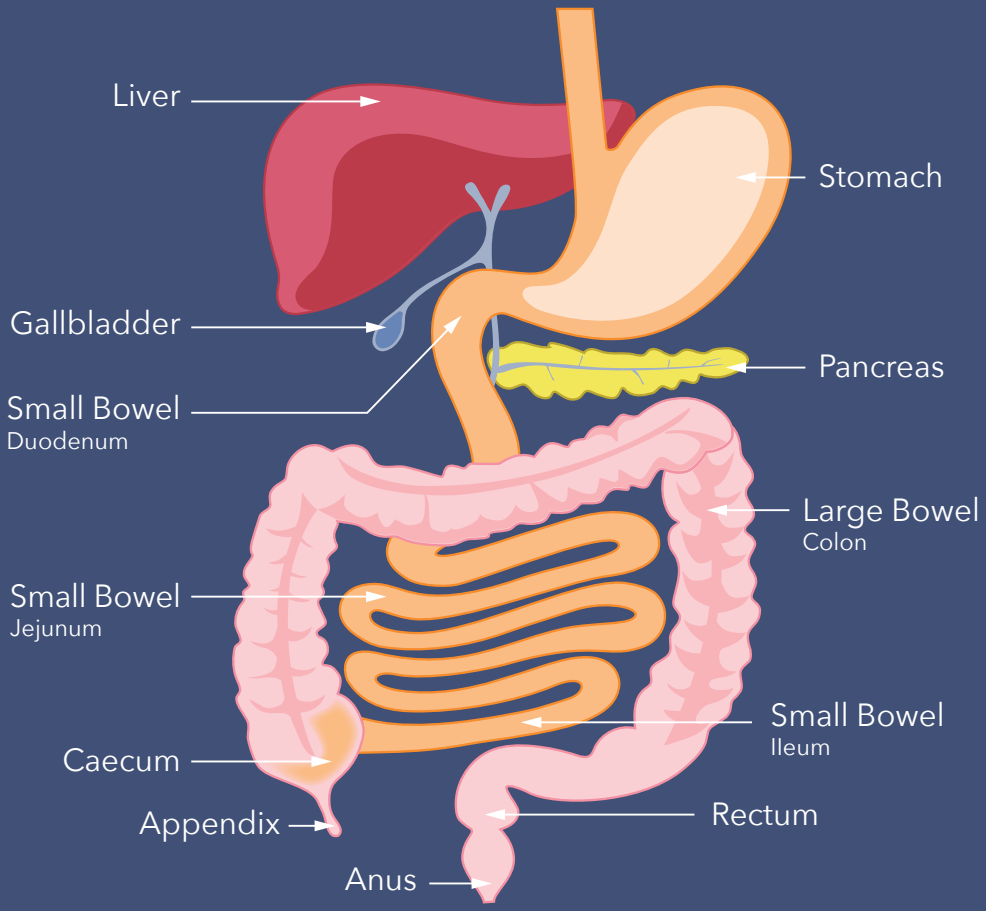
All you need to know about

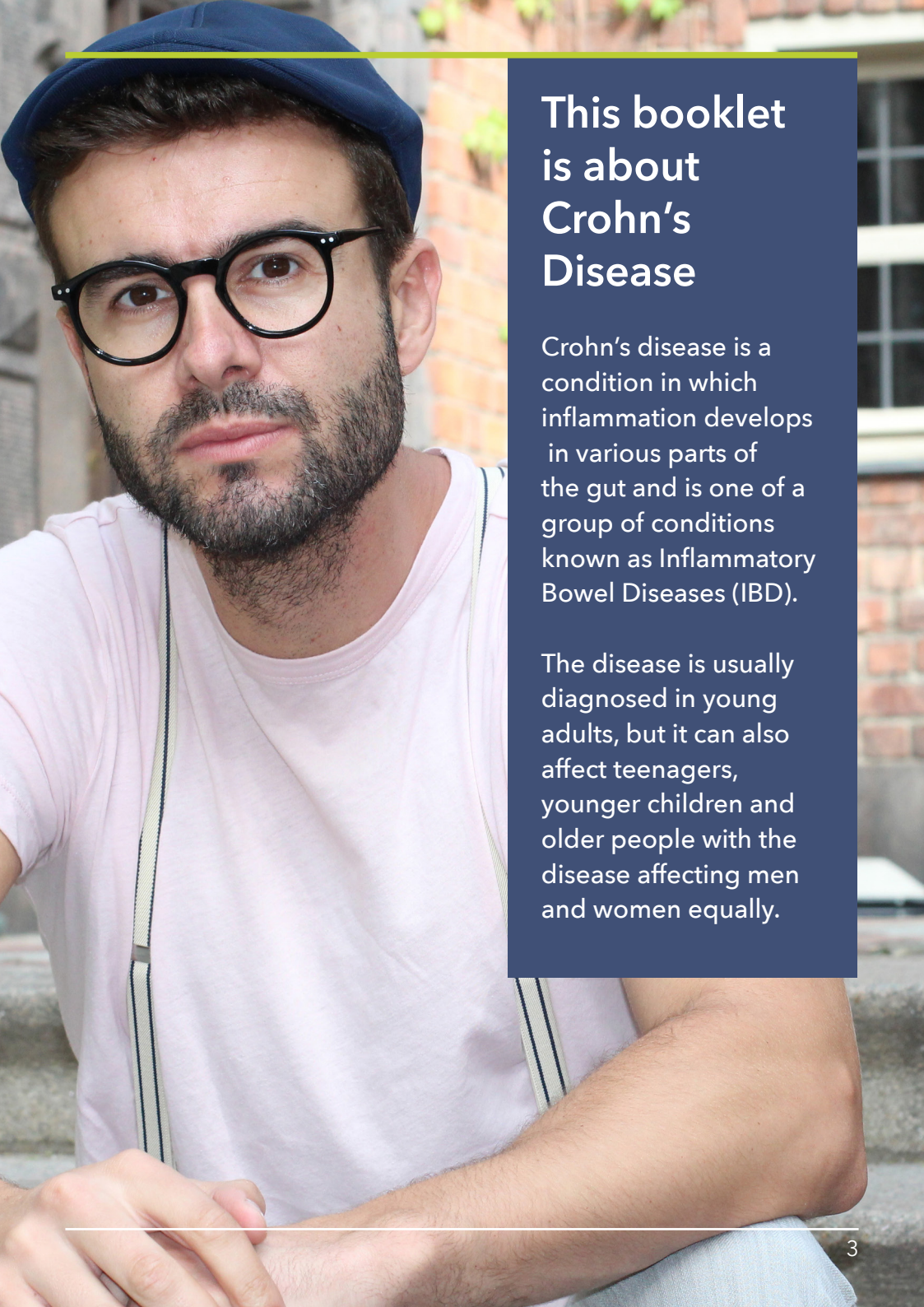
CROHN'S DISEASE

BRITISH SOCIETY OF GASTROENTEROLOGY

Our Digestive System

The Digestive System runs from the mouth to the anus and includes the stomach, the large and small bowels (intestines) and a number of accessory organs. The role of the digestive system is to turn food and liquid into the building blocks that the body needs to function effectively.





This booklet is about Crohn's Disease

Crohn's disease is a condition in which inflammation develops in various parts of the gut and is one of a group of conditions known as Inflammatory Bowel Diseases (IBD).

The disease is usually diagnosed in young adults, but it can also affect teenagers, younger children and older people with the disease affecting men and women equally.

Overview

Crohn's disease is one of a group of conditions that are known as Inflammatory Bowel Diseases (IBD) which also includes ulcerative colitis. Inflammatory Bowel Disease is different to Irritable Bowel Syndrome (IBS), which can cause similar symptoms but does not involve inflammation and is generally less severe.

1 in 4 diagnoses is in a person under 18 years of age. About 1 in 650 people have the condition and it can run in families – about one-fifth of people with the condition will have another family member who has the disease.

Crohn's disease is a disease where inflammation develops in various parts of the gut leading to symptoms such as diarrhoea, abdominal pain and tiredness. The inflammation ranges from mild to severe. Worse cases need strong medicine or even surgery to remove an affected part of the bowel.

What causes the development of Crohn's disease?

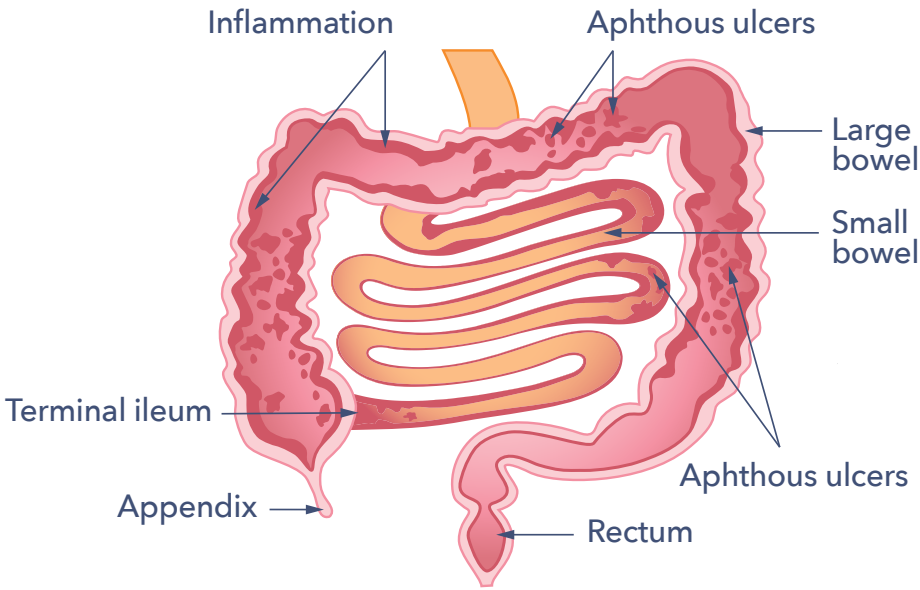
The exact cause is uncertain, but several factors are known to relate to Crohn's disease include genetics, gut bacteria population, and environmental factors such as lifestyle and diet.

It is thought that the disease develops because the guts disease fighting (immune) system reacts abnormally to bacteria at the surface of the gut. Genes play a part, associations have been identified with changes in various genes that affect the natural immune response to gut microbes. Genetically the identical twin of a person with Crohn's disease has only a 1 in 4 chance of developing the disease. Environmental factors appear to have more impact on the cause than genetics.

Crohn's disease is more common in western or westernised countries. It is suspected that low intake of fruit and vegetables and high intake of food additives such as emulsifiers may be a factor. Vitamin D deficiency, which is common in northern countries in the winter months, has been suggested as a risk factor but evidence is still incomplete.

Smoking is an important risk factor and oral contraceptive usage is associated with a slightly increased risk. However all of these suspected causes need more research.

What does Crohn's disease look like?



How does Crohn's disease affect the body?

In most people, Crohn's disease results in patches of bowel inflammation with groups of small sores (aphthous ulcers), which are like mouth ulcers. In moderate or severe cases, ulcers become large and deep with a lot of nearby inflammation.

Inflammation causes redness, swelling and pain and can make the bowel wall thicken up, narrowing the width of the gut which can block the passage of food. Sometimes, deep ulcers break through the bowel wall causing infection outside the bowel (an abscess). Sometimes, if the infection doesn't heal, or it heals but leaves a channel, a tract called a fistula can open up from the bowel to other areas. Fistulas are more frequent around the anus. Also, as healing happens, scar tissue may form, which can in some people lead to an obstruction in the bowel (stricture).

Any part of the gut, from the mouth to the anus, can be affected. The most common area is the end of the small bowel (terminal ileum) through to the large bowel (or 'colon'), near the appendix. In some people, only the large bowel is affected.

This pattern is like a disease called ulcerative colitis and is called Crohn's colitis. In others, many parts of the gut are affected and, rarely, the mouth, gullet or stomach. Sometimes, the gut inflammation can also trigger inflammation outside the bowel leading to arthritis and swollen joints, sore red eyes due to inflammation, or skin complaints (rashes). These are known as 'extra intestinal' symptoms.

Crohn's disease patients typically experience periods of remission, when the disease activity is low, and flare ups when the disease is active, and symptoms are stronger. Treatment aims to cause and maintain remission.

How is Crohn's disease diagnosed?

Diagnosis of Crohn's disease has improved significantly in recent years, however diagnosis can be difficult because the symptoms can be easily confused with other conditions.

For example, there are many causes of diarrhoea in young adults including Irritable Bowel Syndrome (IBS) and infection, such as traveller's diarrhoea. So, when someone visits their GP with symptoms of diarrhoea and abdominal pain, the doctor must decide whether special tests are needed to look for the possibility of Crohn's disease. The doctor will listen to the symptoms, ask about any of the related symptoms and whether there is anyone in the family with inflammatory bowel disease. The doctor might feel the abdomen to find out if there are any signs of inflammation (such as tenderness or a lump) and check whether there are any general signs of illness such as looking pale or underweight. A blood test might be arranged to see if there are changes in the blood suggesting inflammation.

If the doctor suspects that Crohn's disease is possible, they may refer to a specialist or request a stool sample. This will be tested for a protein called calprotectin, which is an indicator of gut inflammation. If this shows that inflammation is present referral to a specialist will then be made for further medical tests. These may include:

Colonoscopy

This is the most frequent test for diagnosing Crohn's disease. This is where a tube, linked to a camera, is passed, via the anus, into the colon and where possible the end of the small bowel. A colonoscopy gives a very accurate picture of the lining

of the bowel and allows the doctor to take samples for examination in the laboratory if needed. Laxative preparation is needed before the examination to clear the bowel contents and allow good views of the bowel lining. In most cases, sedation is given to minimise some feelings of discomfort from the test. If the colon and last part of the small bowel are seen to be normal, Crohn's disease is very unlikely to be present.

If the whole bowel needs to be examined there are several options including:

Magnetic resonance imaging (MRI)

The patient is placed inside a machine that creates detailed pictures of the inside of the body, which can be used to check the structure and function of the gut.

Capsule endoscopy

A capsule containing a tiny camera is swallowed and transmits pictures as it passes through the bowel.

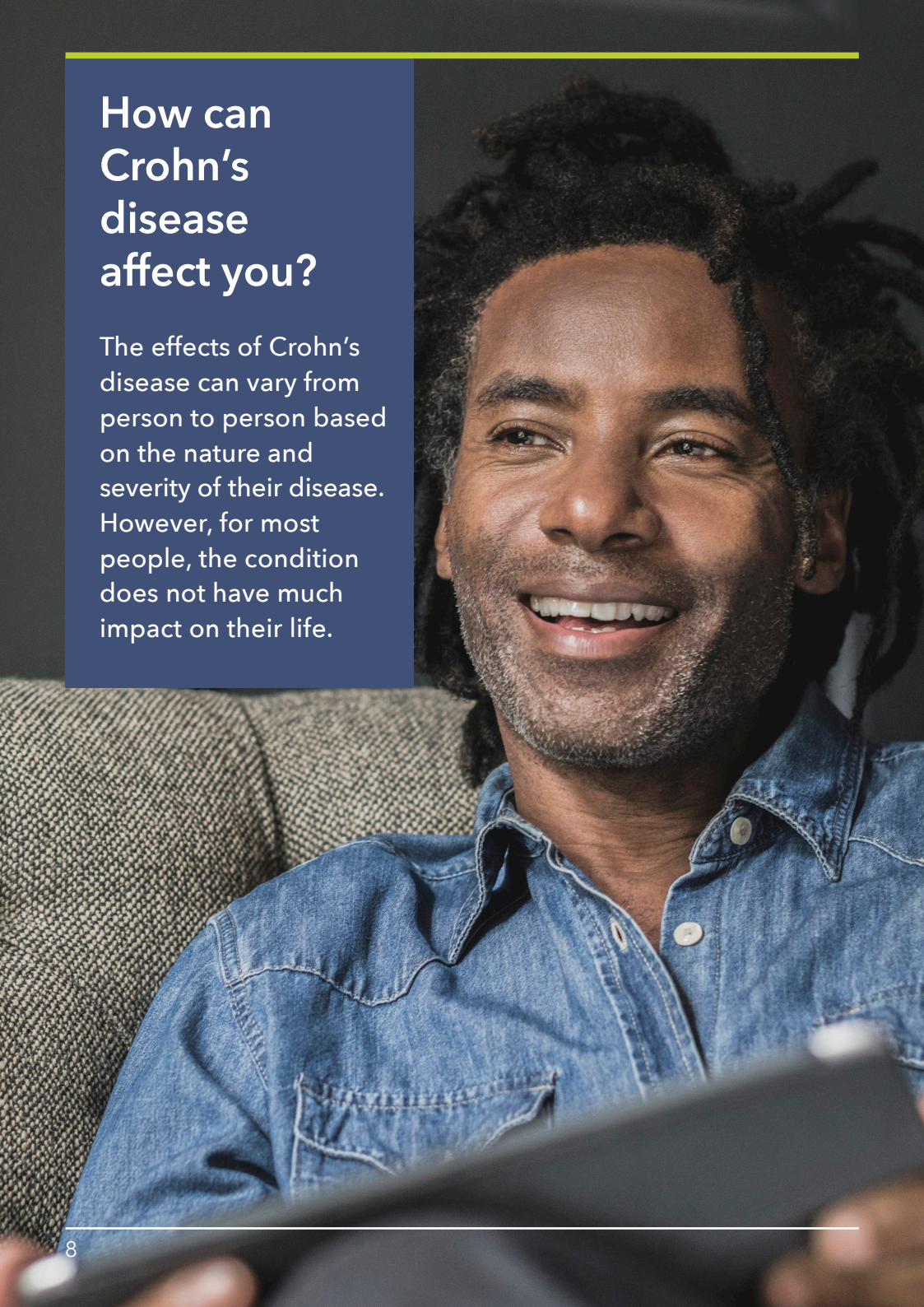
Barium follow through

Liquid barium is swallowed, and x-rays are taken as it passes through the bowel.

Scans such as ultrasound or CT scanning may also be needed, especially if an abscess or problems on the outside of the bowel are suspected.

How can Crohn's disease affect you?

The effects of Crohn's disease can vary from person to person based on the nature and severity of their disease. However, for most people, the condition does not have much impact on their life.



Symptoms

The most common symptom is diarrhoea and abdominal pain. The bowel contents can build up in narrowed and ulcerated areas of the gut. Occasionally the bowel gets blocked. This results in severe symptoms of griping abdominal pain after eating, bloating (swelling) and vomiting. This is an emergency medical problem so seek urgent advice if this happens.

There might be blood or mucus in the poo, especially when the lower bowel is affected. People can lose weight because of avoiding eating due to of symptoms and the body being unable to absorb food. This can also result in extreme tiredness due to low iron levels in the blood and medicine side effects. Often Crohn's disease leads to low mood and poor sleep. People can feel unwell and have night sweats.

Will Crohn's disease affect me over time?

Although in most cases, the condition does not have much impact on the ability to work or to enjoy an active social life, it does take some getting used to.

When it is at an active stage, symptoms such as diarrhoea and abdominal pain often require time away from work, college etc and can make it difficult to cope going out or even being at home. However, treatment usually makes the symptoms better within days or weeks so normal quality of life is restored quite quickly. Crohn's disease does not increase your risk of dying.

Some severe cases of Crohn's disease can have a significant impact on peoples lives. This can be due to a weak response to treatment which makes symptom-free remission difficult to achieve and can involve frequent flare ups.

As there is no cure for this condition, it can relapse intermittently. Flare ups can be triggered by various factors including stress, poor diet, missed medicine or other illnesses. These triggers will be specific to each person. Over time, most people learn how to manage their condition and identify and avoid the factors that may cause a flare up.

Recurrence is twice as likely in smokers compared to those who do not smoke. Medicines including antibiotics and immunosuppressants may help to reduce the chance of recurrence and doctors will decide based on the individual risks of a particular patient.

Overall, Crohn's disease does not have a significant effect on the chances of becoming pregnant or carrying a baby. Risks include inflammation or infection in the pelvis or surgery to this area which can affect the ovaries, fallopian tubes or uterus reducing fertility, but this is rare.

The commonly used drugs in Crohn's disease are safe during pregnancy, however methotrexate must not be taken when considering a pregnancy. Other medicines such as sulfasalazine are known to reduce male fertility, but this is reversible when the medicine is no longer taken. It is always best to talk to your specialist if you have Crohn's disease and are planning a pregnancy or are already pregnant.

If you are losing weight or have restricted your diet in any way, ask your GP for a referral to a registered gastroenterology dietitian.

What treatment is available?

The aim of treatment for Crohn's disease is to heal or reduce the inflammation in the bowel as well as deal with the effects of the disease, such as weight loss. Inflammation is generally treated with medicines but sometimes surgery is needed to remove inflamed or narrowed parts of bowel.

Diet

Many people ask whether they should change their diet, but there is no proven specific diet for Crohn's disease. There are, however, several exclusion diets that are not based on scientific evidence. These restrictive diets can significantly limit the nutritional quality of your diet. If you are thinking about excluding specific foods from your diet, please discuss with your IBD team before making any dietary changes.

The current advice is to follow healthy eating guidelines unless any of the situations below apply. See our Healthy Eating & the Digestive System booklet for guidence.

There are sometimes situations where dietary changes are useful to ease symptoms.

Strictures: This is a narrowing in the bowel. A reduction in fibre and indigestible foods can be helpful to reduce pain. Speak to your IBD team about seeing a dietitian who will be able to help.

Diets to cause disease remission: Specialised liquid formula diets ('elemental' or 'polymeric' diets) are used to treat Crohn's disease, especially in children where maintaining growth and weight is very important. They can also be used in highly dedicated adults or where steroids need to be avoided. It involves taking a prescribed liquid diet to meet your nutritional needs and excludes other food/drinks except water for up to 8 weeks. These diets rest the bowel, reduce inflammation, reduce symptoms and improve nourishment.

Functional bowel symptoms: Some peoples have functional bowel symptoms (IBS) alongside IBD and may benefit from avoidance of specific dietary triggers to manage symptoms. Please ask your IBD team to refer you to a gastroenterology dietitian.

Unintentional weight loss: Speak to your IBD team to refer you to a gastroenterology dietitian if you are concerned that you are unintentionally losing weight.

Probiotics: There is currently no compelling evidence for a beneficial effect of probiotic preparations.

Medicines

These are mainly directed at the immune system in the bowel and include:

Antibiotics (e.g. metronidazole): These are used either by reducing the bacteria, which 'drive' the inflammation, or to treat abscesses. They are not used for long-term treatment.

Aminosalicylates: These are like aspirin and are used to treat milder inflammation or reduce a flare up of inflammation (for example, after an operation).

Steroids: These are much stronger drugs used to suppress inflammation when the symptoms are more severe. Steroids are very effective (about 8 out of 10 patients have a good response). Some can have side effects such as weight gain, insomnia, infection and acne. Prolonged use can result in thinning of the bones. A steroid called budesonide has far fewer side effects that the standard steroids, such as prednisolone. Steroids are only used as a short-term measure (e.g. 3 months) to achieve remission. Many people with Crohn's disease change their diet to try and help with symptoms, but it is very important that adequate calcium is included, as you require more than the general population.

Check your calcium intake here: **www.bda.uk.com/resource/calcium.html**

Immunosuppressive drugs: These are often used to reduce inflammation over a longer period and allow steroids to be stopped. Azathioprine and mercaptopurine are most often prescribed and around 2 out of 3 people have a successful response. Most people tolerate the drugs well and they are now the most used medicine for keeping Crohn's disease under control. Methotrexate is another immunosuppressive drug. This can be the next choice if azathioprine or mercaptopurine have failed.

Biologics: The use of biologics has become more common as evidence increases about their benefits and safety. Examples include infliximab, adalimumab and Golimumab. They are given by regular intravenous drip or injection under the skin. These treatments are very effective but can also have side effects, especially increased rates of infection and allergic reactions, so they are usually reserved for people with moderate to severe disease, or when other medicines have not worked. They need to be used under care of hospital specialists and it is important that you discuss any concerns or questions with your healthcare team. New methods of giving infliximab and vedolizumab are being developed, these are pre-filled injection pens that are injected under the skin. This will make it easier for people, as they can be administered by the person with Crohn's disease or their carers, in their home.

Surgery

Surgical operations can be a very important part of the treatment of Crohn's disease. The main reason for needing surgery is to remove thickened blocked segments of the bowel when medicines would be ineffective. The surgical removal of the affected section of bowel usually works very well, results in few problems post-operatively and restores full health quickly. A common operation for Crohn's disease is a right hemicolectomy, usually performed by laparoscopic (keyhole) surgery to remove a narrowed terminal ileum. Surgery is usually carried out when badly affected parts of the bowel have caused an abscess or fistula in the abdomen or in the perianal area. An operation may sometimes be the best option when severe Crohn's disease is not responding to drug treatment. Occasionally, colonoscopy with special dilating balloons can be used to open up narrowed sections.

Stoma surgery: Many people presume that surgery for Crohn's disease means having a permanent stoma bag. In fact, stomas (ileostomy or colostomy) will often be temporary. After a section of affected bowel has been removed, a very delicate join (or 'anastomosis') is made between the unaffected ends of the bowel. To protect this join while it heals, the surgeon will then create a temporary stoma. It is then taken away at a second, smaller operation a few months later. This happens more when someone is under-weight or taking steroids, which reduce the ability of body tissues to heal.

What to ask your doctor

These are some useful questions you can ask your doctor

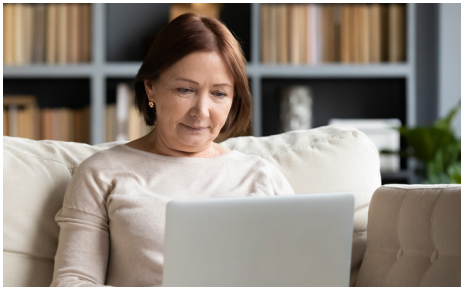
- *Is my Crohn's disease well controlled?*
- *What monitoring do I need?*
- *Please can I have the contact details of the IBD team?*
- *Is my steroid intake being kept to the minimum?*

Where can I get more information?

There are many organisations around for those who suffer from Crohn's disease.

Crohn's and Colitis UK (CCUK)
CCUK are the UK leading charity working on Crohn's disease and other IBDs.
www.crohnsandcolitis.org.uk

Crohn's In Childhood Research Association (CICRA)
CICRA is the UK's only paediatric IBD charity, providing support and information for young sufferers and their families and funding research to find improved treatments and ultimately a cure.
www.cicra.org



Research

There is a lot of high-quality research happening in Crohn's disease, but many questions still remain unanswered.

The James Lind Alliance has carried out a **Priority Setting Partnership (PSP) on Inflammatory Bowel Disease**, which includes Crohn's disease. The PSP has identified 10 research priorities as identified by research users (people affected by the conditions and those who care for them).

NICE (The National Institute for Health and Care Excellence) has listed pending research questions in its guideline for the management of Crohn's disease. Please note that these guidelines are regularly updates and the research recommendations are likely to change to reflect new evidence available.

Guts UK is proud to fund past and current research into Crohn's disease, alongside a large number of other digestive diseases. For further information: **www.gutscharity.org.uk**

Guts UK

The charity for the digestive system

Our guts have been underfunded, undervalued and underrepresented for decades.

"I chose to fundraise for Guts UK because when I was in hospital, I was amongst others with various digestive diseases. It was there that I realised there needs to be so much more awareness for these invisible illness. We must raise much needed funds for this important research!"
Abi, Guts UK fundraiser.

Join our community

It's time the UK got to grips with guts.

With new knowledge, we will end the pain and suffering for the millions affected by digestive diseases. Guts UK's research leads to earlier diagnoses, kinder treatments and ultimately a cure.

Let's get to grips with our guts, and save lives.

Discover more about our fascinating digestive system at gutscharity.org.uk

020 7486 0341
info@gutscharity.org.uk

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Far too many of us ignore or shrug off what our gut is telling us. 58% of people are embarrassed to talk about their digestive condition or symptoms.

Guts UK exists to change that. We empower people to seek help.

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I would like to make a donation to Guts UK and fund life-changing research.

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I would like to support Guts UK with a donation of

£5 ☐ £10 ☐ £25 ☐ £50 ☐ £100 ☐ £500 ☐ Other £

I enclose a cheque payable to Guts UK ☐ **OR Please debit my credit/debit card** ☐

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OR Please call me on **to take my details**

Signature(s) | Date

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I am a UK taxpayer, please treat all donation I make or have made to Guts UK in the past 4 years as Gift Aid donations until further notice. For more information on Gift Aid please see below.

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