



Factsheet

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Pregnancy in acute porphyria

Although nearly all pregnancies for those with an acute porphyria, i.e. AIP, ADP, VP or HCP, are uneventful, there is a very small risk of having an acute attack during or after pregnancy. It is therefore vital that the doctors providing care during pregnancy know that you have an acute porphyria.

Why is there an increased risk of attacks?

Pregnancy is associated with increased levels of hormones such as progesterone, which may aggravate porphyria, however attacks caused in this way are uncommon.

The major risk is that some of the medications used in pregnancy are unsafe for those with acute porphyria, and could be prescribed inadvertently either during the pregnancy or delivery period.

It is important that the SAFE drugs list is always adhered to and advice is sought from a porphyria specialist or the UK Porphyria Medicines Information Service (UKPMIS). The SAFE drugs list can be downloaded at www.wmic.wales.nhs.uk/porphyria_info.php – UKPMIS can also be contacted by telephone on 029 2074 3877 or 029 2074 2251.

If you have a porphyria specialist, they may liaise with the obstetric team to ensure that your file contains a list of SAFE drug options

for each of the circumstances that could occur before, during or after the birth.

Some notable drug points are:

- Safe antibiotics are readily available and can be chosen easily from the SAFE list.
- Vaccines such as whooping cough are safe.
- Prostaglandins given intravaginally are safe, e.g. Oxytocin (Syntocinon®, Pitocin®).
- Ergometrine and ergometrine combinations are dangerous and must be avoided.
- There are many safe opiates, epidurals and general anaesthetics on the SAFE list to choose from.

What happens if I have an attack during pregnancy?

If an attack occurs during pregnancy, it should be treated promptly and according to your normal protocol.

There is no experimental data to verify the safety of haem arginate use in pregnancy, however, it has been safely administered in pregnant women over recent years, with no ill effects to mother or baby.

What about fertility treatment?

Adapted fertility treatments may be possible, but should be administered cautiously and in liaison with an acute porphyria specialist.