



What is osteoporosis?

Osteoporosis occurs when the struts which make up the mesh-like structure within bones become thin causing them to become fragile and break easily, often following a minor bump or fall. These broken bones are often referred to as 'fragility fractures'. The terms 'fracture' and 'broken bone' mean the same thing. Although fractures can occur in different parts of the body, the wrists, hips and spine are most commonly affected. It is these broken bones or fractures which can lead to the pain associated with osteoporosis. Spinal fractures can also cause loss of height and curvature of the spine.

Osteoporosis and children

Osteoporosis and fragility fractures are more common amongst post-menopausal women, but the condition can affect men and women of all ages. However, children and young people form a small but significant proportion of the population with osteoporosis.

Bone is alive and constantly changing. Childhood and adolescence are a very important time for our skeletons as it is during this period that bone growth occurs increasing both the size and strength of individual bones. Despite growth in the length of bones (and therefore gains in height) stopping in the mid to late teens, the overall mass of bone in the skeleton continues to increase into early adulthood. This is important as the store of bone built up over this time acts as protection against the onset of osteoporosis and fractures in later life.

Bone development during these formative years can be severely compromised in children who have chronic conditions or disabilities. Some will 'catch-up' on their bone development if their underlying disease or condition improves. Others however, may continue to have an increased risk of fracture, pain, additional disability and a diminished quality of life.

This factsheet aims to give parents and carers a basic understanding of this condition, how it may affect their child and what may be done about it.

What are the causes of osteoporosis in children?

It is uncommon for a child or teenager to be diagnosed with osteoporosis, but when it is it will usually be classified as either primary or secondary.

Primary osteoporosis: is the result of some specific conditions that your child may have which causes bones to become fragile, for example:

- Osteogenesis imperfecta (OI) – a genetic disorder typically affecting collagen, an important component of bone
- Osteoporosis pseudoglioma syndrome – a rare genetic condition that causes osteoporosis and eye abnormalities with loss of vision
- Idiopathic juvenile osteoporosis (IJO) - this is a condition in which osteoporosis develops in a previously healthy child or teenager and often no clear reason can be found. IJO tends to occur in children from the ages of seven to the early teens but it is extremely rare and affects less than 100 children in the UK

Secondary osteoporosis: This is a much more common cause of osteoporosis in children and is the result of one of several different medical conditions or the medications that are used to treat them. For example: Inflammatory conditions (such as juvenile arthritis or Crohn's disease)

- Anorexia nervosa and nutritional problems
- Delayed puberty and conditions resulting in failure to produce sufficient sex hormones
- Long-term, high-dose oral glucocorticoid treatment (often used for conditions such as asthma or arthritis)
- Conditions where there is reduced mobility, such as cerebral palsy, spinal cord injury and Duchenne muscular dystrophy
- Leukaemia

If your child has a chronic condition they will often have one or more risk factors associated with poor bone health e.g. a child with juvenile idiopathic arthritis can have reduced mobility and may also take long term glucocorticoids ('steroids'). These will increase their risk of developing osteoporosis with fragility fractures.

What are the symptoms?

The symptoms experienced by children with osteoporosis will vary from child to child, but the common symptoms are:

- Bone pain often in the back, hips, legs and feet
- Difficulty in walking/limited mobility
- Fractures (broken bones) in the long bones of the skeleton and in the spine
- Curvature of the spine, or height loss because the bones in the spine have become compressed or misshapen due to fractures

For example, children with IJO may first present with bone pain and walking difficulties but when investigated further they are found to have compression fractures of the bones in the spine (vertebrae) and may develop long bone fractures especially around the weight-bearing joints.

How is it diagnosed?

The World Health Organisation's definition of osteoporosis in adults, and particularly post-menopausal women, is based on the results of a dual energy x-ray absorptiometry (DXA) scan. Bone mineral density (BMD) is calculated and compared to that of young healthy adults and is represented as a T-score. Low bone density significantly below this range (a T-score of -2.5 standard deviations or below) is defined as osteoporosis. Generally the lower the bone density measurement the higher the fracture risk.

The relationship between BMD and fracture risk in children with chronic disease has not been as clearly established as in adults. This is because the large variation in bone size in children of the same age, as well as the rapid growth of bone length during early childhood and puberty, affects the measured bone density value. Therefore, instead of T-scores being used to make a diagnosis, you may hear the doctors discussing Z-scores as these will compare your child's BMD to that of children of the same age and sex. Z-scores of -2.0 or lower are defined as either "low bone mineral density for chronological age" or "below the expected range for age". It is important that, even with Z-scores, an appropriate correction for body size is made if your child is small for their age in order to avoid an underestimation of their "true" bone density.

It is also worth noting that a diagnosis of osteoporosis in your child cannot be made on DXA BMD measurements alone. Key to the diagnosis will be the presence of a clinically significant fracture history.

Most cases of osteoporosis in children are likely to be discovered by investigating the problems they are

experiencing. Examples may be x-rays to investigate pain or a fracture that has occurred very easily (perhaps as a result of a minor injury), or the result of a consultation with a specialist to look into the reasons why they are having difficulty with walking. When a diagnosis of osteoporosis is suspected, more specific investigations are likely to be used. These can include:

- X-rays to examine the whole skeleton for fractures
- Bone density scans (DXA), usually of the whole body or of a specific area such as the spine, to assess the bone density
- Other types of scan are sometimes used, such as quantitative computerised tomography (QCT)
- Bone biopsies which look at the internal structure of the bone in more detail

What are the treatment options?

If your child has been diagnosed with osteoporosis, treatment is not clear-cut as the severity of each case and response to treatments may well differ from child to child. Therefore their management and care will come from a team with specialist expertise in paediatric bone health. For some children with secondary osteoporosis, the emphasis is on treating the underlying cause through the appropriate use of medication to help treat or prevent their original condition from worsening. However, if your child has secondary osteoporosis and the treatment of the underlying condition is not thought to be enough to sort out the bone problems (e.g. they are having repeated long bone fractures or spinal fractures) or if they have primary osteoporosis, they may need other medical treatment specifically to improve their bone strength and reduce the risk of having further fractures.

As the numbers of children affected are low, research trials to support the information about treatments and how well they work are limited. A specialist will make an individual assessment of your child before making any decisions about possible treatments. In some cases your specialist may decide to use smaller amounts of the drugs that are used for adults, especially if your child has been severely affected with fractures. This includes the use of drugs such as bisphosphonates (risedronate, pamidronate or zoledronic acid) which affect certain bone cells and the on-going process of bone maintenance and renewal.

Vitamin D may also be prescribed to improve your child's ability to absorb calcium. All children with osteoporosis will be advised to ensure they have a well-balanced, calcium-rich diet (for more information please see our booklet *All about Osteoporosis*).

Weight-bearing exercises (activities such as walking or running about) generally help to strengthen bones, although naturally this may be difficult if your child has weak bones or has been affected by fractures. They will need to have an individualised exercise plan to ensure they receive intensive and/or specialist physiotherapy which has been tailored to meet their needs and physical ability.

It is likely that the doctors will want to monitor your child's progress in some way. This could be by follow-up x-rays or scans (DXA or QCT) at set intervals. They may also use biochemical markers of bone turnover (specialised urine or blood tests) that can be used to assess how well your child is responding to medications that they have been given.

What does the future hold?

It is important that children at potential risk of fractures caused by secondary osteoporosis are identified early as the acute stages of childhood osteoporosis can affect their growth. This in turn may have an impact on their size as they continue to grow, (although some may catch up in time). Additionally, changes in the shape of the back or limbs and physical limitations as a result of fractures can have an impact on your child and your family as a whole.

If your child has secondary osteoporosis (i.e. osteoporosis caused by another condition or its treatment) the outcome will often largely be dependent on the management and progression of the original disease which caused it in the first place.

If your child has primary osteoporosis most forms are life-long although the frequency of fractures will often decrease as they enter adulthood.

For children with IJO, (where there is no other underlying cause), the outlook may be more encouraging as usually the disease process ends when they get older, and particularly as they reach puberty. But please remember that they may be left with problems as a result of their earlier fractures, and their BMD may be slow to recover.

What help and support is available?

There is lots of help available for you and your child to help you cope with the pain and fractures caused by the condition. This ranges from financial help (in the form of Disability Living Allowance which converts into Personal Independence Payments when your child reaches 16, tax credits and Carer's Allowance), practical help from social workers and other health professionals, to equipment and aids to living.

If your child has a physical or chronic medical condition (including secondary osteoporosis), additional arrangements and support in school may also be needed. Schools have a number of stages of support available for children with special educational needs, the first two are 'School Action' and 'School Action Plus' which follow guidance set out in the Special Educational Needs Code of Practice. The support required is usually described in an individual education plan, however a small number of children may need additional help that only a statutory assessment will identify. This can sometimes lead to a Statement of Special Educational Needs which is a legal document issued by the Local Authority. This sets out your child's particular educational needs and identifies how these needs can be met. The school support and financial help available to you may differ slightly between England, Scotland, Wales and Northern Ireland so make sure that the information you are given is relevant to your geographical area.

As children and young people generally do not like anything that makes them feel "different", interventions should be as unobtrusive as possible. Getting the balance right between reducing fracture risk and not being overly restrictive can be a challenge. Your child's specialist nurse or physiotherapist can help to advise the school on how best to include them in as many P.E based or other physical activities as is safely possible.

Healthcare professionals and social workers are on hand to help and advise you but it can be very difficult to work your way through this system. Charities such as the Brittle Bones Society, SCOPE, Strong Bones and Contact a Family (see useful contacts) have a wealth of knowledge and experience in this area, so please make use of their resources.

The National Osteoporosis Society may be able to link you with other families in a similar situation as we have a small network of helpline volunteers who offer peer support. If you are interested, please contact the helpline for more information and contact details of our volunteers.

Useful contacts

The Brittle Bone Society

The sole UK charity supporting people with Osteogenesis Imperfecta (OI). They also provide advice, signposting and information which is relevant to children with osteoporosis.

Grant-Paterson House
30 Guthrie Street
Dundee DD1 5BS

Tel: 01382 204446

www.brittlebone.org

SCOPE Response

Offers free, impartial and expert information, advice and support to disabled people and their families.

PO Box 833

Milton Keynes

MK12 5NF

(please enclose a SAE if you send a letter and need a reply)

Freephone Helpline- 0808 800 33 33 (text phone available)

Email: response@scope.org.uk

www.scope.org.uk

Strongbones Children's Charitable Trust

A national registered charity set up to help alleviate the pain, suffering and financial burden of families who have children with bone problems.

Unit B9

Romford Seedbed Centre

Davidson Way

Romford

Essex

RM7 0AZ

Tel: 01708 750599

www.strongbones.org.uk

The **National Osteoporosis Society** is the only UK-wide charity dedicated to improving the prevention, diagnosis and treatment of osteoporosis and fragility fractures. The Charity receives no Government funding and relies on the generosity of individuals to carry out its vital work.

For osteoporosis information and support contact our Helpline:

 **0808 800 0035**

 **nurses@nos.org.uk**

To become a member or make a donation:

 **01761 473 287**

 **join online at www.nos.org.uk**

To order an information pack or other publications:

 **01761 471 771**

 **info@nos.org.uk**

or download from our website at www.nos.org.uk

Contact a Family

National charity that exists to support the families of disabled children whatever their condition or disability.

209/211 City Road

London EC1V 1JN

Freephone Helpline 0808 808 3555 (text phone available)

www.cafamily.org.uk

This fact sheet is one of a range of publications produced by The National Osteoporosis Society. If you would like more general information about osteoporosis see our booklet *All about Osteoporosis*.

This information reflects current evidence and best practice but is not intended to replace the medical advice provided by your own doctor or other health professional.