CROHN'S&COLITISUK



Bones

If you have <u>Crohn's</u> or <u>Colitis</u> you may be more likely to develop weaker bones (osteoporosis) or low bone mass. This can mean bones break (fracture) more easily.

This information is for anyone living with Crohn's or Colitis. It may be especially useful for anyone with these conditions who is worried about developing weaker bones.

It looks at:

- Why you might be at risk of developing weaker bones
- What tests are available to measure your bone density
- How you can keep your bones healthy

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Key facts about bones

- If you have Crohn's or Colitis you may be more likely to develop weaker bones (osteoporosis) or low bone mass.
- Inflammation in the gut, taking steroids, low levels of calcium and vitamin D or removal of parts of the small bowel can all increase your risk of having weaker bones if you have Crohn's or Colitis.
- Osteoporosis is a condition where bones become weak and more likely to break. If you are at risk of developing osteoporosis, your doctor may refer you for a bone density scan.
- You can help prevent osteoporosis by doing regular exercise, spending time in the sun, eating calcium-rich food, taking a vitamin D supplement if needed and not smoking.

Bones explained

Bones are living, growing tissue. Throughout your life, your bones go through a process called remodelling. Specialist bone cells break down and remove old or damaged bone tissue and different cells form new bone tissue. This is also how your body repairs bones after a fracture. When the old bone is being broken down at a faster rate than the new bone is being replaced, this leads to a condition called osteoporosis.

During childhood and early adult life, bone density (also known as bone mass or bone mass density – BMD) increases. Your bones are thickest and strongest in your early adult life, reaching a peak in your late 20s. After this, bone mass declines gradually as part of the natural ageing process. Normal peak bone mass may never be reached if a disease affects bones during early life.





Types of bone problems

Osteoporosis

Osteoporosis is a condition where bones become weak and are more likely to break. These fractures usually happen in your wrist, hips or spine after a fall or minor injury. Osteoporosis happens as some people lose bone much faster than normal. This can be caused by a number of reasons. Find out more in What are the main risk factors?

Osteopenia

Osteopenia is also called **low bone mass**. This is when you have mild loss of bone density, but not low enough to be labelled as osteoporosis. It does not always lead to osteoporosis. Research suggests that almost half of all people with Crohn's or Colitis have osteopenia.

Osteomalacia

This is a softening of the bones usually caused by lack of vitamin D or calcium. It can cause pain in your bones and joints. Osteomalacia in children is called rickets. Read more about osteomalacia on the <u>NHS website</u>.

Osteonecrosis

This is a rare but serious side effect of medicine, and can cause joint pain. It happens when steroids cause problems with blood supply to a bone, usually in the hip or knee. You may need medicine or surgical treatment.

How do I know if I have bone loss?

There are usually no obvious symptoms of bone loss or osteoporosis. It does not cause pain. It is sometimes called a 'silent disease' because you may not know that you have osteoporosis until you break a bone. Some older people with osteoporosis develop a rounded back as small breaks in your spine mean it can no longer support the weight of the body.





What are the main risk factors?

Many factors can increase the risk of developing weaker bones or osteoporosis.

These include:

- Age some loss of bone density happens naturally with age.
- Gender women are more at risk of developing osteoporosis as their hormones change during the menopause and affect bone density.
- Having a family history of osteoporosis.
- Being underweight, with a BMI of 19 or less. Check your BMI on the NHS website.
- Smoking smoking has been linked to bone loss and increased risk of fracture.
- Drinking more than 14 units of alcohol per week evidence suggests that excessive alcohol intake is linked to bone loss and higher risk of fracture.
- Low levels of physical activity. Weight-bearing exercise (where your feet and legs support your weight) is important to keep bones strong and healthy.

The Royal Osteoporosis Society has made a tool to check your risk of osteoporosis. You can use this <u>tool</u> to help you understand what might increase your chances of getting osteoporosis and broken bones. 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.

Also, it is not made specifically for people with Crohn's or Colitis. <u>Other factors</u> related to your Crohn's or Colitis can make your risk of osteoporosis higher.

Other risk factors for people with Crohn's or Colitis

There are some other factors that are thought to increase the risk of developing osteoporosis that are related to Crohn's or Colitis.

These include:

Inflammation





Crohn's and Colitis cause inflammation in the gut. This inflammation means that people with Crohn's or Colitis can have a higher level of proteins called cytokines in their bodies. These proteins can affect the rate at which new bone is formed and lead to bone loss and osteoporosis.

Inflammation in the gut can also sometimes be related to pain and swelling in your joints (arthritis). Unlike osteoporosis, arthritis can be very painful. If you have pain or swelling in your joints, talk to your doctor or IBD team and find out more in our information on joints.

Steroids

<u>Steroids</u> are often used to help control flare-ups in Crohn's and Colitis. They are usually only used for a short time as they can cause unwanted side effects. Taking a high dose of steroids, or taking them for a long time can weaken your bones and increase your risk of developing osteoporosis.

Steroid treatment can increase the risk of weak bones because:

- The rate that bone-building cells work is slowed down. This means bone loss happens more quickly.
- Steroids can make it harder for your body to absorb calcium. Lower levels of calcium mean bones are weaker.
- Taking steroids can reduce the levels of hormones in your body which can have an impact on how fast you lose bone.

If you are worried about taking steroids and how this might affect your bones, speak to your doctor or IBD team. Find out more in our information on **steroids**.

Reduced absorption of nutrients

Calcium and vitamin D help build your bones and keep them healthy. But many people with Crohn's or Colitis have low levels, increasing the risk of weaker bones.

This can happen because:

You might find it hard to get enough calcium in your diet.





- You have been taking steroids which makes it harder for your body to absorb calcium.
- You have had surgery that makes it harder for your body to absorb nutrients. This
 includes surgery where you have had sections of your small bowel removed.
- Inflammation in the gut can limit how much calcium you absorb.

Avoiding dairy foods

You might avoid eating dairy if you find it makes your Crohn's or Colitis symptoms worse. This means you are more likely to have a shortage of calcium in your diet. Low levels of calcium can lead to weaker bones and osteoporosis.

What tests are used to find out if you have weak bones?

To diagnose or assess your risk of osteoporosis, your doctor may refer you for a bone density scan. Bone density scans are also called DXA or DEXA (dual energy X-ray absorptiometry) scans. Bone density scans use low dose X-rays to scan your bones and see how strong they are. The scan is simple and painless. Read more about bone density scans in our information on <u>tests and investigations</u> or on the <u>NHS website.</u>

Your IBD teams may do a blood test to check your levels of vitamin D. If you have low levels, you may be offered vitamin D supplements.

Will I be offered these tests?

You are most likely to be referred for a bone density scan if you have <u>Crohn's</u> or <u>Colitis</u> and other <u>risk factors.</u>

Your doctor may also use a scoring system such as FRAX or QFracture. These are tools that consider several factors including your age and steroid use to calculate the chance of breaking a bone over the next 10 years. The results will help your doctor decide if you should have a bone density scan. See the FRAX tool at

www.sheffield.ac.uk/FRAX/tool.aspx





What do the results mean?

The results from your bone density scan are compared to that of an average healthy young adult and are called a T score.

T Score	Bone density
0 to -1	Healthy bone density
-1 to -2.5	Osteopenia - mild loss of bone density
-2.5 and above	Osteoporosis

Treatment for osteoporosis is based on your T score and other risk factors such as your age, sex, steroid use or whether you have previously broken bones.

What can I do to reduce the risk?

Prevention and treatment of low bone density and osteoporosis aims to:

- Strengthen bones
- Prevent further bone loss
- Reduce the risk of bones breaking.

To prevent or treat low bone density or osteoporosis, your doctor or IBD team may recommend that you:

Exercise

Exercise and movement can help keep your bones strong and healthy. Find out about the different types of exercise you can do to help your bone strength on the Royal Osteoporosis Society website.

Outdoor exercise is especially valuable as this will increase your exposure to sunlight and boost your vitamin D production. However, some medicines for Crohn's or Colitis can make you more sensitive to sunlight, or increase your risk of skin reactions. These include <u>adalimumab</u>, <u>azathioprine</u>, <u>filgotinib</u>, <u>golimumab</u>, <u>infliximab</u>, <u>mercaptopurine</u>, <u>methotrexate</u> and <u>tofacitinib</u>. If you are taking these medicines for your Crohn's or Colitis





it is important to take care in the sun. The NHS has more information on sun safety. If you are not sure, ask your doctor or IBD team for advice on exercise.

Stop smoking

Stopping smoking can help reduce the risk of developing weak bones and osteoporosis. Ask your IBD team or GP if they can refer you to a stop smoking programme or clinic. Find out more in our information on **smoking**.

Limit alcohol intake to two units or less a day

The National Osteoporosis Guideline Group have found that drinking three or more units of alcohol a day may increase your risk of developing osteoporosis. Find out more about alcohol units on the **NHS website.**

Increase calcium intake

The NHS recommends adults aged 19 to 64 get 700 mg of calcium per day from your diet. If you are not getting enough calcium from your food or are avoiding dairy products you may need calcium supplements. Read more about sources of calcium on the NHS website.

Take vitamin D

Your body makes vitamin D when your skin is exposed to sunlight. In winter, most people do not get enough sunshine to make it. The NHS suggests everyone considers taking a daily supplement containing 10 micrograms of vitamin D during the autumn and winter. On a packet or bottle, 10 micrograms might be written as 10µg.

The Department of Health and Social Care recommends you take a daily supplement containing 10 micrograms of vitamin D throughout the whole year if you: 12,13

- Are not outdoors often
- Are in a care home
- Usually wear clothes that cover up most of your skin
- Have dark skin. For example, if you are from an African, African-Caribbean or south Asian background.





Some medicines used to treat Crohn's and Colitis can make your skin sensitive to sunlight. Find out more in our **medicines information**.

Continue to take your prescribed medicines

Continuing to take your medicines to treat your Crohn's or Colitis may reduce the risk of osteoporosis by minimising the amount of ongoing inflammation in the gut. After 3 years in stable remission, your bone density may return to normal levels. Research has also found that bone density can be improved if you are being treated with anti-TNF medicines such as <u>infliximab</u>, <u>adalimumab</u> and <u>golimumab</u>.

Talk about bone loss prevention with your IBD team if you are taking steroids

Taking steroids can weaken your bones. Taking them for a long period of time (more than 3 months), puts you at higher risk. Your doctor may give you vitamin D and calcium supplements while you take steroids. This will help protect your bones and keep them strong. Your doctor should assess your risk of bone fractures when you start taking steroids. If the risk of bone fractures seems high, they may suggest you have a **bone density scan**.

Rectal steroids and oral budesonide are less likely to cause bone weakness than oral prednisolone and intravenous steroids. This is because they work directly in your bowel and don't tend to cause side effects in other parts of your body. Budesonide often goes by different brand names depending on what part of the bowel it targets. Examples include Cortiment, Budenofalk and Entocort CR.

Talk to your IBD team about bisphosphonate medicines

Bisphosphonates are medicines that can reduce your risk of breaking bones if you have osteoporosis. They work by slowing down the rate that bones are broken down in your body.

If you are at <u>higher risk</u>, your doctor may offer you bisphosphonates. This includes if you have been taking steroids to treat your Crohn's or Colitis.





Read about bisphosphonates and other medicines used to treat osteoporosis on the NHS website.

Other organisations

Royal Osteoporosis Society: https://theros.org.uk/

Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our award-winning information on Crohn's Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships and employment. We'll help you find answers, access support and take control.

All information is available on our website: crohnsandcolitis.org.uk/information

Our Helpline is a confidential service providing information and support to anyone affected by Crohn's or Colitis.

Our team can:

- Help you understand more about Crohn's and Colitis, diagnosis and treatment options
- Provide information to help you live well with your condition
- Help you understand and access disability benefits
- Be there to listen if you need someone to talk to
- Help you to find support from others living with the condition

Call us on 0300 222 5700 or email helpline@crohnsandcolitis.org.uk.

See our website for LiveChat: crohnsandcolitis.org.uk/livechat.

Crohn's & Colitis UK Forum





This closed-group community on Facebook is for everyone affected by Crohn's or Colitis. You can share your experiences and receive support from others at: facebook.com/groups/CCUKforum.

Help with toilet access when out

Members of Crohn's & Colitis UK get benefits including a Can't Wait Card and a RADAR key to unlock accessible toilets. This card shows that you have a medical condition, and will help when you need urgent access to the toilet when you are out. See crohnsandcolitis.org.uk/membership for more information, or call the Membership Team on 01727 734465.

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

About Crohn's & Colitis UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This information is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis: call **01727 734465** or visit **crohnsandcolitis.org.uk**.

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We hope that you've found this information helpful. You can email the Knowledge and Information Team at evidence@crohnsandcolitis.org.uk if:

- You have any comments or suggestions for improvements
- You would like more information about the research on which the information is based
- 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 contact us through the Helpline: 0300 222 5700.

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