



**Down's Syndrome
Association**

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Health Series



Gastrointestinal conditions in adults



The
Down Syndrome
Medical Interest
Group

A Down's Syndrome Association publication

Our resources and Information Team are here to help

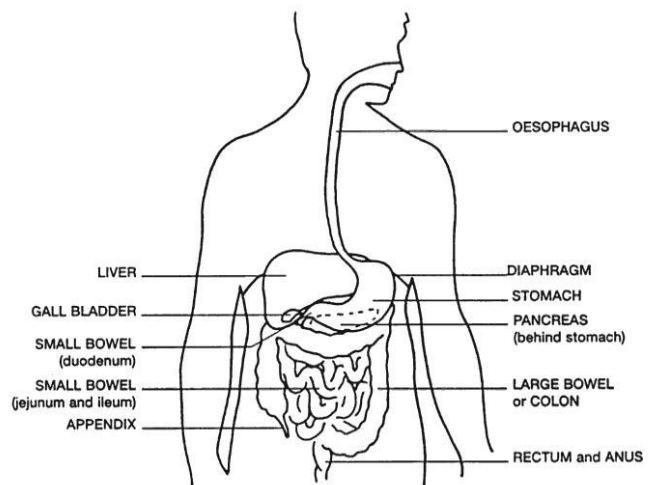
Please see our website for up-to-date information: www.downs-syndrome.org.uk

If you would like to talk about any of the issues raised in this resource, then please get in touch with our helpline by calling 0333 1212 300 or by emailing us on info@downs-syndrome.org.uk.

Helpline Monday - Friday 10am-4pm | Telephone: 0333 1212 300

The gastrointestinal tract covers all parts of the body involved in the processing of food. It includes the mouth, the oesophagus, stomach, small intestines or bowel (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 with Down's syndrome. Some will have obvious symptoms such as diarrhoea, vomiting, marked weight loss, severe abdominal pain, that suggest a problem with the gastrointestinal tract. Others may have subtler symptoms that can easily be missed and perhaps put down to behavioural or even psychological problems. Less obvious 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 with Down's syndrome, a change in their behaviour may be the first sign that something is wrong.

If a person with Down's 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, parents/supporters should never allow symptoms to be explained away by the fact that person has Down's syndrome.

You should always expect health professionals to take your concerns seriously.

Gastroesophageal Reflux Disease (GORD)

This is where stomach acid flows backwards in to the oesophagus. It appears to be more common in people with Down's 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, sleep apnoea and gallstones. However, it isn't always possible to identify a cause.

One of the most common symptoms of GORD is heartburn which is a burning sensation or a pain in the chest after eating. Other symptoms and signs include:

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

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 upper body slightly raised where the person has reflux when they wake up. 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 think the person you support is suffering from GORD. The GP may prescribe medication to reduce acid levels in the stomach. They may also prescribe medication 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 an inflammation of the small intestine which destroys the villi which are tiny projections on the wall of the intestine which help us to absorb food. The loss of the villi reduces the intestine's ability to absorb vitamins, minerals and calories. Over time this leads to the malabsorption of nutrients in food. Coeliac disease is more common in people with Down's syndrome than in the general population. It can occur at any age, **even** in people who have never had any symptoms before.

For Annual Health Checks we recommend:***'Coeliac disease******Screen clinically by history and examination annually.******Testing in those with suspicious symptoms or signs, including:***

- ***Disordered bowel function tending to diarrhoea or to new onset constipation***
- ***Abdominal distension***
- ***General unhappiness and misery***
- ***Arthritis***
- ***Rash suggesting dermatitis herpetiformis***
- ***Test all those with existing thyroid disease, diabetes or anaemia.'***

Source: Annual Health Checks for people with Down's syndrome Check List

The most commonly recognised 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
- abdominal pain
- swollen abdomen
- muscle cramps
- abnormal stools
- irritability
- anaemia
- tiredness
- malaise
- vomiting
- seizures
- dizziness
- nervousness
- increased appetite
- excessive flatulence

The process of diagnosing Coeliac disease starts with an assessment by a GP of a person's symptoms and a physical examination. The GP may then arrange for a blood sample to be taken to test for antibodies that are usually present in people who have Coeliac disease.

If the antibodies are present, the GP will make a referral for a biopsy of the gut. This will usually be performed by a Gastroenterologist and 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 tissue will be taken for analysis. This procedure is known as an endoscopy. This is the only way to be absolutely certain that a person has Coeliac

disease. A local anaesthetic or sedative may be given for the endoscopy to help the patient relax. There is a link to an easy read resource about having an endoscopy at our website in the 'health and wellbeing' section under 'Coeliac disease'.

It is possible to have Coeliac disease and not have the antibodies in your blood. If symptoms continue, the GP may still make a referral for a biopsy anyway.

Treatment of the condition (as advised by the GP/Gastroenterologist) is by the elimination of gluten from the person's diet. They should avoid cereal wheat, rye, barley and possibly oats. Advice and support should be sought from a dietician.

We know a number of adults who, with support, cope very well with sticking to a gluten-free diet. In fact, the tendency of people with Down's syndrome towards sameness and repetition can be usefully employed in some people to make sure they stay on track with their new 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 the person you support 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 with Down's 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 with Down's syndrome, but that tests should only be done if the health practitioner feels that this is a real possibility.

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). As far as we know there is no one 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

'IBS is probably more common in adults with Down's syndrome. The motility of the gut is commonly abnormal in people with Down's syndrome. In addition, many people with Down's syndrome seem to physically react to stress with a change in their gastrointestinal system.'

Source: Chicoine & McGuire, *The Guide to Good Health for Teens & Adults with Down Syndrome*, Woodbine House (2010)

Food sensitivity

As already mentioned earlier in this resource, sensitivity to gluten (Coeliac disease) is more common in people with Down's syndrome. The inability to digest lactose, a sugar found in cow's milk, may also be more common in people with Down's syndrome. People with lactose intolerance do not produce enough of the enzyme lactase that breaks down lactose.

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/or by the person taking a simple non-invasive lactose breath hydrogen test.

Once a diagnosis of lactose intolerance is made, the person should avoid foods that contain lactose. Foods treated with lactase, lactase tablets and soy milk are now more widely available. 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 with Down's

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. Bile contains bile salts, cholesterol and bilirubin (a break-down product of red blood cells). If the bile duct contains an imbalance of these substances, gallstones will form.

Gallstones are more common in people with Down's syndrome. There is some evidence that the bile duct in people with Down's syndrome is slower at releasing bile into the small intestine. This means the bile is sitting around for longer which increases the chance of gallstones forming. In addition, people with Down's syndrome may have a higher turnover of red blood cells which could lead to higher levels of bilirubin and an imbalance in the make-up of the bile. 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.

'Some people with Down's syndrome may not be able to report their symptoms, and may therefore have behavioural changes in response to the symptoms. We have seen several individuals who reacted to gallstones with periodic aggressive or agitated behaviour. Their behaviour improved after treatment of the gallstone.'

Source: Chicoine & McGuire, *The Guide to Good Health for Teens & Adults with Down Syndrome*, Woodbine House (2010)

Hernias

Hernias are more common in people with Down's 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 with Down's 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, your doctor will discuss with you whether or not surgery to repair the hernia is necessary.

Constipation

Constipation refers to bowel movements that are infrequent or hard to pass. Constipation happens to people with Down's 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 as a result of Coeliac disease and thyroid condition (hypothyroidism); both of which are more common in people with Down's 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. As already mentioned, diarrhoea may occur as a result of constipation, Coeliac disease, IBS and food sensitivity. In addition, it can occur as a result of bowel infection, bowel disease, metabolic problems, emotional problems or contaminated food and drink.

Symptoms include loose motions, stomach cramps/pain, weight loss, distress and blood in the stools.

Diarrhoea usually clears up without treatment after a few days.

Everyone's bowel habits are different. Any change in normal bowel habits for the person you support 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), the person whom you support should be checked out by their GP.

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. We have come across cases where 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 with Down's syndrome go on to develop obsessions about not eating where refusal to eat becomes 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 such as a loss of appetite.

There may be instances where a person's eating habits haven't changed but they are still losing weight. Auto-immune disorders are common in people with Down's syndrome. As already covered in this resource, Coeliac disease, which is an auto-immune disease, can lead to weight loss as it reduces the intestine's ability to absorb vitamins, minerals and calories. Over time this leads to the malabsorption of nutrients in food. In addition to Coeliac disease, there are other auto-immune disorders, that may result in weight loss even where the person still has a good appetite (e.g. hypothyroidism, diabetes).

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. There is further information about CLDTs towards the end of this resource.

'While overweight and obesity are common in people with Down's syndrome (and without Down's syndrome), we have seen a number of individuals with Down's syndrome who are underweight and/or have problems with unexplained weight loss'

Source: Brian Chicoine (Medical Director), Adult Down Syndrome Center, Illinois, USA

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, as a result of excess body fat. For many years there has been a myth circulating around the inevitability of people with Down's syndrome gaining weight. Maybe this persists from the old days of institutions and hospitals. There are certainly many people with Down's syndrome who defy this stereotype by leading very active and healthy lives. Obesity is not inevitable for people with Down's syndrome.

Having said that, there may be factors that people with Down's syndrome have to overcome that are either not present, or at least not as common, in the wider population (e.g. lower metabolic rate, less physical activity as a result of lower muscle tone and delayed development and health conditions such as hypothyroidism, mitral valve issues, obstructive sleep apnoea and coeliac disease). As in all people, obesity may be related to a diet which is high in fats and sugars combined with an inactive lifestyle. 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. There is further information about CLDTs towards the end of this resource.

Tips for weight management

There are no special approaches or interventions for people with Down's syndrome where weight is concerned. We suspect that, as with the rest of us, prevention is easier than cure. It is easier to lay the foundations for lifelong healthy lifestyles by early education and building on healthy routines than tackling weight issues later in life. 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.

'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'

A common misconception is that weight management is all about dieting and losing weight when it is more about managing time, food and activity levels. As with anything, focusing on the positives, rather than a punitive approach, is the best way to go. None of us respond very well to being told what is wrong about us! 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 with Down's syndrome will 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 as a result of being taught with a 'green' and red' food labelling system. People need to be able to exercise choice in other areas of their lives too. One of the issues that we sometimes hear about is people leaving home and going wild with unhealthy food shopping because it's the first time they have had a choice and they are taking advantage of new found freedom.

Children and adults should be involved in planning meals, shopping for ingredients and in preparing meals. An obvious point, but a person with Down's 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 people will need 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, many love it and it makes some of us inwardly groan! The idea of going to a gym would make some of us run a mile in the other direction! The good news is that it doesn't have to look like exercise in the traditional sense; activity is the important part rather than the location! Fun recreational social activities can provide the benefits of exercise without feeling too much like hard work. Building regular walks with family and/or friends into the week can really help. Social activities such as dancing or drama groups can be really good motivators for people with Down's syndrome. Exercise DVDs, particularly those featuring a favourite actor or TV personality, or Wii fitness or Wii workout are enjoyed by many adults.

'My brother has always stayed fairly slim because his whole life he's exercised and I think that's key. You need to find an activity they love and roll with that.'

'My son joined Special Olympics. He attends a session every night of the week. Athletics, golf basketball, football and dance. Not only helps with his weight but has added so much to his social life'

With the best will in the world, it may be that when your son/daughter leaves home and moves into a more independent environment they gain weight. There are no quick and easy fixes in these situations. What seems to work best are small changes to lifestyle,

consistently applied over time rather than larger unrealistic changes and goals. Parents tell us that peer mentoring, clubs such as weightwatchers, food diaries and visual timetables with targets can all be useful tools in weight management. There is further advice about weight management when someone leaves home in our resource 'Supported living – An introduction for parents and carers'. This can be downloaded from the 'where to live' section our website.

'We went to our GP who gave us a free 3 months' subscription to Slimmer's world or Weight Watchers. We did not stick to it rigidly but my daughter has lost 2 stone over 12 months and is looking and feeling great. We had tried many different things previous to this but nothing seemed to make a difference.'

Take a look at our DSActive programme which has been created to provide opportunities for people with Down's syndrome in England and Wales to be fit and healthy. To find out more, go to www.dsactive.org.uk or call Tel: 0333 1212 300 /Email: dsactive@downs-syndrome.org.uk

Getting a voluntary or paid job might provide opportunities for activity. Our Workfit programme may be able to help the person for whom you care get a job. See www.workfit.org.uk or call Tel: 0333 1212 300 / Email dsworkfit@downs-syndrome.org.uk for more information.

'Body Mass Index (BMI) is a measurement that compares weight to height. For example, a person who is 5 feet 5 inches tall (165 cm) and weighs 150 pounds (68kg) has a BMI of 25. BMI is used to calculate the definitions of obesity and overweight:

- ***Overweight means a BMI greater than 25.***
- ***Obesity means a BMI greater than 30.***
- ***Severe obesity means a BMI greater than 40.***

Body mass calculators can be found on the Internet by entering "body mass index calculator" into a search engine. Sex, height, and weight can then be entered and BMI will be calculated.

Another way to look at a person's weight is to compare his or her weight to Ideal Body Weight (IBW). IBW can be roughly calculated as follows:

- ***For women, start at 100 pounds (45kg) for the first 5 feet of height (152 cm) and add 5 pounds (2.3kg) for each additional inch (approximately 2.5cm). A woman's IBW is within +/- 10% of that number.***
- ***For men, start with 106 pounds (48kg) for the first 5 feet (152 cm) and add 6 pounds (2.7kg) for each additional inch (approx. 2.5 cm). IBW is within +/- 10% of that number.***

In addition, there are weight tables for people with DS. However, these aren't very useful in determining whether a person with DS is overweight since the weight tables just reflect the actual weights of the individuals with DS in a research group, not the ideal weight.'

Source: Chicoine & McGuire, *The Guide to Good Health for Teens & Adults with Down Syndrome*, Woodbine House (2010)

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.

End note

The gastrointestinal issues covered in this resource are some of those that are more commonly seen in people with Down's syndrome. These are not the only gastrointestinal issues that people with Down's syndrome may develop. There are numerous gastrointestinal conditions many of which have similar symptoms. Some symptoms may be subtle; therefore, it is a good idea to keep any eye out for any behaviour changes in the person whom you support. For many people with Down's syndrome a change in behaviour may be the first indication you have that something may be wrong.

If in doubt, get it checked out by the GP!

Healthcare - general

Making decisions - Mental Capacity Act (MCA) (2005) and Code of Practice

This law, which applies in England and Wales, sets out what should happen if someone is unable to make a decision for themselves. Its purpose is:

- To support individuals to make their own decisions wherever possible
- To protect those who cannot.

The Act is supported by a Code of Practice with specific guidance for professionals (e.g. social care, health, paid carers) who work with people who lack capacity. It is important for family carers to be aware of what the Code says.

The Act has five key principles to guide carers who have concerns over someone's capacity to make a decision:

- Every adult has the right to make their own decisions if they have the capacity to do so. Family carers and healthcare and social care staff must always assume that a person has capacity to make a decision unless it can be established they do not.
- People must have support to help them make their own decisions. This principle is to stop people being automatically labelled as lacking capacity just because they have a learning disability. Types of support could include using a different form of communication, providing information in different formats (photographs, drawings, tapes) or having a structured programme to improve a person's capacity to make particular decisions (e.g. a healthy eating programme)
- People have the right to make decisions others might think are unwise - it does not mean they lack capacity. They may need further support to help them understand the consequences of their decision.
- It is important that any decision made on behalf of someone is made in their 'best interests' and that the person themselves and those who know them best are involved in the decision-making.
- A person making a decision on behalf of someone must always ask themselves if there is another option that would interfere less with the person's rights and freedoms.

There is information about making every day financial, health and welfare decisions post 16 years old at the 'families and carers' section of our website.

Annual health checks

Every adult with Down's syndrome should have a comprehensive and thorough annual health check with their GP. Free annual health checks for adults with learning disabilities, with their GP, were introduced 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 in 2008 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.

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'.

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.

It's never too early (or late) to join your GP's Learning Disability Register; you can join at any age.

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

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 to ensure that services work equally well for everyone.

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.

Health – sources of support

GP

Your GP will be your main source of information and support. Your GP can make referrals for you to social services, other relevant health services and local support/information services.

Community Learning Disability Teams (CLDTs)

CLDTs have been set up to serve the particular health needs of people with a learning disability and their family members, family carers and paid staff. CLDTs vary in size and make up but typically they will contain community learning disability nurses, a psychologist and a psychiatrist. You can discuss with your GP whether or not a referral to the local CLDT is appropriate. Some CLDTs take direct referrals from people with learning disabilities, their families or paid supporters thus cutting out the need to ask your GP to make a referral. You can find your local CLDT by searching online.

How we can help

Helpline

You can call our Helpline team Tel 0333 1212 300 or email us using info@downs-syndrome.org.uk if you have any questions about people with Down's syndrome and health issues.

Training

We offer a range of training to help family members and practitioners understand and support people who have Down's syndrome throughout their lives. Please contact us at training@downs-syndrome.org.uk to discuss your needs.

Benefits

You can call Tel: 0333 1212 300 or email using info@downs-syndrome.org.uk to find out if the person for whom you care is receiving the benefits they are entitled to. If you call us, please ask to speak to a benefits adviser.

Free membership of the DSA for adults with Down's syndrome

Adults with Down's syndrome are entitled to free membership of the DSA. Further information about membership can be found at our website in the 'support us' section.

DSA resources

If you would prefer a hard copy of this resource, or any of the resources referred to, please call us Tel: 0333 1212 300 or email using info@downs-syndrome.org.uk

Stuart Mills (DSA Information Officer) 2018

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.

Contact us

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www.dsactive.org



www.dsworkfit.org.uk



www.langdondownmuseum.org.uk



www.langdondowncentre.org.uk



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