GROWING OLDER WITH CROHN'S OR COLITIS

This information is for older people with Crohn's or Colitis, and those who support or care for them. It discusses some of the issues that may affect you as you grow older if you have Crohn's or Ulcerative Colitis. Many of these issues will also affect you if you have Microscopic Colitis.

There is no official definition of an 'older person'. Generally, the information here is aimed at those aged 60 years and older.

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KEY FACTS ABOUT GROWING OLDER WITH CROHN'S OR COLITIS

- About 3 in every 10 people with Crohn's or Colitis are over 60.
- About 8 in every 10 people with Microscopic Colitis are over 60.
- Much of the management of Crohn's and Colitis is similar whatever age you are. But some things change as you grow older that may affect the management of your condition.
- Some of the symptoms and complications of Crohn's and Colitis may be different in older people. Or they may change as you get older.
- Having other long-term conditions can affect the management of Crohn's and Colitis.

- There is a higher risk of medicine side effects and interactions in older people. This can affect the choice of treatment for your Crohn's or Colitis.
- Surgery is still an option for older people. But there may be a higher rate of complications after surgery.

INTRODUCTION

When talking about your condition, it is important that you use the language you feel most comfortable with. Throughout this information we use the term 'poo'. We understand that everyone uses their own language for this kind of thing. So, this term might not be the right term for you. You might prefer to use 'stool', 'bowel movement' or another word.

In the UK about 3 in every 10 people, or 30%, who have a diagnosis of Inflammatory Bowel Disease (IBD) are over 60 years old.

Older people with Crohn's or Colitis fall into two different groups:

- Those diagnosed with Crohn's or Colitis as a child, young adult or in middle age and have grown older with the condition.
- Those diagnosed with Crohn's or Colitis in later life, after the age of 60 years. This is sometimes referred to as Late-onset IBD.

The number of people living with Microscopic Colitis is much lower than Crohn's or Ulcerative Colitis. But many of those who are living with Microscopic Colitis are over 60. In the UK about 8 in every 10 people who have a diagnosis of Microscopic Colitis are 60 years or older. About two thirds of these are diagnosed after they are 60.

Much of the management of Crohn's or Colitis is similar whatever age you are. But some things change as you grow older that may affect the management of your condition. While some of these will apply to people with Microscopic Colitis, not all will.

This diagram shows some of these issues.

As we age, our body processes start to decline. For example, our bones become weaker, and our kidneys do not work as well as they did. Older adults are likely to have other long-term conditions, such as heart disease or diabetes. And the risk of infection becomes greater as our immune system gets weaker.

You're only as old as you feel!

The changes that happen as we grow older affect us in different ways, and at different times. For example, two people may be the same age, but one may be quite 'fit' and the other quite 'frail'. When making decisions about your treatment, you and your healthcare team should think about your physical and mental fitness as well as your age.

To find out more about frailty see **Understanding Frailty** (Age UK).

What matters to you?

It's important to think about what you want most from your treatment. For example, you might care more about controlling your symptoms now than reducing complications later.

LATE-ONSET IBD

Crohn's and Colitis often begin in childhood or early adulthood. But about one in every four people, or 25%, with Crohn's or Colitis are diagnosed when they are over 60. This is often referred to as Late-onset IBD.

Diagnosis

It can be difficult to confidently reach a diagnosis of Crohn's or Colitis at an older age. This is often because it is hard to tell between symptoms of Crohn's or Colitis and normal age-related changes or other gut conditions. Signs and symptoms in Late-onset IBD can be different from those in younger people. This can add to the challenge of getting a diagnosis.

If you do not already have a diagnosis of Crohn's or Colitis, try our **symptom checker**. It can help you decide if you should speak to your GP about your symptoms.

Common conditions that have similar features to Crohn's or Colitis include:

- Infection of the colon.

- Diverticular disease. Small bulges or pouches, called diverticula, form in the wall of the colon. These can become inflamed and infected.
- Inflammation of the colon caused by medicines, such as ibuprofen.
- Irritable bowel syndrome.

Signs and symptoms

At diagnosis, people with Late-onset IBD often have fewer symptoms than those diagnosed earlier in life. And their symptoms tend to be milder. Inflammation is often limited to the large bowel rather than the small bowel and upper gut. Symptoms outside the gut, known as extraintestinal manifestations, are less common.

In people with Late-onset IBD, symptoms tend to be more stable than in those diagnosed earlier.

Sign up to our support emails

Have you have recently been diagnosed with Crohn's Disease, Ulcerative Colitis or Microscopic Colitis?
Our eight, bite-sized, weekly emails can help you:

- Understand more about life with your condition
- Read other people's stories
- Find out about the support that's available to you

Sign up to our series of emails to help you navigate life after diagnosis at [www.crohnsandcolitis.org.uk/supportemails.](www.crohnsandcolitis.org.uk/supportemails)

LIVING WITH MULTIPLE CONDITIONS

Many older people have one or more long-term conditions as well as their Crohn's or Colitis. This can affect the choice of treatment for Crohn's or Colitis, how well treatments work, and the side effects that you might experience.

Common long-term conditions in older people include:

- Heart disease
- Vascular disease, such as a stroke or transient ischaemic attack (TIA)
- Diabetes
- Some cancers
- Bone disease, such as osteoporosis
- Joint disease, such as arthritis
- Kidney disease
- Mental health problems

Some of these are more common in people with Crohn's or Colitis.

Taking many medicines

If you are managing several health conditions, you may be taking lots of medicines. This can increase the risk of side effects and interactions between medicines. Some people find it hard to take so many medicines.

Taking medicines for Crohn's or Colitis can further add to this. Along with your IBD team, you will need to balance the risks and benefits of your different treatments.

To reduce the impact of having to take many medicines consider:

- Checking with your pharmacist or IBD team if any of your medicines are likely to interact.
- Reporting any side effects to your healthcare team.

- Speaking to your pharmacist if you are finding it hard to take many medicines. They may be able to find ways to make it easier for you.
- Asking your GP for a regular medicine review. They can confirm whether you need to keep taking all the medicines that you have been prescribed.

SYMPTOMS AND COMPLICATIONS OF CROHN'S AND COLITIS IN OLDER PEOPLE

Bowel incontinence

If you are experiencing bowel incontinence or urgency, you are not alone. Bowel incontinence affects up to one in every four people, or 25%, with Crohn's or Colitis at some point. Bowel control problems become more common with increasing age. Bowel incontinence and urgency can be more difficult to manage if you have limited mobility and cannot always get to the toilet in time.

We know that urgency and bowel incontinence can be difficult to talk about. You might not think that anything can be done. Or you may feel too ashamed or embarrassed to talk about it. You might not know who to ask. Or you might think that your healthcare professional will not understand or be interested. These feelings are quite normal. But healthcare professionals are used to talking about these issues, and they can help. Remember to use the language that you feel most comfortable using.

There are ways of managing and treating bowel control problems. So, make sure you ask for help from your GP or IBD team. It's important to remember that:

- Bowel incontinence is not something to feel ashamed of, and there is help available.
- There is a range of treatments and ways to manage urgency and bowel incontinence.

- It will not usually go away on its own. Most people need help to manage urgency or bowel incontinence.

See our information on **bowel incontinence and urgency** for further sources of support.

Always check with your IBD team before taking anti-diarrhoeal medicine. They may not be suitable for everyone with Crohn's or Colitis.

Fatigue

There is still more to learn about how fatigue affects older people with Crohn's or Colitis. We know fatigue can affect many aspects of daily life, including physical, social and emotional activities, and memory and concentration.

Fatigue is more common in people with active disease. So getting your condition under control is one of the most important things you can do to help fatigue. By controlling inflammation and symptoms such as pain, you may be able to reduce your fatigue.

We have a separate resource you can read on **managing fatigue.**

Pain

Pain in Crohn's and Colitis can come from different parts of your body. Tummy pain is common, although older people report it less often. Tummy pain associated with Crohn's or Colitis might be due to inflammation of the gut. Or it may be caused by:

- **Strictures,** which is a narrowing of the gut
- Adhesions, which are bands of scar tissue that form between tissue and organs, or
- Scar tissue due to surgery

Tummy pain can also have causes other than Crohn's or Colitis. For example, irritable bowel syndrome, indigestion, kidney stones, gall stones or pancreatitis.

Joint pain is common in people with Crohn's or Colitis. But it may also be due to another condition, such as arthritis. See our information on **joints** for further details.

It is common for older people living with Crohn's or Colitis to also have other painful conditions. These include arthritis, spondylitis, osteoporosis and cancer. You will need to take these into account when you think about your IBD pain.

You can take some over-the-counter painkillers to manage any pain. Paracetamol is likely to be the safest option. Ask your pharmacist or IBD nurse if you are not sure. Always stick to the recommended dose on the packet.

Non-steroidal anti-inflammatory drugs (NSAIDs) can help with pain due to inflammation, especially pain in your joints. But NSAIDs do not treat the inflammation in your gut that you get with Crohn's or Colitis. And they may make Crohn's or Colitis symptoms worse or trigger flare ups.

NSAIDs include:

- Ibuprofen, also known as the brand name Nurofen
- Naproxen, also known as the brand name Naprosyn
- Diclofenac, also known as the brand name Voltarol

Some NSAIDs are available to buy over the counter at pharmacies. Others are only available with a prescription. You should only take NSAIDs if your doctor has advised you to.

Aspirin is also an NSAID and is not recommended as a painkiller for people with Crohn's or Colitis. This is because the dose needed for pain relief may be enough to trigger flare-ups.

Some people take a lower dose of aspirin to help prevent strokes and heart attacks. This appears to have no effect on Crohn's or Colitis symptoms in older people and should be taken as prescribed.

Bone health

If you have Crohn's or Colitis, you may be more likely to develop weaker bones, known as osteoporosis, or low bone mass. This means that bones can break more easily.

Reasons for weaker bones in people with Crohn's or Colitis include:

- Taking steroids
- Low levels of calcium and vitamin D
- Removal of parts of the small bowel

Your bones also become weaker as you grow older.

Women lose bone mass more quickly for a few years around the time of the menopause. This is due to a drop in the level of the hormone oestrogen. But men are still at risk of osteoporosis and fractures.

People with a low body weight are more likely to develop osteoporosis than people with a healthy weight.

Your doctor should assess your risk of bone fractures if you have Crohn's or Colitis and other risk factors. They may suggest you have a bone density scan, also known as a DEXA scan.

If you are taking steroids for longer than three months, you should have a DEXA scan. Tell your doctor or IBD team if you have not had one and think you need one.

If you are at high risk of bone fractures, your doctor will offer you a type of medicine called a bisphosphonate. This can help keep your bones strong.

Keeping active and eating a balanced diet can help you maintain healthy bones.

Our information on **bones** explains the risk factors for developing weaker bones, some of the tests you might have, and what you can do to reduce your risk.

The Royal Osteoporosis Society has a tool to check your risk of osteoporosis. You can use this **risk-checker** to help you understand your chances of getting osteoporosis. But, if you already know you have osteoporosis or have had your bones checked by a doctor, this tool is not for you. And it cannot tell you if you have osteoporosis.

The risk checker is not made specifically for people with Crohn's or Colitis. **Other factors** related to your Crohn's or Colitis can make your risk of osteoporosis higher.

Risk of cancer

In general, the risk of most cancers increases with increasing age. And there are other things that affect your risk of cancer. These include your lifestyle, diet, genes and environment. Having Crohn's or Colitis may also slightly increase the risk of certain cancers in some people. This includes bowel and other gut cancers, and some blood and skin cancers.

Often cancer is preventable and can be successfully treated if it is found early. And there are things that you can do to help keep your risk as low as possible.

Any increase in risk for bowel and other gut cancers is mainly due to having had Crohn's or Colitis for a longer time. See our information on **bowel and other gut-related cancers** to find out more about your risk and how you can reduce it.

For blood cancers or melanoma, any increase in risk may come from taking immunosuppressants for a longer time. For more on the side effects of immunosuppressants, see our **treatments** page to find information about the medicine you are taking.

Bowel cancer and surveillance

The risk of bowel cancer starts to increase eight to ten years after the start of Crohn's or Colitis symptoms. Your IBD team should offer you a surveillance colonoscopy if you have Crohn's or Colitis affecting the colon or rectum for eight years or longer.

A surveillance colonoscopy is a 'check-up' colonoscopy. Its aim is to detect anything odd in the lining of the colon or rectum that might suggest a higher risk of bowel cancer.

Depending on the results you may be offered a repeat colonoscopy. How often you have repeat colonoscopies will depend on your risk of developing pre-cancerous cells, called polyps.

Colonoscopies are the best way to detect bowel cancer early and even prevent it. Often, bowel cancer can be prevented by removing pre-cancerous cells during a colonoscopy.

We understand that you may feel nervous or worried about having a colonoscopy. To help you feel more comfortable, you may be offered:

- Painkillers.
- Sedation: a medicine to help you feel sleepy and relaxed.
- Nitrous oxide: a medicine that you breathe in to help you relax, known as 'gas and air.'

There is no defined age when you should stop having surveillance colonoscopies. You and your doctor or IBD team may want to discuss:

- How well you will be able to tolerate the colonoscopy, including the bowel prep before
- Your risk of complications
- The likely outcome if an abnormal growth or development of cells is found
- Whether you would be fit enough to have an operation to remove part or all the large bowel if needed
- Any other long-term conditions you have that could affect your course of treatment

Find out more about surveillance colonoscopy in our information on **bowel cancer**.

Poor nutrition

If you have Crohn's or Colitis, what you eat may affect your symptoms. But it is different for everybody. There is no particular diet that works for everyone with Crohn's or Colitis. What works for one person might not work for another.

It's important to try to eat a healthy, balanced diet that gives you all the nutrients you need to stay well. You might need to take supplements if you are low on nutrients. But it can be difficult to eat a healthy, balanced diet if you have Crohn's or Colitis. This means you have a higher risk of malnutrition than other people. Malnutrition is when you do not get the right amount of energy or nutrients. You might be getting not enough, too much, or the wrong balance of energy or nutrients. Malnutrition can make it harder for your body to heal and fight off infections.

This is especially important in older people with Crohn's or Colitis as they are at greater risk of becoming malnourished. Higher levels of vitamin D deficiency, vitamin B12 deficiency and iron deficiency have been noted in older people with Crohn's or Colitis.

Eating a healthy, balanced diet can be even harder if you have other medical conditions that may involve changes in diet. These might include diverticular disease, heart disease or diabetes. Our information on **food** has an overview of how other medical conditions may involve changes in your diet.

Sometimes, you might get conflicting dietary advice for different conditions. If you have complicated dietary needs, you could ask to be referred to a dietitian.

Blood clots

People with Crohn's or Colitis have an increased risk of getting blood clots. The risk is greater when the conditions are active. The clot usually develops in a vein in your body, often the leg. It can then stay in the leg and cause pain and swelling. Or it can move to the lungs causing breathlessness and chest pain. Without treatment, a blood

clot can restrict or block blood flow and oxygen. This can damage the body's tissue or organs.

Other factors that make you more likely to get a blood clot include:

- Increasing age.
- Smoking.
- Some medicines used to treat Crohn's or Colitis. This includes **steroids** and JAK inhibitors such as **filgotinib**, **tofactinib** and **upadacitinib**. Please discuss with your IBD team.
- Taking the oral contraceptive pill or hormone replacement therapy (HRT), but only when taken by mouth.
- A stay in hospital, even if it is not related to your Crohn's or Colitis.
- Surgery, especially, bowel surgery.

If you are admitted to hospital, you should be assessed for your risk of blood clots. You may be offered measures to reduce your risk. This may include compression stockings, and heparin injections.

Make sure you know the signs of a blood clot

Signs to look out for include:

- A painful, red, swollen leg
- Sharp chest pain
- Breathlessness

Contact your GP or NHS 111 straight away if you think you have a blood clot.

The NHS has **more information about blood clots**.

Infections and vaccinations

As you grow older, your immune system changes. Your immune system is your body's natural defence system. These changes mean that you are not able to fight off infections as well as you used to. Some medicines for Crohn's or Colitis can weaken your immune system. So, infections, especially serious infections, tend to be more common in older people with Crohn's or Colitis. This is especially the case if you're taking steroids.

Even though your risk of infection may be greater, it should not stop you from living life as before. See our information on **immunosuppressant precautions** to find out some practical things you can do to reduce your risk of infection.

Keeping up to date with your vaccines is one way of reducing your risk of a serious infection. In general, guidelines for having vaccines are similar for older people with Crohn's or Colitis. If you are taking a medicine that weakens your immune system, you should be offered the following vaccines:

- Annual flu injection
- COVID boosters
- Shingles (Shingrix) vaccine
- Pneumococcal vaccine

If you are between 75 and 79 you should also be offered the RSV vaccine. Respiratory syncytial virus (RSV) is a common cause of coughs and colds. In most people it usually gets better by itself. But in some people, especially babies and older people, it can lead to serious lung or chest infections.

These are all 'non-live' vaccines and are safe for you to have.

You should not have any 'live' vaccines while you are taking an immunosuppressant. Live vaccines are made using weakened versions of living viruses or bacteria. If you have a lowered immune system, there is a possibility they might cause infections. Live vaccines used in the UK include:

- BCG for tuberculosis
- Chickenpox vaccine
- Measles, mumps and rubella vaccines, either as individual vaccines or as the triple MMR vaccine
- Nasal flu vaccine used in children, but the injected flu vaccine used in adults is not live
- Rotavirus vaccine, this is for babies only
- Yellow fever vaccine
- Oral typhoid vaccine, but the injected typhoid vaccine is not live

MEDICINES FOR CROHN'S AND COLITIS IN OLDER PEOPLE

Medical treatment is generally similar to treatment for younger people. But there is a higher risk of side effects and medicines interactions in older people. This can limit your choice of medicine. Changes in your body, such as a decrease in how well your kidneys work, can also affect how different medicines work.

Older people are rarely included in trials of medicines. This means that we do not always know how well they will work in older people, or what side effects they may cause.

5-ASAs

About half of all older people with Ulcerative Colitis take 5-ASAs. They are generally well tolerated in older people with few serious side effects.

5-ASAs are not recommended for use in Crohn's.

Issues with 5-ASAs in older people can include:

- The number of tablets you need to take.
- The size of tablets if you have difficulty swallowing.
- Using suppositories or enemas if you have limited movement or uncontrollable movements, like spasms, jerking or shaking.

- Bowel problems that already exist, such as piles, fissures or fistulas. These can make it hard to keep rectal medicines in your bowel.

Speak to your IBD team if you are finding it difficult to take your 5-ASA medicines. You may be able to change several tablets for a once-a-day form. Or you might find a foam-based preparation with an easy applicator easier to use.

Possible risks or side effects in older people include:

- A decrease in how well your kidneys work, or worsening kidney disease. As we get older our kidneys function less well than they did. Using 5-ASAs may make this worse. You may need blood tests so that your doctor can check how well your kidneys are working.
- When taken with azathioprine or mercaptopurine, there is a higher risk that your white blood cells will be affected. This can lead to infections.

See our information on **5-ASAs** for more details.

Steroids

Steroids are an important treatment for getting your symptoms under control. But they should not be used long-term. Steroids can have several unwanted side effects. These are worse with higher doses and when steroids are taken for longer.

Possible risks or side effects include:

- Fluid retention. This can make heart failure and high blood pressure worse.
- Increased risk of infection including serious infections like pneumonia and sepsis.
- Worsening control of blood sugar in people with diabetes.
- Osteoporosis and bone loss. This can increase the risk of fractures and frailty.
- Eye problems, such as cataracts and glaucoma.
- Mood changes, such as depression, irritability or extreme highs and lows in your mood.

Budesonide MMX or rectal steroids may be good options if your symptoms are mild or moderate. This is because they work directly in your bowel and don't tend to cause side effects in other parts of your body.

If you are taking steroids:

- Do not stop taking steroids suddenly. For oral steroids, you may need to reduce the dose gradually to prevent side effects.
- Make sure that other long-term conditions such as heart failure, high blood pressure and diabetes are being monitored.
- Your IBD team may do a blood test to check your levels of vitamin D. If you have low levels, they may suggest vitamin D supplements. This will help protect your bones and keep them strong.
- Ask your doctor for a DEXA scan, a type of bone scan, if you're taking steroids for longer than three months. If you're at high risk of bone fractures, your doctor may offer a type of medicine called a bisphosphonate. These are medicines that can reduce your risk of breaking bones if you have osteoporosis.
- Have regular eye checks, especially if you have a history of glaucoma or cataracts.
- Keep active and eat a balanced diet to help you maintain healthy bones. We have more about this in our information on **bones**.

See our information on **Steroids** for more details.

Immunomodulators

Azathioprine and 6-mercaptopurine are thiopurines and can be useful in some older people with Crohn's or Colitis.

The risk of side effects with thiopurines increases in older people. This includes:

- Bone marrow suppression. This is when your bone marrow doesn't make enough blood cells. This can lead to anaemia, infections and problems with blood clotting.
- Lymphoma, non-melanoma skin cancer and bladder cancer. Taking a thiopurines and an anti-TNF medicine, such as adalimumab or infliximab, further increases the risk of lymphoma.

The risk of side effects increases with age and length of treatment. So, the decision to start or continue treatment should consider both the benefits and the risks. If you are over 60 and are taking a thiopurine you might want to discuss with your IBD team if this is the best treatment for you. And if you are taking a thiopurine you should have regular blood tests and a yearly check to make sure that it is still the right treatment for you.'

For more information about these medicines see **azathioprine and mercaptopurine**.

Methotrexate might be an alternative at the low doses used in Crohn's disease. But there is no specific information about its use in older people.

See **methotrexate** for more information about this medicine.

Anti TNF medicines

Anti-TNFs, such as infliximab and adalimumab, are among the most effective treatments for moderate to severe Crohn's or Colitis. But they are used less often in older people with Crohn's or Colitis. We do not know for sure, but some studies suggest that anti-TNFs do not work as well in older people. Older people are more likely to experience severe side effects associated with anti-TNFs. This includes a higher number of severe infections. Because of this, many older people who start taking an anti-TNF have to stop taking it because it is not working, or they are getting side effects.

Given the increased risk of infections, it is important to be up to date with your **vaccinations**.

People who have heart failure or severe liver disease should not take anti-TNFs.

Vedolizumab

Studies of vedolizumab have not included many older people. But in those who were included, vedolizumab appears to be safe and effective.

Ustekinumab

Studies of ustekinumab have included few older people. Several small studies suggest that it is safe and effective in older people with Crohn's. Side effects were generally mild.

One study compared ustekinumab and vedolizumab in treating older people with Crohn's. The study found that they were similar in safety and effectiveness.

JAK inhibitors

The JAK inhibitors tofacitinib, filgotinib, and upadacitinib are not recommended for use in people over 65 years. Studies have linked their use with an increase in the risk of heart attacks and stroke, blood clots, some types of cancer and infections, including shingles.

Your IBD team might consider them if there are no other treatment options available for you.

> "Until I read this information, I did not really think about the effect of being older with IBD and the implications for treatment options. I will now ask some different, age-specific questions next time I see my IBD team."
>
> **ANONYMOUS,**
> **LIVING WITH ULCERATIVE COLITIS**

Other treatments for Crohn's and Colitis

Antibiotics

People with Crohn's or Colitis are at a higher risk of developing an infection called *Clostridium difficile* (*C. difficile*). *Clostridium difficile* infection (CDI) can cause severe diarrhoea and serious complications. Taking antibiotics can increase this risk.

In older people, CDI can be particularly severe.

Contact your IBD team if you are taking antibiotics and develop the symptoms below or feel very unwell. This also applies if you are taking antibiotics for infections not related to your Crohn's or Colitis. Symptoms of CDI infection can include:

- Diarrhoea
- A high temperature of 38 degrees centigrade or more
- Feeling sick
- Tummy pain
- Loss of appetite

Iron

Many people with Crohn's or Colitis do not have enough iron. This can lead to iron-deficiency anaemia. This is when you make fewer red blood cells than usual. Iron supplements can help to get your iron levels back to normal.

If you are not having a Crohn's or Colitis flare-up, your doctor may suggest taking an iron tablet. Iron tablets can cause side effects, including:

- Constipation
- Diarrhoea
- Stomach pain

Let your doctor or IBD team know if you get these side effects while you are taking iron supplements.

Loperamide

Loperamide is a type of medicine that can help to control diarrhoea. Possible side effects include:

- Constipation
- Headaches
- Feeling sick

Always check with your IBD team before taking any anti-diarrhoeal medicine.

- In older people, loperamide can cause dizziness and drowsiness. This can lead to an increased risk of falls.
- Do not use anti-diarrhoea medicine if you are in a flare-up. This can lead to a serious complication called **toxic megacolon**. Toxic megacolon is widening or swelling of the colon that can cause perforation.
- You may not be able to take anti-diarrhoea medicines if you have a narrowing of the bowel called a **stricture**.

Bile salt binders

If you have a condition known as bile acid malabsorption (BAM), you may be prescribed bile salt binders. Bile salt binders work by combining with the bile salts and stopping them from reaching the colon so that they cannot cause diarrhoea.

Bile salt binders include colestyramine, also known as the brand name Questran, and colesevelam, also known as the brand name Cholestagel.

Bile salt binders can also affect how well your body absorbs other medicines. You will need to leave a gap before or after taking other medicines. Check the instructions in the patient information leaflet or ask your pharmacist.

Your pharmacist can help if you are finding it difficult taking medicines at different times during the day.

SURGERY

There is some uncertainty around the risks of surgery in older people with Crohn's or Colitis. Some studies show an increased risk of complications compared with younger adults. But other studies have found no difference. Complications include infection, blood clots, bleeding, and stroke. It is likely that any increased risk is related to factors affected by older age, such as other long-term conditions, increased frailty, nutritional status, and steroid use.

Surgery is still an important treatment option in older people. Surgery should not be delayed just because of a person's age. If you are considering having surgery for Crohn's or Colitis, you and your IBD team might want to consider:

- How severe your condition and symptoms are
- Whether surgery is likely to affect how well you can function day to day
- Whether surgery is likely to affect your independence
- How well you are likely to recover from surgery
- What are the possible complications of surgery

- What are the alternatives

Living with a stoma

After certain types of surgery, you may have a stoma. A stoma is an opening on the wall of your tummy that brings your bowel to the outside. If you have a stoma, the contents of your gut do not travel all the way through your bowel to come out of your bottom. Instead, they come out of the stoma into a bag you wear on your tummy.

You may have had a stoma for many years and managed it very well. Or you may have recently had a stoma. Whichever the case, as you grow older you may face problems managing your stoma. This might be due to physical or mental impairment, or to other health conditions that are more common in older people. For example:

- Wrinkles and sagging can result in problems with the health of your skin
- Weight loss, or weight gain, can lead to changes in the shape and size of the stoma and surrounding area
- Visual impairment can make it difficult to manage your stoma appliance
- Painful joints and reduced manual dexterity can make it difficult opening products, cutting the flange or changing your stoma appliance
- Tremor, jerking or spasms can make it difficult to manage your stoma appliance
- Mental impairment, memory loss and having dementia can make it hard to look after a stoma

If you are finding it difficult to manage your stoma, speak with your stoma nurse.

You can find out more about stomas, including how to get help in our information on **living with a stoma**.

Looking after a person with a stoma and dementia can be hard. But help is available. Colostomy UK have a booklet on **Caring for a person with a stoma and dementia** (PDF). This booklet gives hints and tips on bag changing and stoma care, and details of how you can get support.

LIVING WITH CROHN'S OR COLITIS

Physical health

Mobility

Reduced mobility is common in older people. Some conditions that affect the joints, bones, muscles and spine, become more common with increasing age. And problems with joints and bones caused by Crohn's or Colitis can make this worse. Reduced mobility is associated with an increased risk of falls, hospital admission and loss of independence. Other areas where limited mobility can affect people with Crohn's or Colitis include:

- Struggling to manage a stoma
- Inserting rectal medicines
- Getting to the toilet in time
- Cleaning yourself after you have been to the toilet

But there are things that can be done to help with mobility.

- If you are struggling to manage your stoma, speak to your stoma nurse. They may be able to suggest an alternative appliance.
- If you are unable to use rectal medicines due to reduced movement or dexterity, speak to your IBD team. There may be an alternative that you can try.
- If you find it difficult to get to the toilet on time you might find our information on **bowel incontinence and urgency** useful.

- There are many aids and adaptations that can help you around your home. The NHS has information about **gadgets** and **home adaptations** to make life easier. It includes information on how to get help with the costs too.
- You may qualify for Personal Independence Payment (PIP) or Attendance Allowance if you need more help. See our information on **finance** to find out more.
- If you need help to cope on a day-to-day basis you can get a needs assessment from your local council. You can find out more about **getting a care needs assessment** on the NHS website.

Being active

Being active is very important for your physical and mental health. It can help reduce fatigue and improve mood. It is also important for bone health, helps to keep you more mobile, and less at risk of falling. Exercising with Crohn's or Colitis is safe and shouldn't cause a flare-up.

The amount and type of physical activity possible will vary from person to person. And it will change as you get older. But whatever your age, there will be something for you. At home or out and about, from seated exercises to walking football. Whatever you can do will help to keep you healthy.

It's never too late to start being active. Watch our video on **being active with Crohn's or Colitis** for more information and tips about getting active.

Age UK also has some great information and resources to help you **stay active as you get older**.

Mental health and wellbeing

Coping with a long-term condition like Crohn's or Colitis can have a big impact on your mental health and wellbeing. Research suggests that people living with Crohn's or Colitis may be twice as likely to experience mental health problems, like anxiety

and depression, as the general population. And poor mental health is more common in older people.

Crohn's, Colitis and mental health problems can be taboo subjects and difficult to talk about. But it is important that you get the support you need. Our information on **mental health and wellbeing** can help you recognise when you are experiencing poor mental health, and find out how you can get the help you need.

Thinking and memory

Some changes in thinking and memory are common as people get older. Though these changes can be frustrating, they are a natural part of ageing. But for others, the decline in thinking and memory can be more severe, with age being the biggest factor in developing dementia.

Changes in thinking and memory can affect how you manage your Crohn's or Colitis. For example, you may have trouble remembering to take your medicines. Or it can make you at greater risk of being incontinent.

Talk with your doctor if you're concerned about changes in your thinking and memory. They can help you determine whether those changes are normal or whether it could be something else.

The **Alzheimer's Society** and **Dementia UK** provide practical information and support for people with dementia and their carers. This includes information on managing incontinence, eating and drinking, hydration, and caring for a person with a stoma and dementia.

Loneliness and isolation

Everyone feels lonely from time to time. But for many, particularly in later life, loneliness can start to take over and have a significant impact on wellbeing. Symptoms such as bowel incontinence or fatigue due to Crohn's or Colitis means that some people feel unable to leave home. This can add to the feeling of isolation.

If you are feeling lonely, remember there is support for you. **Age UK** has lots of information about dealing with loneliness. This might be through having a chat with one of their volunteers or making new connections through a friendship group or social activity.

If you're missing the social connections you used to have through work, you could consider volunteering or going to classes such as those run by the **University of the Third Age**.

Your local council or library will have details of local community groups and activities for older people.

Sexual health

Menopause

Menopause tends to occur earlier in women with Crohn's or Colitis than in those without. Early menopause is when menopause happens before the age of 45. Early menopause is linked with an increased risk of osteoporosis, heart disease and stroke.

The likelihood of having a flare-up after the menopause is not different from having one before the menopause. But there is some research that women who take hormone replacement therapy (HRT) may have improved symptoms of their Crohn's or Colitis after the menopause.

Find out more about the menopause with Crohn's or Colitis, including your risk of osteoporosis and taking HRT, in our information on **reproductive health and fertility**.

Relationships

Relationships with those around us are always changing. As you get older, you may need more support from family and friends to help you manage your Crohn's or Colitis. This can place stress on relationships, and loved ones often become caregivers. The emotional burden of a long-term condition such as Crohn's or Colitis

can also affect how you interact with family and friends. Avoiding social activities because of symptoms like needing the toilet often and fatigue can impact social relationships.

Equally, supportive relationships can provide practical support and help. To help you maintain positive relationships you could try:

- Regularly reaching out to family and friends through calls, texts or video calls – whatever works for you.
- If you feel able, joining a social group. This can help you meet new people and form new relationships.
- Giving people your full attention when spending time with them to get the most out of your relationships.
- Using open and honest communication, which is key to maintaining healthy relationships. Tell people what you are thinking and be prepared to listen to them.

Talking about Crohn's and Colitis

Talking about your Crohn's or Colitis can be hard. We know that people use different ways to explain symptoms such as diarrhoea and constipation. And many people feel uncomfortable talking about poo. The most important thing is that you use the language that you feel most comfortable with to talk about your symptoms, the difficulties you're having, and how you're feeling.

If you find it hard to have difficult conversations with people, our **Talking toolkit** can help you find the right words.

Continuing to work

Many people with Crohn's or Colitis will either want or need to work into their 60's or 70's. And there is no reason why you should not, now a forced retirement age no longer exists.

You might find it helpful to show your employer a copy of our **guide for employers**. This guide can help employers and managers understand what it means to have Crohn's or Colitis. It helps them understand what they can do to support employees. And it can help them put plans in place to become a more accepting and accommodating place to work.

Our **guide for employees** will help you understand your options and rights at work or while looking for a job. If you are finding it difficult to continue working, for example due to fatigue, there are options you could consider. For example, you might want to consider asking your employer if you can work more flexibly or work part time. The guide also provides details of financial help that may be available to you.

Benefits and finance

If you live with Crohn's or Colitis you may worry about the extra costs it can bring. But you may be eligible for help with your finances. Our information on **benefits and finances** outlines some of the support available and possible ways of reducing costs.

Age UK also has information about **money and legal** matters that you might find useful.

For free and impartial help with money, you could try **MoneyHelper**. MoneyHelper is backed by the government and provides free advice on many aspects of managing your finances.

Getting out and about

Toilet access

For some people, the anxiety about finding a toilet when they are out and about can mean that they limit going out. Planning ahead can give you more confidence being away from home.

Can't Wait Card

Members of Crohn's & Colitis UK get a 'Can't Wait' Card'. This explains that, due to your condition, you need toilet facilities urgently. It may be helpful to show this if there is a long queue for the toilet, or if you want to use a shop's facilities.
See **Become a member** for further details.

Radar Key

A Radar Key is a key for accessible public toilets. A Radar Key is available from Crohn's & Colitis UK if you **become a member**. You can also buy one from **Disability Rights UK**.

Travelling by car

Many people who experience incontinence plan their journeys by toilet stops. This is sometimes called toilet mapping. There are many toilet map apps available that can help you plan your journey. Or you could use online resources such as the **Great British Toilet Map** to help you find the nearest public toilet when out and about.

Travelling by public transport

Using public transport can be a challenge if you need easy access to a toilet. For long-distance travel, most coaches now have an on-board toilet. And you can check the location of facilities at train stations in the UK via the **National Rail website**.

Travelling by air

If possible, request in advance an aisle seat near the toilet. Take a small supply of everything you need in your hand luggage. An '**emergency kit**' can be useful, but check with the airline if they allow neutraliser spray on the plane.

Blue badge

A Blue Badge is a parking permit that allows people with disabilities or health conditions to park closer to their destination, often free of charge. We know that it is difficult for some people living with Crohn's or Colitis to successfully **apply for a**

Blue Badge. Having another condition, especially one that affects your mobility, may increase your chances of getting a blue badge. So, make sure that you mention any other conditions you have when you apply.

CARING FOR AN OLDER PERSON LIVING WITH CROHN'S OR COLITIS

Crohn's and Colitis don't only affect the person living with the condition. They can also have a huge impact on friends and family too. And as people grow older, the level of help and support they need may increase. If you are caring for an older person living with Crohn's or Colitis, we're here to support you.

We have separate information on **supporting someone with Crohn's or Colitis** that you might find helpful.

Carers organisations such as **Carers UK** provide information, advice and support for unpaid carers.

IMPORTANCE OF MULTIDISCIPLINARY WORKING

If you have more than one long-term condition, you may be looked after by more than one clinical team. For example, if you also have arthritis, the rheumatology team may look after you in addition to your IBD team. And you may see your GP or practice nurse for some conditions. It is important that these teams work together to provide you with the best care possible. Let other healthcare professionals know that you have Crohn's or Colitis, and what treatment you have for it. And make sure your IBD team knows if you are receiving treatment from anyone else for another condition.

Access to healthcare professionals

We understand that it can be difficult to access the right healthcare professionals when you need them. And you may feel that the care you have received was not

satisfactory. If you have any concerns or problems, it may help to contact the **Patient Advice and Liaison Service** at your hospital, known as PALS. PALS can provide confidential advice and are there to help resolve concerns or problems when you're using the NHS in England. Equivalent organisations exist in:

- Scotland, as the **Patient Advice and Support Service**
- Wales, as the **Llais team**
- Northern Ireland as the **Patient and Client Council support service**.

If you are having issues accessing primary care, you may want to contact your practice manager.

If in England

You can also complain to the commissioner of the service, either **NHS England** or the local **integrated care board (ICB).**

Wales

The **LLais** is an independent body which provides free and confidential complaints advocacy and support. In Wales you can also speak to your **Local Health Board**.

Scotland

In Scotland you can speak to your **Local Health board.**

Northern Ireland

You can also speak to your local **Health and Social Care Trust.**

If you want to complain about private healthcare you have received, you won't be able to use the NHS complaints system. Instead, you should ask for the complaints procedure of the private provider.

OTHER ORGANISATIONS

Age UK: UK's largest charity working with older people **www.ageuk.org.uk**

Alzheimer's Society: Charity providing information and support for everyone affected by dementia **www.alzheimers.org.uk**

Bladder and bowel community: Provides information and support for all types of bladder and bowel related problems. **www.bladderandbowel.org**

Bladder and Bowel UK: Supporting bladder and bowel health for everyone. **www.bbuk.org.uk**

Bowel Cancer UK: To raise awareness and campaign for better treatment & care and provide practical support & info for people with bowel cancer **www.bowelcanceruk.org.uk**

Carers UK: Charity to make life better for carers **www.carersuk.org**

CAB: Giving people the knowledge and confidence they need to find their way forward - whoever they are, and whatever their problem. **www.citizensadvice.org.uk**

Colostomy UK: Charity offering advice & support for people with a colostomy **www.colostomyuk.org/**

Dementia UK: Specialist dementia nurse charity that provides information and support to people affected by dementia. **www.dementiauk.org**

Diabetes UK: Charity to support and campaign for people with diabetes **www.diabetes.org.uk**

Disability Rights UK: The UK's leading Disabled People's Organisation (DPO) led by, run by, and working for Disabled people. **www.disabilityrightsuk.org**

IA Ileostomy & Internal Pouch Association: Supporting people living with an ileostomy or an internal pouch. **www.iasupport.org**

Macmillan Cancer Support. Supporting people affected by cancer. **www.macmillan.org.uk**

MIND. Information and advice about living with a mental health condition and treatments. **www.mind.org.uk/**

Moneyhelper: Helps to make your money and pension choices clearer. **www.moneyhelper.org.uk**

Parkinson's UK: Information and support for people living with and affected by Parkinson's. **www.parkinsons.org.uk/**

Royal Osteoporosis Society: Improving diagnosis, prevention and treatment of osteoporosis. **www.theros.org.uk**

The Silver Line Helpline: Confidential, free helpline for older people across UK. **www.thesilverline.org.uk**

Versus arthritis: Information and support for those with arthritis and musculoskeletal conditions. **www.versusarthritis.org/**

HELP AND SUPPORT FROM CROHN'S & COLITIS UK

We're here for you. Our information covers a wide range of topics. From treatment options to symptoms, relationship concerns to employment issues, our information can help you manage your condition. We'll help you find answers, access support and take control.

All information is available on our **website.**

Helpline service

Our helpline team provides up-to-date, evidence-based information. You can find out more on our **helpline web page.** Our team can support you to live well with Crohn's or Colitis.

Our Helpline team can provide support by:

- Providing information about Crohn's and Colitis
- Listening and talking through your situation
- Helping you to find support from others in the Crohn's and Colitis community
- Providing details of other specialist organisations

You can call the Helpline on **0300 222 5700**. Or visit our **LiveChat service**. You can read our information on **when the Helpline** is open for more details..

You can email **helpline@crohnsandcolitis.org.uk** at any time. The Helpline will aim to respond to your email within three working days.

Our helpline also offers a language interpretation service, which allows us to speak to callers in their preferred language.

Virtual Social Events

We offer people affected by Crohn's or Colitis the chance to join a virtual social event with others across the UK. The events will be a chance to chat, share

experiences and potentially learn from others. Each event may have a specific topic but the overall discussion will be driven by what those attending wish to talk about.

Family, friends and colleagues are more than welcome to attend.

Visit our **Virtual Social Events** page to find out what is available.

Crohn's & Colitis UK Forum

This closed-group Facebook community is for anyone affected by Crohn's or Colitis. You can share your experiences and receive support from others. Find out more about the **Crohn's & Colitis UK Forum.**

Help with toilet access when out

There are many benefits to becoming a member of Crohn's & Colitis UK. One of these is a free RADAR key to unlock accessible toilets. Another is a Can't Wait Card. This card shows that you have a medical condition. It will help when you are out and need urgent access to the toilet. See **our membership webpage** for more information. Or you can call the Membership Team on **01727 734465**.

ABOUT CROHN'S & COLITIS UK

We're Crohn's & Colitis UK and we're changing what it means to live with these lifelong gut conditions. 1 in 123 people in the UK have Crohn's Disease or Ulcerative Colitis. These are unpredictable conditions that could flare up at any time.

No one should face that alone. That's where we can help.

We provide trusted information and support cutting-edge research. We also lead bold campaigns to get more people talking about Crohn's and Colitis. We help people understand these conditions, give them the attention they deserve and bring people together to create change.

This year, 25,000 people will be told they have Crohn's or Colitis. Once diagnosed, the obstacles continue. Today, there is no cure. People simply don't understand these conditions. So, we have listened. It's time for change & we're leading the way.

Our information is available thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis by calling **01727 734465.** Or you can visit **our website**.

About our information

We follow strict processes to make sure our information is based on up-to-date evidence and is easy to understand. We produce it with patients, medical advisers and other professionals. It is not intended to replace advice from your own healthcare professional.

You can find out more on **our website**.

We hope that you've found this information helpful. Please email us at **evidence@crohnsandcolitis.org.uk** if:

- You have any comments or suggestions for improvements
- You would like more information about the evidence we use
- You would like details of any conflicts of interest

You can also write to us at **Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE.** Or you can contact us through the **Helpline** on **0300 222 5700**.

We do not endorse any products mentioned in our information.

Growing older with Crohn's or Colitis, Ed 1

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Trusted Information Creator

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