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Osteoporosis in children

What is osteoporosis?

Osteoporosis literally means 'porous bones'. It occurs when the struts which make up the mesh-like structure within bones become thin causing bones to become fragile and break easily following a minor bump or fall. These broken bones are often referred to as fragility fractures. The terms 'fractures' and 'broken bones' 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.



**Strong
dense
bone**



**Fragile
osteoporotic
bone**

Osteoporosis in children

Bone is alive and constantly changing. Childhood and the early adult years are a very important time for our skeletons as it is during this period that rapid bone growth occurs increasing both its size and strength.

Osteoporosis in children or teenagers is an uncommon condition. When it does occur it is usually as a result of one of several different medical conditions, or the medications that are used to treat them such as corticosteroids. However, on rare occasions when no underlying illness or disease is identified, a diagnosis of idiopathic juvenile osteoporosis (IJO) may be made.

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

This leaflet covers specific information on osteoporosis in children. If you would like more general information on osteoporosis, please ask us for a copy of our publication *All About Osteoporosis*.



Osteoporosis that occurs as a result of another illness, disease or its treatment is called secondary osteoporosis. Causes of secondary osteoporosis in children include:

- Inflammatory conditions (such as juvenile arthritis or Crohn's disease).
- Anorexia nervosa.
- Long-term, high-dose oral corticosteroid treatment (often used for conditions such as asthma or arthritis).
- Osteogenesis imperfecta (OI) – a genetic disorder that affects the collagen which is an important part of bone.
- Conditions causing immobility (such as cerebral palsy or spinal cord injury).
- Idiopathic juvenile osteoporosis. This is when bone density loss is observed in a previously healthy child or teenager that seems to have occurred for no apparent reason. IJO tends to occur in children from the ages of seven to the early teens and is extremely rare, affecting less than 100 children in the UK.



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.**
- **Fractures (broken bones) in the long bones of the skeleton and in the spine.**
- **Curvature of the spine, or a height loss where the bones in the spine have become squashed or misshapen due to fractures.**

How would it be diagnosed?

Most cases are likely to be discovered initially through investigations into the problems that the child is suffering with. Examples of this may be x-rays to investigate pain or a fracture that has occurred very easily (rather than as a result of an injury), or that result from a consultation with a specialist to look into the reasons why a child is having difficulty walking.

Once a child has been diagnosed with osteoporosis, more specific investigations are likely to be used. These can include:

- X-rays to examine the skeleton for fractures.

- Bone density scans, sometimes of the whole body or of a specific area such as the spine, to assess the degree of bone density loss. These are called dual energy x-ray absorptiometry (DXA).
- Sometimes other types of scan are used, such as quantitative computerised tomography (QCT or CT).
- Bone biopsies can also be used to look at the internal structure of the bone in more detail.

What would the treatment be?

Treatment of childhood osteoporosis is not clear-cut as the severity of each case and response to treatments may well differ from child to child. Most children with osteoporosis will be advised to ensure they have a well-balanced, calcium-rich diet (for more information see our leaflet *Healthy bones – facts about food*) and do plenty of weight-bearing exercise (activities where they are on their feet walking or running about).

Some children may need a specific medication to help prevent their condition from worsening. Children who have osteoporosis as a result of another medical condition or its treatment (for example, children who need to use steroid tablets for asthma) and some children who

Most children with osteoporosis are advised to do weight bearing activities.



have had several fractures may need drugs that affect the cells inside the bones.

As the numbers of children affected are low, research trials to support the information about treatments and how well they work are limited. Any decisions about treatment need to be made on individual assessment of the child concerned by the specialist. Some specialists may decide to use smaller doses of some of the drugs that are used in adults, such as a bisphosphonate (drugs that affect the bone cells and the ongoing process of bone renewal) or forms of vitamin D to influence the body's absorption of calcium. Physiotherapy may also be a feature in the treatment of these children.

It is likely that the doctors will want to monitor the child's progress in some way. This could be by follow-up scans (DXA or QCT) at intervals and possibly with a bone biopsy at some stage. Biochemical markers of bone turnover are specialised urine or blood tests that can show how well a person is responding to the medications they have been given, and these may also be used to monitor a child's progress.

What does the future hold?

The acute stages of childhood osteoporosis can affect a child's growth and this may have an impact on their size as they continue to grow, although some may catch up in time. The possible change in shape and disability that others may experience due to fractures may be permanent.

For children who have secondary osteoporosis (where this has been caused by another condition or its treatment), the future outcomes will be dependent on the management and progression of that other disease. For children with IJO, where there is no other underlying cause, the outlook is generally quite encouraging. It seems that as children get older the disease process gradually ends, and the child recovers after a few years.

What help and support is available?

There is lots of help available for children and their parents and carers affected by the disease. This ranges from financial help in the form of disability living allowance and invalid care allowance, assessments and statements in school environments, practical help from social workers and other health professionals, to equipment and aids to living.

The Education Act of 1996 tries to ensure that, wherever practical, children with special educational needs can be educated alongside their peers rather than in a special school. To ensure that the needs of the child, the school and the other children are all cared for, the local authority may need to carry out an assessment to look at the situation. This may then result in a statement about the child's requirements and how they are best met. This is an official procedure and parents have the right to put forward their views and appeal against the decisions made.

Healthcare professionals and social workers are on hand to help and advise parents and carers of children with conditions such as osteoporosis. Healthcare professionals such as doctors and nurses can help with the medical aspects of a child's care and social workers can guide parents and carers through the benefits system and other aspects of social welfare.



Useful contacts

Contact a Family

209/211 City Road
London EC1V 1JN

Tel: 0808 808 3555 (freephone helpline or
0808 808 3556 Textphone open 10am-4pm,
Monday-Friday)

www.cafamily.org.uk

The Brittle Bone Society

Grant-Paterson House
30 Guthrie Street
Dundee DD1 5BS

Tel: 08000 282459 (freephone helpline
open 9.00am-4.30pm, Monday-Friday)

www.brittlebone.org

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Our publications are free of charge but we would welcome a donation

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 **01761 473138**

 **www.nos.org.uk**

Factors which can help to maintain healthy bones are a well-balanced diet with adequate calcium-rich foods; regular weight-bearing exercise; avoiding smoking and keeping alcohol consumption within the recommended limits.

