HIV in pregnancy:
information for you

Royal College of Obstetricians and Gynaecologists

Setting standards to improve women's health

Published February 2005 by the RCOG
Due to be reviewed in 2007

Contents

Key points

- If you are HIV positive you should be offered specialist care and regular health checks during your pregnancy.
- If you are HIV positive you can pass the virus on to your baby:
  - through the placenta while you are pregnant
  - during the birth
  - through your breast milk.

You can greatly reduce the risk of passing on HIV to your baby if you avoid breastfeeding.

- Having anti-retroviral treatment during your pregnancy also reduces this risk. It may help your own health as well.
- You may also reduce this risk if you choose to have a planned caesarean section.
- You may also be offered medication at the time of your delivery to help to reduce this risk.
- To reduce the risk of your newborn baby developing HIV, he or she should usually be given medication for four to six weeks after birth.

About this information

This information is intended to help you if you have been diagnosed with HIV and you are pregnant or planning to have a baby. It is based on the Royal College of Obstetricians and Gynaecologists (RCOG) guideline **HIV in pregnancy** (published in April 2004) and explains the recommendations the guideline contains.

This information tells you:

- what it can mean for you and your baby if you have HIV
- what the guideline says about the most effective ways of:
  - treating you during your pregnancy and labour
  - protecting your baby from HIV in the womb, during the birth and in the first weeks of its life.

This information aims to help you and your healthcare team make the best decisions about your care. It is not meant to replace advice from a doctor or midwife about your own situation. It does not tell you about treatments for women with HIV who are not pregnant, about what you can do to avoid HIV infection before you are pregnant or about the continuing care you can expect after you have had your baby.

➢ This information was correct at the time of writing (January 2005) but this is a rapidly changing area of knowledge.

➢ Some of the recommendations here may not apply to you. This could be because of some other illness you have, your general health, your wishes, or some or all of these things. If you think the treatment or care you get does not match what we describe here, talk about it with your doctor or with someone else in your healthcare team.

About HIV

HIV is short for human immunodeficiency virus. This virus prevents the body's immune system from working properly and makes it hard to fight off infections.

HIV can be passed from one person to another through body fluids. These are:

- blood
- semen
- vaginal fluids
- breast milk.

If you have the HIV virus, this is sometimes known as being HIV positive. The drugs that are used to treat people with HIV work by blocking the action of the virus. Because HIV is what is known as a retrovirus, these drugs are known as anti-retroviral drugs. They seem to work best when three or more types are used together. This combination is known as highly active anti-retroviral therapy (HAART for short).

What could it mean for my baby?

You can pass HIV on to your baby:

- through the placenta while you are pregnant
- during the birth
- through your breast milk.

You can reduce the risk of this if you:

- avoid breastfeeding and choose other ways of feeding your baby (by using formula milk, for example)
- have treatment with anti-retroviral drugs
- choose to have a caesarean section (an operation to deliver the baby by cutting through the wall of your abdomen and womb).

➢ You will greatly reduce the risk of passing on HIV to your baby if you avoid breastfeeding.

➢ Getting appropriate anti-retroviral treatment also reduces the risk. This may be of benefit to your own health as well.

What extra antenatal care can I expect?

The RCOG recommends that all women should be offered a test for HIV early in pregnancy.

If you are HIV positive you should be offered specialist care and regular health checks. Your doctors will usually offer you anti-retroviral drugs during your pregnancy and at the birth, if you are not taking them already. This is to help prevent you passing the HIV virus on to your baby and to stop any HIV symptoms you have from getting worse.

You should be cared for and advised by a team of specialists that includes:

- a doctor who specialises in HIV
- an obstetrician (a doctor who specialises in the care of pregnant women)
- a midwife
- a paediatrician (a doctor who specialises in children's health)
- other specialists if you need them.

Screening tests

If you have a sexually transmitted or vaginal infection that has not been diagnosed and treated, it may:

- infect your baby
- affect your pregnancy
- and increase the risk of passing on HIV to your baby.

You should therefore be offered tests for vaginal and sexually transmitted infections as soon as possible in your pregnancy. The tests will usually be repeated around the 28th week of your pregnancy. You should be offered treatment if you need it.

You should be offered other screening tests, such as those for Down syndrome and/or scans for abnormalities in the baby, in the same way as women who do not have HIV.

We do not know for sure whether having amniocentesis (which means putting a needle through your abdomen and womb to take a sample of the fluid around the baby) increases the risk of passing on HIV to your baby. In theory, it is possible. If you need to have amniocentesis, or any other similar test which involves piercing the sac that lines your womb and protects the baby, you may be offered treatment with HAART (highly active anti-retroviral therapy) if you are not already taking it. This reduces the risk of the HIV virus infecting your baby.

Anti-retroviral treatment

In consultation with other members of your antenatal healthcare team, your HIV specialist will recommend those drugs he or she considers best for you. The specialist will also recommend when you should start and stop taking them. He or she will usually offer you anti-retroviral drugs for the birth, whatever method of delivery you choose.

If you are not already taking anti-retrovirals

If you do not need HIV treatment for yourself you should still be offered treatment to stop you passing on the virus to your baby. This treatment may be either an anti-retroviral drug called zidovudine or a combination of anti-retroviral drugs (HAART). Your doctor will usually recommend you start the treatment around the 28th to 32nd week of your pregnancy and continue until the baby is born.

If you are already taking HAART (highly active anti-retroviral therapy)

If you are already taking HAART your doctors will usually recommend that you continue with it. They may change the drug combination after the 13th week of your pregnancy if blood tests show it is no longer working well enough.

If you have advanced HIV

If you need HIV treatment for yourself you should be offered HAART, usually starting around the 13th week of your pregnancy. This treatment will usually be continued after the birth.

If you are diagnosed late in pregnancy

If you are diagnosed with HIV late in your pregnancy, or during labour, you should usually be offered treatment with HAART, including zidovudine, during and after your labour. The HAART treatment should continue until blood tests show whether the virus is active in your system. Your doctors may adjust your treatment after that.

What is the best way to give birth?

If you are not taking HAART, you can reduce the risk of passing on HIV to your baby by having a planned caesarean.

If you are already taking HAART, this reduces the risk of HIV for your baby. A planned caesarean may further reduce this risk. We need to do more research about the effects of planned caesarean for mothers and babies in terms of HIV transmission.

To help you to decide what kind of delivery to have, your doctors should discuss with you the specific risks and benefits, for you and your baby, of the methods you are considering.

You should be offered a planned caesarean section, usually in the 38th week of your pregnancy, if:

- you are taking zidovudine alone; or
- you are not taking HAART; or
- if the HIV virus can be detected in your blood.

If you wish to have a vaginal birth, your doctors should respect your views. They will also take account of the circumstances of any previous pregnancies and the levels of the HIV virus in your blood in deciding what method of delivery to recommend.

Whatever method you choose, a sample of your blood should be taken at the time of the birth to check the amount of the virus in your system.

What happens if I have a planned caesarean section?

You should be offered antibiotics to reduce the risk of other infections.

If you have not been taking HAART, or if the HIV virus can be detected in your blood, you should be offered an infusion of zidovudine, beginning four hours before your caesarean. The infusion delivers the drug at a steady rate through a drip (by means of a needle inserted into a vein in your hand or arm). It should continue until your baby is born and the umbilical cord has been clamped.

What happens if I have a planned vaginal birth?

You should be offered HAART treatment throughout your labour. Your doctor may also recommend that you should be offered a zidovudine drip (see previous section). If so, the drip will start when you go into labour and finish once your baby is born and the umbilical cord has been clamped.

The earlier in labour that your waters break, the higher the risk is of passing on the HIV virus to your baby. Your healthcare team should therefore delay breaking your waters for as long as possible. They should also avoid putting electrodes on the baby's scalp to monitor its heartbeat and avoid taking blood samples from the baby before it is born.

What treatment will my baby need after birth?

Your baby's umbilical cord should be clamped as soon as possible after the birth. The baby should be bathed immediately after the birth.

After the birth, your baby should usually be given anti-retroviral drugs by mouth until he or she is between four and six weeks of age.

What is the best way to feed my baby?

- You can greatly reduce the risk of passing on HIV to your baby if you do not breastfeed and do not use your own expressed breast milk. This is the single most important means of reducing the risk to your baby. If you are HIV positive, it is safer to use an alternative, such as formula milk.

Is anti-retroviral treatment safe?

Anti-retroviral drugs, including zidovudine, are generally safe, but they can sometimes have side effects including:

- stomach and digestive problems
- liver problems
- rashes
- diabetes
- fatigue (extreme tiredness)
- high temperature
- breathlessness.

Some of these side effects are similar to symptoms of pre-eclampsia (a condition that can occur in the second half of pregnancy) and of cholestasis (a liver disorder). Although pre-eclampsia is usually mild, it can cause serious problems for you and your baby if it is not detected and treated. Some evidence suggests pre-eclampsia may be more common in women who take HAART.

Zidovudine may reduce the levels of iron in your blood (this is called being anaemic) for a short time.

- Because some side effects are similar to signs of other conditions, it is important to tell your doctor or midwife straight away if you experience any unusual symptoms while you are pregnant.
- If you show any signs of pre-eclampsia or cholestasis an HIV specialist should see you as soon as possible.
- Always ask your doctor or midwife if you are worried about anything.

What if I don't have anti-retroviral treatment?

If you do not have anti-retroviral treatment there is a much greater risk that you will pass on the HIV virus to your baby.

Fewer than two women in every 100 who have appropriate treatment pass the virus on to their baby. Around 25 in every 100 HIV positive women pass on HIV if they have no anti-retroviral treatment.

Will anyone else be told about my HIV status?

All the people in your healthcare team need to be aware that you are HIV positive, so that they can provide the best care possible for you and your baby.

If you have not yet told your sexual partner that you are HIV positive, your healthcare team will encourage you to do so, in order to reduce the risk of passing on the HIV virus.

Members of your healthcare team should not tell anyone about your HIV status, without your permission. They should respect your right to confidentiality and use care and sensitivity in all situations where information about you could be disclosed to your partner or relatives.

The only exception to this is when your healthcare team thinks that, by not telling a sexual contact that you are HIV positive, you are putting that person's life at serious risk. In these circumstances, the General Medical Council says that health professionals may tell a sexual contact about a woman's HIV status. Your healthcare team must discuss this with you first. They must weigh up any risks involved for you (such as violence and/or abuse) before they decide what to do. If they decide to reveal your HIV status to a sexual contact, they must be able to show why they think this is necessary.

Is there anything else I should know?

- If you are thinking of having a baby and you or your partner, or both of you, are HIV positive, you should be offered pre-pregnancy counselling.
- If one of you is HIV positive and you are thinking of having a baby, you may wish to consider artificial insemination, IVF, sperm washing or other kinds of assisted conception. These help reduce the risks of passing on HIV.
- No treatment can be guaranteed to work all the time for everyone.
- You have the right to be fully informed about your health care and to share in making decisions about it. Your healthcare team should respect and take your wishes into account.
- The National Study of HIV in Pregnancy and Childhood monitors how many mothers pass on HIV to their baby. Doctors report all cases of women with HIV who are pregnant. These reports do not include women's or babies' names, so you cannot be individually identified. This study provides up-to-date information about treatment in pregnancy and can help us to improve care for women and their babies.

Sources and acknowledgements

This information is based on the Royal College of Obstetricians and Gynaecologists (RCOG) guideline **HIV in pregnancy** (published in April 2004 and due for review in 2007). This information was correct at the time of writing (January 2005) but this is a rapidly changing area of knowledge. The guideline contains a full list of the sources of evidence we have used. You can find it online at:
www.rcog.org.uk/mainpages.asp?PageID=106&GuidelineID=67

Clinical guidelines are written for health practitioners. They are drawn up by teams of medical professionals and consumers' representatives who look at the best research evidence there is about care for a particular condition or treatment. The guidelines make recommendations based on this evidence.

This information has been developed by the Patient Information Subgroup of the RCOG Guidelines and Audit Committee, with input from the Consumers' Forum and the authors of the clinical guideline. It was reviewed before we published it by HIV positive women in Glasgow, London and the South East. The final version is the responsibility of the Guidelines and Audit Committee of the RCOG.

Other information and organisations

Evidence-based information about HIV is available from NAM (National Aids Manual), a UK-based organisation, at: www.aidsmap.com

Other information about aspects of pregnancy and childbirth is available from the RCOG website at: www.rcog.org.uk/mainpages.asp?PageID=1271

NICE (the National Institute for Clinical Excellence) has produced evidence-based information for the public about routine antenatal care. The leaflet "Routine antenatal care for healthy pregnant women" is available on the NICE website at: www.nice.org.uk

These organisations offer support:

Positively Women
347-349 City Road
London EC1V 1LR
Helpline: 020 7713 0222
Website: www.positivelywomen.org.uk
Email: info@positivelywomen.org.uk

THT Direct
52-54 Grays Inn Road
London WC1X 8JU
National helpline: 0845 1221200
Website: www.tht.org.uk