



BONES AND IBD

INTRODUCTION

As we grow older our bones become thinner and more fragile. Having Inflammatory Bowel Disease (IBD) may make developing weaker bones more likely. This leaflet provides information for anyone with Ulcerative Colitis (UC) or Crohn's Disease (the two main forms of IBD) who may be worried about developing fragile bones. It looks at why this may happen, and recent developments in prevention, diagnosis and treatment.

WHAT IS BONE?

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 repairing themselves. Throughout our lives, specialist bone cells break down and remove old worn out bone (bone resorption), and other cells lay down new bone (bone formation).

WHAT CAUSES BONE LOSS?

Some loss of bone density happens naturally with age. The process of bone formation slows down and bone resorption begins to happen faster than bone formation, so our bones become less dense. During childhood and early adult life, bone density, also known as bone mass, increases, reaching a peak in your late 20s. After this, bone mass generally 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.)

Bones can lose density if there is insufficient calcium in the body to form enough bone tissue. A shortage of sex hormones (oestrogen and testosterone) can also lead to a reduction in bone formation.

Corticosteroids (also known as steroids) such as prednisolone, used to treat IBD can reduce bone formation. Lack of exercise may also result in increased bone loss because regular impact, or weight-bearing exercise, stimulates the body to strengthen the bones. Additionally, smoking can also affect bone formation. Smoking accelerates bone loss and can lead to calcium not being absorbed as well.

WHAT TYPES OF BONE LOSS ARE THERE?

- **Osteoporosis** is the most common type of serious loss of bone density. 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** is the term used to describe a mild loss of bone density not severe enough to be labelled as osteoporosis.
- **Osteomalacia** is a decalcification (softening) of the bones usually caused by lack of vitamin D. Osteomalacia in growing children is known as rickets and can lead to bone deformity.
- **Avascular necrosis** is a rare condition where there is a reduction in blood supply to a bone, such as a hip, causing the bone and the surrounding cartilage to deteriorate.

More information about bones and osteoporosis can be obtained from the National Osteoporosis Society (see **Further help**).

WHY DOES LOSS OF BONE DENSITY MATTER?

Bone density is sometimes known as BMD (bone mineral density) and is usually measured by a DEXA scanner (see below). Having a serious loss of bone density, or a low BMD measurement, does not automatically mean that your bones will break. But it does mean you might be at greater risk of fracturing (breaking) a bone. Thin bones are not in themselves painful, but fractures usually are, and some, such as hip or spine fractures, can lead to a serious loss of mobility.

HOW CAN I TELL IF I HAVE LOSS OF BONE DENSITY?

Perhaps surprisingly, there are usually no obvious symptoms of bone loss apart from fractures. So, the best way of working out how likely you are to be affected is to consider how many of the main risk factors may apply to you (see below).

WHAT ARE THE MAIN RISK FACTORS?

For the general population, the main factors associated with a higher risk of developing bone loss are:

- age – although loss of bone density can affect any age group, it is most common in the elderly
- gender – women have smaller bones and tend to lose bone faster than men. This is because hormonal changes during the menopause accelerate the breakdown of bone. Younger women who have been through an early menopause may also be more at risk
- ethnic background – people of Caucasian (white) or Asian race appear to be more likely to develop bone loss because their bones are smaller and weaker
- genes – having a family history of osteoporosis or fractures
- previous fractures – if you have already broken bones easily you are more likely to have fractures in the future
- weight – being underweight for height (low body mass index)
- smoking
- drinking too much alcohol (the NHS website provides advice about alcohol intake, see **Further help** for details)
- in men, low levels of testosterone

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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!

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Sarah, age 33

Diagnosed with Ulcerative Colitis in 2013

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- poor diet – if it is low in calcium or in vitamin D, which helps the body absorb calcium
- inadequate exposure to sunlight since vitamin D, which helps bone formation, is made by the action of sunlight on bare skin
- long-term immobility or an inactive lifestyle (for example, being housebound).

WHAT ARE THE ADDITIONAL RISKS IF YOU HAVE IBD?

Research has suggested that having IBD is another factor that may make bone loss and fractures more likely. Many people with IBD are affected by bone loss, with a greater risk found for those with Crohn's Disease than UC.

People with IBD may find that the inflammatory process affects their joints (see our booklets **Crohn's Disease** and **Ulcerative Colitis** for further information about this). If you have concerns about your joints, talk to your doctor or IBD team.

WHY ARE PEOPLE WITH IBD AT EXTRA RISK?

Several factors might be contributing to this increased risk:

- **The use of corticosteroids ('steroids')**

Treatment of UC or Crohn's Disease with steroids can increase the risk of having weak bones. This is because steroids can decrease the rate at which the bone-building cells work, which accelerates bone loss. Steroids can also affect the amount of calcium absorbed from food, and increase the calcium lost from the body in urine. How seriously the bones are affected usually depends on the dose and length of steroid treatment.

Steroids taken rectally (in enemas or suppositories) are less likely to cause bone weakness than steroids taken by mouth or intravenously, because they are not so easily absorbed into the blood. Using steroids short term is unlikely to result in harm, but repeated courses with limited intervals between courses or long term use may mean greater risks to bones. It is important to avoid overuse if possible. If you are concerned about taking steroids and how this might affect your bones, speak to your doctor or IBD team.

- **Avoidance of dairy foods**

If you avoid 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, unless you are taking a regular supplement. This shortage can slow down bone formation. (See **How can bone loss be prevented** for more information about calcium supplements.)

- **The inflammatory process itself**

People with active IBD tend to have a higher level of cytokines (hormone-like proteins), which are released as part of the inflammatory process. These chemicals can affect the rate at which new bone is formed.

- **Poor absorption of nutrients because of inflamed intestines**

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

- **Sex hormones**

The combination of inflammatory cytokines and poor nutrition can lower levels of oestrogen and testosterone, which in turn can affect bone health.

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HOW DO DOCTORS DIAGNOSE WEAK BONES?

Osteoporosis is best diagnosed by measuring bone density or BMD using a 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 20 minutes.

Smaller and more portable peripheral DEXA (pDEXA) scanners and ultrasound scanners can be used to measure the bone density in areas other than the hip or spine. For example, they may be used to scan your finger, heel or forearm. These scans can then be used to decide whether you need treatment, or whether you should go on to have a hip or spine DEXA scan. DEXA hip scans remain the preferred way to confirm a diagnosis of osteoporosis.

Conventional x-rays are of little help, unless fractures have already occurred.

Biochemical tests, including blood vitamin D, calcium and phosphorus levels, can be helpful in identifying patients at risk of osteomalacia.

Avascular necrosis of the hips can be diagnosed by an x-ray of the hip joint, or by an MRI scan, that can detect earlier changes. MRI scanners produce computer images of internal organs and the bones using strong magnets and radio waves rather than x-rays.

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WILL I BE OFFERED THESE TESTS?

You are most likely to be offered a DEXA bone scan if you not only have IBD, but are also in a higher risk group for other reasons: for example, if you are a postmenopausal woman, have been through an early menopause, or have been taking steroids. Some doctors may measure your bone density even if you do not come into the above categories.

Your doctor may also use a scoring system such as 'FRAX®' (produced by the World Health Organisation) and 'QFracture™'. These take into account a number of clinical features (including age and steroid use) to calculate your chance of breaking a bone over the next 10 years. The results will help your doctor decide if you should be referred for a DEXA scan.

While some experts believe vitamin D and calcium levels should be measured in the blood of IBD patients thought to be at risk of bone disease, there are currently no guidelines available around vitamin D testing for those with IBD.

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WILL I BE OFFERED TREATMENT?

The results from a DEXA scan are used to work out a bone density 'score' by comparing your bone density to that of the general population. Treatment recommendations then depend on this score and on your other risk factors, for example, whether you have used steroids or have had fractures in the past.

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“ 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

WHAT TREATMENTS ARE THERE?

Treatments for low bone density and osteoporosis are aimed at strengthening existing bones, preventing further bone loss and reducing the risk of fractures.

- **Calcium and vitamin D** – ensuring that you are taking enough of these is an important first step, and supplements may be recommended. Supplementation is offered for people found to have low levels or who have been undergoing corticosteroid treatment. If you have difficulty absorbing nutrients, as sometimes happens with Crohn's Disease, you may be prescribed additional high dose vitamin D supplements. Research suggests that people with IBD who have low levels of vitamin D are more likely to be hospitalised or have surgery related to IBD, compared to those with higher levels of vitamin D. It is, however, unclear whether low levels are a consequence of more severe IBD.
- **Bisphosphonate drugs** - for example, alendronate, ibandronate and risedronate sodium, have been used for some years in the treatment of osteoporosis. They work by slowing down cells which break down bone (osteoclasts) and allow the bone building cells (osteoblasts) to work more effectively. Research shows bisphosphonates are effective and well tolerated in people with IBD, and can be used to prevent and treat bone loss linked to steroids.

Bisphosphonates, which can be taken daily, weekly, monthly or even once every three months depending on the type prescribed, usually come in tablet form. Some bisphosphonates, such as ibandronate, can be given as an intravenous (into a vein) injection. If you are prescribed oral (by mouth) bisphosphonates, it is important to take the tablets exactly as directed. This may be, for example, upright while sitting or standing, with plenty of water, to reduce the risk of irritating the lining of the oesophagus (gullet). Since bisphosphonates are poorly absorbed they must be taken on an empty stomach – the patient information leaflet that comes with your tablets will tell you exactly how long you should wait before eating.

Questions exist around duration of bisphosphonates, and there have been side effects reported as a result of the treatment including a rare dental disease (osteonecrosis of the jaw). Guidance suggests that all patients receiving intravenous bisphosphonates should have a dental check-up before starting treatment. Bisphosphonates are not recommended for women who are pregnant, or might become pregnant in the future, or who are breastfeeding. Pregnant women need to weigh up with doctors their individual benefits for continuing treatment against possible risks to the pregnancy. Speak to your doctor or IBD team if you are taking bisphosphonates and you are thinking of starting a family.

- **Taking extra oestrogen (also known as hormone replacement therapy or HRT)** - particularly in post-menopausal women, can help reduce bone loss. However, HRT is less commonly used for osteoporosis because research found a small but significantly increased risk of breast cancer, blood clots (venous thromboembolism), stroke and ovarian cancer. If you are concerned, it may be worth discussing this with your doctor or IBD team. For some men with osteoporosis, testosterone replacement may be effective. This may be given as injections, implants, daily patches or tablets.
- **Other drugs for osteoporosis** - your doctor may prescribe these. Raloxifene belongs to a group of drugs called selective estrogen receptor modulators (SERMs) that mimic the action of oestrogen on certain organs, (such as bone) and block it in others (such as breast tissue). This overcomes the risk of breast cancer that has been observed with HRT. Strontium ranelate (which has the dual action of increasing new bone production and reducing old bone breakdown) is reserved for people in whom other osteoporosis drugs do not work.

- **Chinese herbal medicines** - can be used to treat osteoporosis, but a recent analysis of multiple studies concluded that the beneficial effects were uncertain and more research was needed. The use of complementary or alternative medicines, nutritional supplements, herbal and homeopathic remedies should always be discussed with your health care team.

Avascular necrosis of the hip is a rare but serious condition that often needs surgical treatment. If you develop hip pain during steroid therapy, report it to your doctor or IBD team.

With effective treatment, improved bone density can usually be confirmed with follow up DEXA scans. However, as bone strengthening is a gradual process, it will not show up immediately.

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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.

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Pat, age 72

Diagnosed with Ulcerative Colitis in 1974

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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.

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Edmund, age 38

Diagnosed with Ulcerative Colitis in 2012

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HOW CAN BONE LOSS BE PREVENTED?

Osteoporosis is far better prevented than treated. If you are concerned that you may develop weak bones, the following suggestions may help:

- 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, can also be useful, as 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 for guidance on exercise.
- Avoid smoking and reduce alcohol intake. (See **Further help** at the end of this leaflet for details).
- Ensure you have adequate calcium and vitamin D, which are important for bone strengthening. (See **Further help**). The daily recommended intake of Vitamin D is 800 units. Guidelines for people with IBD recommend a daily intake of 1000 mg of calcium for people under 55, and 1200mg for over 55s.
- If you are not getting enough calcium from your food, perhaps because you are avoiding dairy products, you may need calcium supplements. It may be worth discussing this with your doctor or IBD Team as they may be able to prescribe combined calcium and vitamin D supplements. Some people overestimate their dairy sensitivity, and avoid milk and milk products unnecessarily. Recent studies suggest calcium supplements can increase the risk of heart disease, but other research has not confirmed this finding.
- If you are taking steroids, talk about prevention of bone loss with your doctor or IBD team. Calcium and vitamin D supplements are often used for those on steroid treatment. You may also be given bisphosphonates while on steroids. Some of the newer steroids, such as budesonide, may be less harmful to the bones as they usually only affect the bowel, and so may be helpful for people with some forms of Crohn's Disease. For people with UC, newer forms of budesonide, such as multimatrix or 'MMX' allows the drug to be released throughout the colon. Prolonged use of steroids can sometimes be avoided by taking immunosuppressants such as azathioprine and biological drugs, for example, infliximab. New research suggests infliximab may also have the additional benefit of improving bone density in people with Crohn's Disease. See our individual drug treatment sheets for more information.
- If you are a woman with IBD who has reached the menopause and is at risk of thinning bones, it may be best to speak to your doctor or IBD team about bone loss, even if you are not on steroid treatment.

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- Continuing to take your IBD medications may reduce the risk of osteoporosis by minimising the amount of ongoing inflammation in the gut. Speak to your IBD team to weigh up the risks and benefits that taking steroids may have on your bones.

By being aware of the risk of bone loss, you may be able to change your diet or lifestyle to help prevent it. Also, appropriate treatment can now significantly reduce the risk of bone disease.

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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

SOURCES OF CALCIUM

Dairy sources

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

Non-dairy sources

- Fortified soya milk
- Tofu
- Green leafy vegetables such as broccoli and cabbage
- Fish with edible bones, such as pilchards and sardines
- Nuts

Sources of Vitamin D

- Exposure to sunlight
- Oily fish such as salmon and sardines
- Eggs
- Fortified fat spreads and breakfast cereals.

For more information on eating healthily with IBD see our booklet: **Food and IBD**.

HELP AND SUPPORT FROM CROHN'S AND COLITIS UK

All our information sheets and booklets are available to download from our website: www.crohnsandcolitis.org.uk, or you can get a copy by calling our call or email the **Information Line** (details below).

Crohn's and Colitis UK Information Line: 01727 734470, open Monday to Friday, 9 am to 5 pm, except Thursday open 9am to 1pm and excluding English bank holidays. An answer phone and call back service operates outside these hours. You can also contact the service by email info@crohnsandcolitis.org.uk or letter (addressed to our St Albans office). Trained Information Officers provide callers with clear and balanced information on a wide range of issues relating to IBD.

Crohn's and Colitis Support: 0121 737 9931, open Monday to Friday, 1 pm to 3.30 pm and 6.30 pm to 9 pm, excluding English bank holidays. This is a confidential, supportive listening service, which is provided by trained volunteers and is available to anyone affected by IBD. These volunteers are skilled in providing emotional support to anyone who needs a safe place to talk about living with IBD.

FURTHER HELP

National Osteoporosis Society

Camerton
Bath
BA2 0PJ
Helpline: 0808 800 0035
Website: www.nos.org.uk

NHS Choices

Provide guidance on range of health matters, including alcohol consumption.
Website: www.nhs.uk

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ABOUT CROHN'S & COLITIS UK

We are a **national** charity established in 1979. Our aim is to improve life for anyone affected by Inflammatory Bowel Diseases. We have over 28,000 members and 50 Local groups throughout the UK. Membership costs start from £15 per year with concessionary rates for anyone experiencing financial hardship or on a low income.

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