CROHN'S & COLITIS UK

FIGHTING INFLAMMATORY BOWEL DISEASE **TOGETHER**

INFORMATION SHEET

BONES

WHAT YOU NEED TO KNOW IF YOU HAVE CROHN'S OR COLITIS

INTRODUCTION

If you have Crohn's or Colitis you may be more likely to develop weaker bones (osteoporosis) or low bone mass. This can mean bones break (fracture) more easily if you have a minor fall.

Inflammation in the gut, taking steroids, low levels of calcium and vitamin D or removal of parts of the small bowel can all contribute to bone loss if you have Crohn's or Colitis.

This information is for anyone with Inflammatory Bowel Disease (IBD) who may be worried about developing fragile bones.

It looks at:

- why you might be at risk of bone loss
- what tests are available to measure your bone density
- how you can keep your bones healthy
- drugs that can help prevent bone loss.

CONTENTS

BONES EXPLAINED 1
WHAT TYPES OF BONE LOSS ARE THERE? 2
HOW DO I KNOW IF I HAVE BONE LOSS? 2
WHAT ARE THE MAIN RISK FACTORS? 2
WHAT ARE THE ADDED RISKS IF YOU HAVE CROHN'S OR COLITS? 3
WHAT TESTS ARE USED TO FIND OUT IF YOU HAVE WEAK BONES? 4
WHAT DO THE RESULTS MEAN? 4
WHAT CAN I DO TO REDUCE THE RISK OF BONE LOSS? 5
HELP AND SUPPORT FROM CROHN'S & COLITIS UK 7

BONES EXPLAINED

Bone is living, growing tissue. It is made mostly of collagen, a protein that provides a soft framework, and calcium phosphate, a mineral that adds strength and hardens the framework. Our bones are constantly remodelling themselves. Throughout our lives, specialist bone cells break down and remove old bone (bone resorption), and different cells lay down new bone (bone formation).

During childhood and early adult life, bone density (also known as bone mass or bone mass density - BMD) increases, reaching a peak in the 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. See our booklet **IBD in Children: A parent's guide** for more information.

WHAT TYPES OF BONE LOSS ARE THERE?

- **Osteoporosis.** Most of our bones have a hard outer shell with a strong honeycomb-like inner structure. In osteoporosis, (which means 'porous bones') the struts of bone that make up the inner structure become thin, so the bone becomes fragile and breaks more easily.

- **Osteopenia.** This is a mild loss of bone density not severe enough to be labelled as osteoporosis. Research suggests that almost half of all people with Crohn's or Colitis have osteopenia.

- **Osteomalacia.** This is a softening (decalcification) of the bones usually caused by lack of vitamin D. Osteomalacia in growing children is known as rickets and can lead to bone deformity, in adults it can cause pain.

- **Ostenecrosis.** This is caused by a reduction in blood supply to a bone, such as a hip, and can result in the death of bone and the surrounding cartilage. This sometimes causes pain and stiffness but may have no symptoms. Osteonecrosis (also known as avascular necrosis) is a rare but serious condition and can be a complication of steroid treatment.

HOW DO I KNOW IF I HAVE BONE LOSS?

There are usually no obvious symptoms of bone loss until a bone breaks. Thin bones are not painful, but broken bones (fractures) usually are. Some, such as fractures of the spine, can lead to a serious loss of mobility.

WHAT ARE THE MAIN RISK FACTORS?

If you have Crohn's or Colitis many of the factors associated with bone loss are the same as those for the general population. These include:

- **Age.** Some loss of bone density happens naturally with age. The process of bone formation slows down, and bone resorption happens faster, so our bones become less dense.

- **Gender.** A shortage of sex hormones (oestrogen and testosterone) can lead to a reduction in bone formation.

    - Women have smaller bones and tend to lose bone faster than men. This is because hormonal changes during the menopause increase the rate that bone breaks down. Younger women who have been through an early menopause may also be more at risk.

    - Men have lower levels of testosterone as they get older and this leads to weaker bones.

- **Family history.** If members of your family have osteoporosis or a history of broken bones you are also more likely to be at risk.

> "I do worry that my bones will become more damaged over time as I've had several courses of steroids, but with density scans getting better and more treatments available, I hope to still be running well into old age!"
>
> **Sarah,** age 33
> Diagnosed with Ulcerative Colitis in 2013

- **BMI (Body Mass Index) less than 18.5 kg/m².** This is a measure of the relationship between your weight and height. A BMI of less than 18.5kg/m² indicates that you have a low body weight for your height. The chances of breaking a bone are greater as people with low body weight have less bone tissue. Find out your BMI at **nhs.uk/bmi**

- **Smoking.** Smoking reduces the mineralisation of bone, which means bones are not as strong. It also speeds up bone loss and can lead to calcium not being absorbed as well. See our information on **Smoking and IBD**

- **Drinking excessive amounts of alcohol.** Alcohol consumption of three or more units of alcohol a day can impact on bone health. Too much alcohol is thought to affect the rate of bone remodelling and can result in weaker bones.

- **Low levels of calcium or vitamin D.** Calcium is important in bone mineralisation and vitamin D helps the body absorb calcium.

- **Little physical activity**. Weight bearing exercise is particularly important because this stimulates the body to strengthen the bones. People with Crohn's or Colitis often reduce their physical activity, perhaps because of weakness, fatigue, pain, diarrhoea or nausea.

WHAT ARE THE ADDED RISKS IF YOU HAVE CROHN'S OR COLITS?

Research has suggested that having Crohn's or Colitis is another factor that may make bone loss more likely. Studies have found this is common in both men and women, with 5 out of 10 people with Crohn's or Colitis experiencing low bone mass or osteoporosis.

- **Inflammation**

People with active Crohn's or Colitis have a higher level of cytokines (hormone-like proteins), which are released as part of the inflammatory process in the gut. These chemicals can affect the rate at which new bone is formed.

Inflammation in the gut can sometimes be associated with an inflammatory process affecting joints. If you have pain or swelling in your joints, talk to your doctor or IBD team and find out more in **Joints.**

- **Steroids (corticosteroids)**

Steroids are often used to help control flare-ups in Crohn's and Colitis. But they do not maintain remission and are not used as long-term therapy.

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
- the amount of calcium absorbed from food is reduced, and calcium lost from the body in urine increased. This loss of calcium means bones are weakened.

How seriously the bones are affected usually depends on the dose and length of steroid treatment.

Using steroids for a short time is unlikely to cause problems. But repeated courses with limited time between them or longer use may mean greater risks to bones. If you are worried about taking steroids and how this might affect your bones, speak to your doctor or IBD team.

Steroids taken in enemas or suppositories (via the rectum) are less likely to cause bone weakness than taking them by mouth or injected into a vein (intravenously). This is because they are not so easily absorbed into the blood. Find out more about **Steroids** in the drug information sheet.

Osteonecrosis of the hip is a rare but serious condition that often needs surgical treatment If you develop hip pain when you are taking steroids, tell your doctor or IBD team.

- **Reduced absorption of nutrients**

The nutrients important to bone formation, especially calcium and vitamin D, are absorbed in the small intestine. If you have extensive Crohn's Disease that affects the small bowel, or have had parts of your small intestine removed, you may be at additional risk.

- **Avoiding dairy foods**

If you do not eat dairy products, perhaps because of lactose (milk sugar) intolerance or abdominal pain, you are more likely to have a shortage of calcium in your diet. Low levels of calcium can slow down bone formation.

- **Lower levels of sex hormones**

The combination of inflammatory cytokines and reduced absorption of nutrients can lower levels of sex hormones (oestrogen and testosterone). These hormones are important in maintaining bone health.

WHAT TESTS ARE USED TO FIND OUT IF YOU HAVE WEAK BONES?

Osteoporosis is diagnosed by measuring bone density using a DXA (DEXA - dual energy x-ray absorptiometry) scanning machine. This uses low dose x-rays to take a scan of your hip or spine. It is a simple, painless test which takes about five minutes.

Blood tests can be used to measure levels of vitamin D, calcium and phosphorus. This can be helpful in identifying people at risk of osteomalacia.

WHAT DO THE RESULTS MEAN?

The results from a DXA scan are used to work out a bone density score. Your bone density is compared to that of an average healthy person in their 20s and is known as 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

WILL I BE OFFERED THESE TESTS?

You are most likely to be offered a DXA bone scan if you have Crohn's or Colitis and other risk factors such as:

- a woman after the menopause
- a woman who has had an early menopause
- a person who has been taking steroids

> For the past five years, I have had to manage my IBD, on and off, with steroid medication. I have been diagnosed with osteopenia but I make sure I take calcium and vitamin D supplements to help maintain my bones.
>
> **Zaineb,** age 23
> Diagnosed with Crohn's Disease in 2010

Your doctor may also use a scoring system such as FRAX or QFracture. These 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 DXA scan. See the FRAX tool at **www.sheffield.ac.uk/FRAX/tool.aspx**

IBD teams may measure blood levels of vitamin D and calcium if you are thought to be at risk of bone disease. Around 1 in 3 people with Crohn's or Colitis have been found to be deficient in vitamin D, which has also been associated with greater disease activity, poorer quality of life and increased risk of surgery.

WHAT CAN I DO TO REDUCE THE RISK OF BONE LOSS?

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

- strengthen bones
- prevent further bone loss
- reduce the risk of bones breaking.

Your health professionals can also help you to protect your bones, especially if you are taking steroid medications. By being aware of the risk of bone loss, you might also be able to change your diet or lifestyle to help prevent it.

Take regular exercise that is suitable for you
If you can, take regular weight-bearing exercise, such as brisk walking, jogging, dancing, aerobics, or active team sports. Gardening and housework, even just using the stairs whenever possible, is also useful. Any weight-bearing activity stimulates bone formation. Outdoor exercise is especially valuable as this will increase your exposure to sunlight and boost your vitamin D production. If in doubt, ask your doctor or IBD team for guidance on exercise.

Stop smoking
Research shows smoking increases the severity of Crohn's Disease. For people with Ulcerative Colitis, the relationship between smoking and active disease is a more complex issue. For more information see **Smoking and IBD**. Many GPs and hospitals run stop smoking programmes.

Limit alcohol intake to two units or less a day
The National Osteoporosis Guideline Group recommend drinking two units or less of alcohol a day for good bone health. Find out more about alcohol units **www.nhs.uk/live-well/alcohol-support/calculating-alcohol-units.**

Calcium
Current guidelines from Public Health England suggest you need 700 mg of calcium per day in your diet. If you are not getting enough calcium from your food or are avoiding dairy products you may need calcium supplements.

Dairy sources of calcium

Milk (skimmed milk contains slightly more calcium than whole milk)
Hard and soft cheeses
Yoghurt, fromage frais, dairy ice cream

Non-dairy sources of calcium

Fortified soya milk,
Tofu
Green leafy vegetables such as broccoli, cabbage and okra (but not spinach)
Fish with edible bones, such as pilchards and sardines
Nuts

> I am very careful to eat healthily, have always drunk lots of milk, and make sure I keep myself active. I've got 2 dogs so that's a good incentive to get out whatever the weather! I enjoy gardening too – so these two activities ensure I get plenty of sunshine and vitamin D.

Pat, age 72
Diagnosed with Ulcerative Colitis in 1974

Vitamin D
The Scientific Advisory Group on Nutrition recommends a daily intake of 10 micrograms (400 International Units) of Vitamin D for adults in the general population. However, it is suggested that to maintain blood levels of vitamin D for people with Crohn's or Colitis, 25 micrograms (1000 International Units) may be needed.

Exposure to sunlight
The vitamin is made by the body under the skin in reaction to sunlight. From late March to the end of September, most people should be able to get all the vitamin D they need from sunlight on their skin. However, during the winter months vitamin D deficiency is common and the recommendation is to eat foods high in vitamin D.

People whose skin has little or no exposure to the sun, or who always cover their skin when outside, risk vitamin D deficiency and are recommended to take a supplement of 10 micrograms throughout the year.

However, if you take azathioprine or mercaptopurine remember to take precautions in the sun including wearing a hat and using sun screen. These medicines increase the skin's sensitivity to sunlight and the risk of developing some forms of skin cancer. Find out more in the **Azathioprine and Mercaptopurine** drug information sheet.

Food sources of vitamin D

- Oily fish such as salmon and sardines
- Eggs, cheese and red meat
- Fortified fat spreads and breakfast cereals.

Continue to take prescribed IBD medication
Continuing to take your IBD medications may reduce the risk of osteoporosis by minimising the amount of ongoing inflammation in the gut. It has been shown that bone density can return to normal when a person's Crohn's or Colitis has been in remission for three years or more.

> I eat a lot of dairy and fish, exercise every day and don't smoke or drink. I hope that these will offset any problems caused by my steroid treatment.

Edmund, age 38
Diagnosed with Ulcerative Colitis in 2012

Talk about bone loss prevention with your IBD team if you are taking steroids
Calcium and vitamin D supplements are recommended if you are taking steroids. You may also be offered bisphosphonates.

Some of the newer steroids, such as budesonide, may be less harmful to the bones as less of the steroid is absorbed into the body. Find out more in the **Steroids** drug information sheet.

If you have persistently active Crohn's or Colitis, guidelines suggest you should be offered immunosuppressive therapy such as azathioprine or biological drugs such as infliximab or adalimumab. These drugs treat inflammation, can avoid the need for prolonged steroids and so reduce the chances of bone loss. Research suggests infliximab (one of the biological drugs) may also improve bone density in people with Crohn's Disease.

See our information on **Biologic Drugs** and our individual **drug information sheets.**

Bisphosphonate drugs
If you have a T score of -1.5 or less, you may be offered treatment with bisphosphonates. These include alendronate, ibandronate and risedronate sodium. These work by slowing down the cells that break down bone and allow the bone building cells to work more effectively. They can be used prevent and treat bone loss linked to taking steroids and research has shown that they are well tolerated in people with Crohn's and Colitis.

Regular use of these medications may also be indicated to prevent further bone loss in postmenopausal women or in people who have experienced spontaneously broken bones.

For more information to help you and your health professionals consider the options around taking bisphosphonates visit the NICE Decision Support **www.nice.org.uk/guidance/ta464/resources/decision-support-from-nice-information-to-help-people-with-osteoporosis-and-their-health-professionalsdiscuss-the-options-pdf-4608867565.**

If you are a woman who has reached the menopause talk to your doctor or IBD team about bone loss, even if you are not on steroid treatment. You can ask for a referral to a rheumatologist (who will have experience of osteoporosis) or a dietitian.

> “Although I don’t get on well with milk or yoghurt, I ensure I eat plenty of broccoli and green vegetables to make up for the loss of calcium in my diet. I also go for walks outside and run when I feel well enough, so I feel I’m doing all I can to keep my bones healthy.”
>
> **Sarah,** age 33
> Diagnosed with Ulcerative Colitis in 2013

HELP AND SUPPORT FROM CROHN’S & COLITIS UK

We offer more than 50 publications on many aspects of Crohn’s Disease, Ulcerative Colitis and other forms of Inflammatory Bowel Disease. You may be interested in our comprehensive booklets on each disease, and other topics such as:

- Food and IBD
- Joints
- Smoking and IBD
- Steroids
- Biologic drugs and individual drug information sheets

All publications are available to download from crohnsandcolitis.org.uk/quick-list. Health professionals can order booklets in bulk by using our online ordering system. If you would like a printed copy of a booklet or information sheet, please contact our Helpline - a confidential service providing information and support to anyone affected by Crohn’s or Colitis. Our team can:

- help you understand more about IBD, diagnosis and treatment options
- provide inforamtion to help you to live wel with your condition
- help you understand and access disability benefits
- 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 IBD. You can share your experiences and receive support from others at: facebook.com/groups/CCUKforum

Crohn’s & Colitis UK Local Networks
Our Local Networks of volunteers across the UK organise events and provide opportunities to get to know other people in an informal setting, as well as to get involved with educational, awareness-raising and fundraising activities. Visit crohnsandcolitis.org.uk/local-network to find your nearest network.

Help with toilet access
If you become a member of Crohn’s & Colitis UK, you will get benefits including a Can’t Wait Card and a RADAR key. This card shows that you have a medical condition, and combined with the RADAR key will help when you need urgent access to the toilet when you are out and about. See our website for further information: crohnsandcolitis.org.uk/membership or call the membership team on 01727 734465.

FURTHER HELP

National Osteoporosis Society
0845 800 0035
www.nos.org.uk

NHS Choices
www.nhs.uk
Provide guidance on range of health matters, including alcohol consumption.

Crohn's & Colitis UK publications are research-based and produced in consultation with patients, medical advisers and other health or associated professionals. They are prepared as general information on a subject and are not intended to replace specific advice from your own doctor or any other professional. Crohn's & Colitis UK does not endorse or recommend any products mentioned.

Crohn's & Colitis UK is an accredited member of the Information Standard scheme for Health and Social care information producers. For more information see **www.crohnsandcolitis.org.uk** and the Information Standard website: **www.england.nhs.uk/tis.**

We hope that you have found this leaflet helpful and relevant. If you would like more information about the sources of evidence on which it is based, or details of any conflicts of interest, or if you have any comments or suggestions for improvements, please email the Publications Team at **publications@crohnsandcolitis.org.uk.** 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.**

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 publication 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.**

Follow us

/crohnsandcolitisuk

@CrohnsColitisUK

@crohnsandcolitisuk

Health & care information you can trust

The Information Standard Certified Member

Bones and IBD - Edition 6a
Amended Aug 2021
Last review - January 2019,
Amended Aug 2021
Next planned review - 2022

1 Bishops Square | Hatfield | Herts | AL10 9NE | 0300 222 5700 | info@crohnsandcolitis.org.uk | crohnsandcolitis.org.uk