorer mental and physical health and a lower life expectancy for people with learning disabilities. Free annual health checks for adults with learning disabilities, with their GP, were introduced in 2008 as a way to improve people's quality of life.

The annual health check for people with learning disabilities is a Directed Enhanced Service (DES). This is a special service or activity provided by GP practices that has been negotiated nationally. Practices can choose whether or not to provide this service. The Learning Disability DES was introduced to improve healthcare and provide annual health checks for adults on the local authority learning disability register. To participate in this DES, staff from the GP practice need to attend a multi-professional education session run by their local Trust. The GP practice is then paid a sum of money for every annual health check undertaken.

Who can have one?

Annual health checks have been extended to include anyone with learning disabilities aged 14 years or above. So anyone with Down's syndrome aged 14 years or over can have an annual health check.

The benefits of annual health checks

- additional support to get the right healthcare
- increased chance of detecting unmet, unrecognised and potentially treatable health conditions
- action can be taken to address these health needs.

How to get an annual health check

- The GP may get in touch with the person with Down's syndrome to offer an annual health check but this doesn't always happen.
- A person with Down's syndrome and/or a supporter can ask their GP for an annual health check. You do not need to be known to social services to ask for an annual health check.

Not all GPs do annual health checks for people with learning disabilities but they should be able to provide details of other GPs in your area who offer this service.

What happens next?

- The GP practice may send out a pre-check questionnaire to be filled out before the annual health check takes place.
- The GP may arrange for the person with Down's syndrome to have a routine blood test a week or so before the annual health check.

Who attends the annual health check?

If the person with Down's syndrome (age 16 years or over) has capacity and gives their consent, a parent or supporter can attend the health check as well.

How long should an annual health check be?

Guidance from the Royal College of GPs suggests half an hour with your GP and half an hour with the Practice nurse.

What areas of health should be looked at as part of the annual health check?

We have produced a check list for GPs which contains information about what should be included as part of a comprehensive and thorough annual health check. This includes a list of checks that everyone with a learning disability should undergo as part of an annual health check and a list of checks specific to people with Down's syndrome. You can find the health check list at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

What happens after the annual health check?

Your GP should tell you what they and the nurse have found during the annual health check. You should have a chance to ask any questions you have. Your GP may refer you to specialist services for further tests as appropriate. Your GP should use what they have found during your annual health check to produce a health action plan. This should set out the key actions agreed with you and (where applicable) your parent or carer during the annual health check. Your GP has to do this as part of the annual health check service.

Information about health issues for GPs

There is information at our website for GPs about some of the more common health conditions seen in people with Down's syndrome. You will find this information at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

GPs learning disability register

People with learning disabilities experience poorer health compared to the rest of the population, but some ill health is preventable. Over one million people in the UK have a learning disability but only 200,000 are on their GPs learning disability register.

We know that people with a learning disability often have difficulties accessing health services and face inequalities in the service they receive. The Government is asking parents and supporters to speak to their GP and ensure their sons/daughters or the people whom they support are registered. It is hoped that this drive will ensure better and more person centered health care for people with learning disabilities.

The Learning Disability Register is a record of people with a learning disability who are registered with each GP practice. The Register is sometimes referred to as the Quality Outcomes Framework (QOF) Register.

If you are not sure you are on the Register, you can ask the receptionist at your GP Practice to check for you.

The doctor may have made a note on the record that a person has Down's syndrome but this does not automatically mean they have been put on the Register. When you speak to the GP about being registered, the needs and support of the person in health settings can be discussed. This information can be entered on the person's Summary Care Record (SCR) so that all health professionals at the practice know about their needs and how best to support them.

If the person is over 16 years of age or older, they must give their consent (see section in this resource about the Mental Capacity Act 2005):

- for information about their support needs to be added to their SCR
- to which information can be shared and with whom

It's never too early (or late) to join your GP's Learning Disability Register; you can join at any age. It's a good idea for children with a learning disability to join the learning disability register at an early age. This means adjustments and support can be put in place before they reach adult services.

Reasonable adjustments in health care

You may have heard of the term 'reasonable adjustments' and wondered what it meant. Since the Disability Discrimination Act (1995) and the Equality Act (2010) (this does not apply to Northern Ireland) public services are required by law to make reasonable adjustments to help remove barriers faced by people with disabilities when trying to use a service. The duty under the Equality Act to make reasonable adjustments applies if you are placed at a substantial disadvantage because of your disability compared to people without a disability or who don't have the same disability as you.

So for people with physical disabilities reasonable adjustments may include changes to the environment like ramps for the ease of wheelchair users. For people with learning disabilities 'reasonable adjustments' may include easy read information, longer appointments, clearer signs at the practice, help to make decisions, changes to policies, procedures and staff training.

If a patient with Down's syndrome is NOT on their GP's Learning Disability Register then reasonable adjustments to care for that person cannot be anticipated and made.

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The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

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