



# Pregnancy and Osteogenesis Imperfecta

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This factsheet gives information about what to consider if you have OI and are planning a pregnancy.

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Many women with Osteogenesis Imperfecta (OI) have children without any significant problems in pregnancy. But there are a few things to consider, and planning can make things much easier.

The main things to consider are:

1. The best time for you to become pregnant.
2. How your body will manage to carry a baby.
3. Keeping your bones as healthy as possible before and during pregnancy.
4. What the best delivery options are.
5. Whether your baby will have OI.

For women with OI it is recommended to talk to your doctor before becoming pregnant if possible. The wide variation in OI symptoms, and wide variation in pregnancy experiences in all women, make it difficult to predict how pregnancy will affect a woman with OI, but your bone doctor can give you advice, and refer you to ante-natal clinic and genetics for assessments before and during pregnancy.



Personal health and OI-related issues which may cause difficulties and could be important to discuss are; short stature; a history of pelvic or spine fracture; and a history of respiratory compromise.

[See the BBS factsheet Information on OI.](#)

## Pre-conception

Ensure you have a healthy intake of calcium (1000mg a day) and vitamin D (800-2000 units a day) and healthy body weight. You can check your calcium intake using [The Royal Osteoporosis Calcium calculator.](#) Other important lifestyle choices include stopping smoking. The safest approach is not to drink alcohol at all to keep risks to your baby to a minimum.



## Bisphosphonates and Pregnancy

Bisphosphonates should not be used in pregnancy, and women should not become pregnant while they are taking Bisphosphonates.

- Babies can be born with bone problems or low calcium levels,
- There is no good evidence to decide which Bisphosphonate is better to use in women who might want to have a baby soon (ie Pamidronate, Zoledronate, Risedronate)
- Ideally, stop Bisphosphonates about a year before becoming pregnant
- Unplanned pregnancies happen, and problems are very rare. Talk to your bone doctor as soon as you can.

[Please refer to the BBS Bisphosphonate factsheet for more information on Bisphosphonates.](#)

## Genetic Counselling

For the common types of OI, a mother or father with OI has a 50 percent chance of passing on OI to each child (like tossing a coin). The risk would be the same regardless of whether this is your first or later child or the sex of the child. So if you have four children, you may have two with OI and two without OI. But in the same way that you can toss a coin heads or tails four times in a row, you could have four children with OI or four children without OI.

The risk is different in less common forms of OI. If you want to know more about the risk of your children having OI, you can see a genetic specialist, and your bone doctor or GP can make this referral for you. This should be ideally done before your pregnancy (pre-conception) or during your pregnancy (antenatally).



A genetic counsellor can provide information on OI genetics and testing. If the gene causing OI in the parent can be found, there may be options to have IVF and select embryos without the OI gene (preimplantation genetic testing), or to have the baby tested for OI during pregnancy.

Having testing during pregnancy does not mean you have to consider pregnancy termination, but the information may be useful in managing pregnancy and delivery.

## Post Conception

### Prenatal diagnosis

There are three techniques for testing a baby for OI during pregnancy:

- Ultrasound
- Chorionic villus sampling (CVS)
- Amniocentesis

These techniques may not detect OI in 100 percent of cases.

Individualised assessment by a genetic counsellor and/or geneticist is necessary to determine which techniques are most useful for a particular pregnancy. It is also recommended that couples discuss their genetic history with the obstetrician. You may want to make arrangements, prior to the due date, to have a cord blood saved for DNA analysis.

[Please refer the BBS Genetics factsheet and podcast on genetics.](#)

## Antenatal Care

Lots of women with OI have children. However, given that OI is a rare disorder, it may be difficult to find an Obstetrician with experience in treating women with OI. However Obstetricians are specialists in more complex pregnancies, whatever the cause. If you are currently under a Specialist Bone Team, the Obstetrician may wish to liaise with your OI consultant and a multi-disciplinary approach to care may be required.

If you are not under a Bone Team and have not discussed becoming pregnant with anyone prior to becoming pregnant you should book an appointment with your GP and/or Midwife. A woman with a pre-existing condition or where there may be reason to suggest pregnancy complications should expect to be put under Consultant-led specialist care, but you will still see your midwife on a regular basis. If you have mild OI, your obstetrician may just see you once to make a plan, then refer you back to midwife-led care.



## Concerns of Women with OI During Pregnancy and Labour

Many women with OI have no problems in pregnancy.

It is quite common to have some back pain, and ligaments become more loose in pregnancy which can cause pelvis and joint pain.

Women who have short stature, spine or rib problems may get more breathless as the baby grows and may need respiratory monitoring or an earlier delivery.

Fracture risk probably is higher during pregnancy, delivery and post-partum. There is also a slightly increased risk of bleeding during labour.

Women with a history of easy bruising, recurrent nosebleeds or bleeding tendencies following previous surgeries may be more susceptible to excessive bleeding after delivery. Blood coagulation and platelet tests may be undertaken prior to the delivery date as a precautionary measure. Potential anaesthesia concerns for women with OI include hyperthermia (raised body temperature), or difficulties giving epidurals epidural due to spinal curvature or old fractures.

It would usually be recommended that you have frequent scans to monitor the baby's growth and bones.



## Looking after yourself

The baby will use the calcium from your diet to build their own bones, so it's important that you get enough calcium. Talk to your doctor about your diet, and whether you might need a supplement.

All women have a small decrease in bone density during pregnancy and breastfeeding, which does recover over about 12 months, so it's important to keep up your calcium intake after pregnancy too.

Keep active – gentle exercise is good to keep muscles and bones strong for pregnancy, delivery, and looking after the baby when they arrive. If you're not sure what you can do, talk to your doctor, physio or midwife.



## Intrapartum Care and Delivery Planning

In general, decisions about the best mode of delivery (vaginal vs. caesarean) should be made on an individual basis. For example; if you've had pelvic fractures, a caesarean might be the best option.

It has been suggested that caesarean section is less traumatic than vaginal delivery for babies who have OI, however, there is no data to confirm that this assumption is correct. Studies of fractures in pregnant women and babies don't show any clear benefit of caesarean over vaginal delivery.

Obstetric and neonatal teams are experts in looking after tiny delicate babies.

## Postnatal

The neonatal team will check the health of your baby, and usually recommend that they are seen by a bone specialist. It can be difficult to tell whether very young babies have OI, but the bone team will give you advice on what follow-up your baby needs.

## Contraception

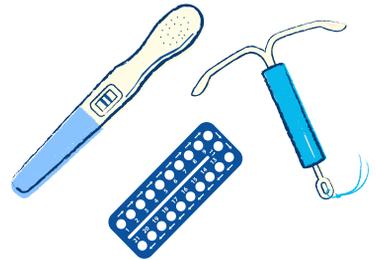
You can get contraception advice from your midwife, GP, bone team or sexual health clinics.

The recommended long-acting methods of contraception for women with OI which are reliable and reversible include:

- Progesterone implant
- Mirena coil
- Copper coil

Other hormonal methods of contraception include:

- Combined pill
- Progesterone-only pill (mini-pill)
- Patch

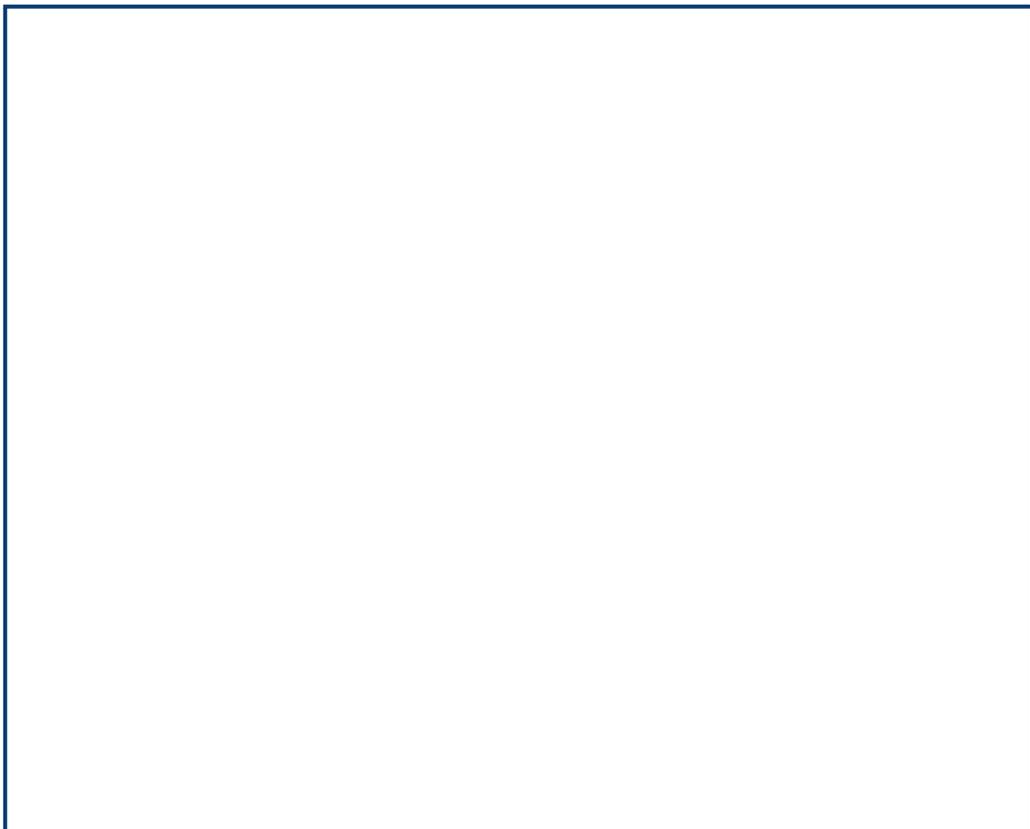


Again, these methods are very reliable so long as they are taken as per medical instructions.

We would advise against using Depo-Provera injections, because they can cause a decrease in bone density in young women.

Remember that hormonal methods and coils don't protect from infection. If needed, use a barrier method too.

## Notes



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