

Working to relieve the pressure!

Idiopathic Intracranial Hypertension (IIH) is often described as a condition affecting “overweight women of child bearing age”, and statistically, it is women who fall into this group who most often develop IIH. The majority of IIH sufferers are women but men and children can also be affected. There are particular issues for women with IIH regarding contraception, pregnancy, and hormone replacement therapy (HRT).



Contraception



'Idiopathic' means 'no known cause', however, there are many medications and other substances that are known or suspected to cause increased intracranial pressure. Studies over the years have shown that hormonal treatments including some contraceptive pills, associated hormone treatments and growth hormones, various types of antibiotics, and even vitamin A have a connection with the development of IIH.

Oral contraceptive pills containing oestrogen have been closely linked with IIH and as such should be avoided. Similarly other forms of contraception that involve hormones, including some intrauterine devices (coils) should also be avoided. The Depo-Provera injection contains a synthetic form of the naturally occurring female sex hormone, progesterone. Progesterone has been found to be safe for women with IIH.

Some women with IIH who have were on the oestrogen based oral contraceptive pill and stopped taking it found their IIH symptoms have significantly improved. Put simply, though the oestrogen contraceptives pill may be convenient, given the dangers of the use of hormones in women diagnosed with IIH, it really is best avoided. Talk to your GP or local family planning doctor about the other choices open to you because of your IIH.

Pregnancy and IIH

A diagnosis of a chronic condition such as IIH can be bad enough, but then to be told it's linked to the contraceptive pill and hormones, and that pregnancy could make your IIH worse can be a double blow. Some women have been told that they won't be able to have children due to their IIH.

This simply isn't true, as many happy parents who've had children since being diagnosed with IIH will testify. They have had healthy children with no serious effect to their own health.

You should always tell your obstetrician and midwife you have IIH, and tell your neurologist that you're pregnant, or if there's a possibility you might be pregnant. Pregnancy affects the medication your doctor can safely prescribe for you, consult your neurologist if you're thinking of starting (or expanding!) a family.



Does pregnancy cause IIH?

There's no evidence that pregnancy causes IIH. Research has shown no difference in the incidence of IIH in pregnant women compared to women their age who weren't pregnant.

As there is a link with IIH and hormones, sometimes IIH is first diagnosed or flares up during pregnancy, but with monitoring and the right treatment, pregnancy shouldn't be too much of a problem with IIH.

Is it safe for me to get pregnant if I have IIH?

If you have IIH, there are some specific issues with pregnancy, and ideally you should consult your doctor about becoming pregnant before starting, or expanding, your family.

If your IIH isn't well controlled your doctor may recommend that you wait until your health is more settled. Most women with IIH have no problems during pregnancy. However, it's better if the pregnancy is planned, so that you and your doctors can agree the best course of treatment for you.

Patients with IIH do not have an increased risk of miscarriage. It's true that the hormones associated with pregnancy can increase intracranial pressure, and therefore the symptoms of IIH (though some people find their symptoms do actually improve during pregnancy), working with your doctor, you should be able to manage these.

Working to relieve the pressure!**Monitoring**

Monitoring during pregnancy is important for everyone. For IIH patients, coming off diuretics can lead to a rise in intracranial pressure and severe visual problems. Your pregnancy may be classed as a 'high risk', if your vision isn't stable and your symptoms aren't well controlled. You should be monitored very closely, having regular neurological and ophthalmological (vision) assessments.

Diuretics and pregnancy

Diamox (Acetazolamide) is classified as a "Category C medication", which means that its safety for use during pregnancy hasn't been verified.

Ideally you should take as little medication as possible when pregnant, as many drugs can be passed to the baby, however you shouldn't stop taking any medication without first discussing it with your doctor.

Some doctors feel that Diamox can affect the production of amniotic fluid, and Diamox has been linked to developmental problems with animal foetuses when used in early pregnancy in large dosages (Lee, et al, 2005). Studies with humans have found no adverse effects, but doctors recommend that Diamox shouldn't be used in the first trimester of pregnancy. Other types of diuretics - glycerol and thiazide diuretics, should not be used in the second half of pregnancy because of the risk of decrease in placental blood flow. Short courses of steroids can be used to protect vision and help to control symptoms.



Tricyclic antidepressants should also be avoided, as should valproate and some of the anti-seizure medications that are used for headache prevention. As always you should discuss your options with your doctor before stopping taking any medication.

Lumbar punctures and pregnancy

It's perfectly safe to have lumbar punctures throughout your pregnancy if you need them. The biggest danger in stopping diuretics is the danger of intracranial pressure rising and causing serious visual problems, but performing regular lumbar punctures, to control symptoms or protect vision, is perfectly safe both for you and your baby.

Shunts and pregnancy

It is perfectly safe for patients who have shunts in place to become pregnant, although patients with lumbar peritoneal shunts should be monitored closely in case the shunt becomes dislodged due to the growing uterus.

Ventriculo-peritoneal shunts can be fitted during pregnancy if needed to save vision, and optic nerve sheath fenestrations can also be performed. If you're in a situation where your vision is being severely affected, you should discuss your options with your neurologist / neurosurgeon / ophthalmologist and obstetrician.

Caesarean births

Most women with IIH will have no problems during their pregnancy. There is no need for a caesarean based only on having IIH. Going through labour and having a natural delivery isn't a problem. If a caesarean section is needed for another reason, there is no problem with having surgery or anaesthetics.

Hormone replacement therapy (HRT)

In common with some oral contraceptives, many hormone replacement therapy (HRT) treatments contain oestrogen. Oestrogen has been linked with IIH, but in low doses some doctors consider HRT to be safe for IIH patients, providing they are closely monitored. Other doctors disagree, and do not recommend HRT. While HRT, in addition to alleviating menopausal symptoms, has protective properties, protecting against osteoporosis and colon cancer, research in the USA (Mayor, 2002) suggests that long term use of HRT causes an increased risk of breast cancer, stroke, and pulmonary embolism. Menopausal symptoms can be very draining and debilitating though. It may be worth talking to your doctor about natural and non-pharmaceutical ways to manage your symptoms.