



# INTRAVENOUS BISPHOSPHONATES

## Frequently asked questions



### Introduction

This leaflet provides you with answers to questions that children and families often ask about bisphosphonates. If you have any more questions after reading this leaflet then it might be helpful to write them down and discuss them with the doctor or nurses helping you care for your child.

### What are bisphosphonates?

Bisphosphonates are a group of medicines used to treat conditions that affect bones. They are sometimes used to make bones stronger (e.g. in osteogenesis imperfecta or other types of osteoporosis), to treat pain coming from bones or when there is a high level of calcium in the blood.

The two bisphosphonates prescribed for children in the UK and Ireland given through a vein (intravenous treatment) are zoledronic acid and pamidronate.

### How do they work and what do they do?

In the body there are cells that make bone (osteoblasts) and those which take it away (osteoclasts). Bisphosphonates work by slowing down the cells which take away bone. So, overall, the body is left with more bone which is then stronger.

Often bisphosphonates are given to children when one or more of the bones in their back (vertebrae) have lost height because the bone is weak. Treatment can protect them from further damage and allow them to regain their shape and size as the child grows. Bisphosphonates strengthen all the skeleton, so treated children are less likely to suffer a broken bone (fracture). Treatment can help with pain from bones and improve stamina. Altogether these things can allow a child to do more and be more active; activity is good in itself and helps the bones get even stronger.

### Can my child take other medicines at the same time as being on bisphosphonates?

Although it is unusual, bisphosphonates should sometimes not be taken with other medicines. Make sure that your doctor knows of any medicines that your child is taking, including ones that you have bought yourself.

### How is the treatment given to my child?

On the day of treatment you will come to hospital and your child will be seen to make sure that they are well enough to have the treatment. A thin plastic tube called a cannula is put into the vein using a small needle; some anaesthetic cream is often put on beforehand to help numb the area. The bisphosphonate medicine is given through the cannula as a “drip” from a bag of fluid. An infusion will usually last between 30 minutes and 4 hours and, depending on the treatment, will be given either as one infusion or two to three over the same number of days. Treatment is usually repeated every few months.

### How is the effect of treatment monitored?

As well as blood tests taken at the time of treatment, urine samples are sometimes needed. Imaging of the back is sometimes done to see the effect of treatment on the spine. The amount of bone in the skeleton can be measured using dual energy x-ray absorptiometry (DXA) scans, depending on the age of the child. The most important way in which treatment is monitored is by seeing members of the team caring for your child’s bone problems.



## How long will my child need treatment?

The length of time a child is treated differs from child to child and depends on the reason they are being treated. Decisions about which bisphosphonate is given, how much, how often and for how long are taken together with the team caring for your child's bone problems.

## What are the side-effects?

Children usually cope with bisphosphonate treatment very well. A common side-effect is a "flu-like" reaction that often happens in the few days after treatment. Children get a high temperature, aching and sometimes feel sick. This "flu-like" reaction normally only happens after the first (and sometimes second) dose.

As with any medicine, rare side-effects can happen. A small number of children have mild allergic reactions but these can often be treated with antihistamines. Joints or muscles may ache in the first couple of weeks. This can normally be treated with simple painkillers such as paracetamol but if it carries on you should let your doctor know. Very rarely, children can get inflammation in the eye e.g. redness, pain or changes to vision. If this happens or if your child already has a problem with their eyes then let your doctor know.

There are some reports of kidney problems after treatment. Although this risk is very small in children, it is important to make sure that a child has plenty to drink before and during treatment

## What about calcium and vitamin D?

Calcium and vitamin D are needed for strong bones. It is important that your child has a normal vitamin D level and that they are getting enough calcium in their diet (mostly found in foods such as milk, cheese and yoghurt). Doctors will sometimes prescribe

calcium and vitamin D when a child is on bisphosphonate treatment. This will help keep the level of calcium in the blood normal after the first dose of treatment.

## Can bisphosphonates cause any problems with my child's teeth?

Your child should have regular check-ups of their teeth by a dentist. It is very important that teeth and gums are kept healthy (e.g. regular brushing). You must tell the dentist if your child is on bisphosphonate treatment and let them or your doctor know if there is pain or swelling in the mouth. If your child's teeth or gums are not healthy then they should be seen by a dentist before starting treatment.

Part of the reason for keeping the teeth and gums healthy is that for **adults** on treatment there is a very small chance of getting something called osteonecrosis of the jaw (ONJ). This is when a part of the jaw bone can die. In adults it usually happens to someone who already has cancer and/or has poor dental hygiene. **ONJ is rare in adults and currently has never occurred in a child or teenager on bisphosphonates.**

## Are there any other concerns about the effect of bisphosphonate?

As bisphosphonates work by "sticking" to bone, a small amount stays in the body for years. In some ways this is helpful but it has led to some other concerns (see below). However, most of these concerns are not supported by scientific evidence nor by the experience of the doctors and nurses who care for children with bone disease.

## Bisphosphonates do not affect healing after a broken bone.

Sometimes healing after orthopaedic operations may be slower in children who have had bisphosphonates but this does not usually cause a problem. It is important to let your medical team know if your child is going to have any orthopaedic operations.

An unusual and rare type of break in the thigh bone (a so-called "atypical femoral fracture") may be more common in elderly people who have been on treatment for a number of years.

**There is no good evidence that this is the case in children.**

There is no evidence that the unborn child is affected if a girl on treatment gets pregnant. However, it is strongly advised that a girl on treatment should be using a reliable form of contraception if sexually active. **Treatment should be stopped if they do become pregnant.** If a young person is not sure whether they are pregnant then a pregnancy test can be performed when they come to the hospital for treatment.

Although this treatment has been used safely in children since the 1990's and has become standard of care for many children with osteoporosis, the longer term side-effects are still unknown.

## What do I do if I have any concerns after treatment has been started?

If you have any questions or worries about treatment before or after it has started then speak with your doctor or another member of the team caring for your child's bone problems.