

Information for women who are HIV-positive and pregnant

This leaflet is for women who have had a test for human immunodeficiency virus (HIV) and have been told that they are 'HIV-positive'.

This leaflet gives information about:

- being HIV-positive when you are pregnant and after you have had your baby;
- ways to reduce the risk of passing HIV to your baby; and
- the monitoring and treatment which is available to you.

There is a lot of information in this leaflet so you may want to read it one section at a time over the next few days.

What your blood test result means

An HIV-positive result means that at some time you have been infected with the HIV virus (there is information about how you can catch HIV later in this leaflet). HIV is a virus that attacks the immune system (the body's defence system). Over time, usually many years, the immune system becomes weaker, meaning that the body becomes less able to protect itself against serious illnesses.

There is no cure for HIV at the moment. However, there is treatment available to slow down and even stop the progress of the virus.

Knowing you have the infection means that you can be monitored (that is, have special health checks and blood tests), supported by a specialist team and receive treatment when you need it. This can improve your health.

HIV can be passed from mother to child. This means that without any treatment (or special steps being taken), there is a chance that you could pass the virus to your baby. This could happen during pregnancy, when you give birth or when you breastfeed.

The benefit of knowing you are HIV-positive is that by taking the steps listed later in this leaflet, there is a very good chance you can prevent passing the virus to your baby. This will reduce the chance of HIV being passed to your baby to **less than one in 100**. Without taking these steps, the chance of passing the virus to your baby is much higher.

What will happen next?

We will offer you an appointment at a specialist clinic for a full health check-up and assessment (or review) of the stage of your HIV infection. The HIV specialist will be able to answer your questions about HIV and give you support. He or she will continue to see you regularly, during pregnancy and after your baby is born.

Your midwife will also help you to plan your care and discuss your choices with you.

Monitoring the HIV infection

A number of blood tests are used to check the HIV infection. Two in particular help to decide when treatment is necessary. These are:

- CD4 count – a measure of the state of your immune system; and
- viral load – the level of HIV in your blood.

These tests will be arranged, as well as any others that are needed, and the results explained to you.

Treatment for you

All women with HIV will be recommended treatment at some time during their pregnancy and when they give birth. This is to:

- help keep you in the best health possible; and
- try to prevent the baby becoming infected during pregnancy and when it is born.

Anti-HIV drug therapy (or treatment) is sometimes known as HAART – Highly Active Antiretroviral Therapy. These drugs help stop the HIV virus reproducing itself in human cells. The drugs cannot get rid of the HIV virus completely from your body. But, by keeping the HIV at very low levels in your body, your immune system can be protected. This will reduce the risk of serious health problems which can be related to HIV. Since HAART was introduced in 1996, it has been effective for many people in controlling HIV. The long-term outlook for people living with HIV infection is now very good.

When you are offered treatment with HAART during your pregnancy, it will be discussed with you. The drugs will be tailored to your needs. After starting treatment, you will be monitored closely using blood tests and you will have regular appointments to make sure that the drugs are suitable for you. If you have any side effects, they can be dealt with. It usually depends which side effects you have, but they can often be treated with a short course of medication, or by changing the times you take your HAART.

If you have any worries, it is important that you discuss them with the HIV specialist team as they may be able to help. Remember that there is always help and support for you.

After your baby is born it may be possible for you to stop HAART. This will depend on the stage of your HIV infection. You will still need to be monitored and supported by the HIV specialist team, to make sure that if you need further treatment it can be started at the right time for you.

What your diagnosis of HIV means for your baby

If you did not know that you have HIV, you will not have been able to take steps to try and stop the virus passing to your baby. Without steps being taken, about one in four to six babies born to HIV-positive women will be infected.

If you take the steps listed below, the chance of your baby becoming infected with HIV is less than one in 100.

There are four important steps that we will discuss with you.

1 Drug treatment in pregnancy and when you give birth

2 Delivery

The risk of your baby becoming infected will be reduced if you have a planned caesarean section. However, depending on previous deliveries and how well your HIV infection is controlled near the date the baby is due, it may be possible to plan for a normal vaginal delivery. Your midwife and obstetrician will discuss this with you.

3 Feeding your baby

HIV can be passed to your baby in breast milk. Breastfeeding is not recommended to HIV-positive women in the UK because there are safe alternatives available. It is advised that you give your baby formula milk. You can discuss this with your specialist team and your midwife. In Wales, free formula is available to HIV-positive mothers from the specialist clinics from birth until cow's (or other) milk can be introduced as a drink. You should give your baby formula milk until he or she is about 12 months old.

4 Treatment for your baby

Anti-HIV medicine will be prescribed for your baby for the first four weeks after birth. This medicine will give your baby extra protection against HIV infection. Your baby may also be prescribed antibiotics.

HIV testing and treatment for your baby

As part of your care during pregnancy you will normally be offered an appointment at a paediatric (children's) clinic that has special skills in managing HIV. The specialist nurse or doctor will discuss tests and treatment for your baby with you.

By the time your baby is three months old, specialists can be 98% (that is, 98 out of 100 times) certain that if your baby has tested HIV-negative they have not been infected. But the doctors cannot say for certain they are definitely not infected until they are 18 months old. This is because your baby may carry your antibodies to HIV until they are this age. An HIV test cannot tell the difference between your antibodies (passed to your baby before birth) and antibodies produced by your child because they have HIV infection.

Who needs to know about your HIV infection?

For you and your baby to have the best care, it is necessary for you to have care from a number of specialists – for example, the HIV clinic team, obstetrician (hospital doctor) and paediatrician (baby and child doctor). Your midwife will ask you if they can share information about you with the specialists directly involved in caring for you and your baby. We will not share information with others without your permission.

We will ask you whether you want us to tell your general practitioner (GP) that you have HIV. If you prefer that your GP does not know, we will respect your wishes.

If you are in a relationship, you may want to ask your HIV specialist about how to explain your positive test results to your partner. If your partner does not know whether they are infected, you should use condoms for sex to prevent you from passing the virus to your partner. Your partner should consider getting tested for HIV.

How can HIV be caught?

- An HIV-positive mother passing the infection to her baby during pregnancy, when giving birth or by breastfeeding. If you have other children, your HIV specialist will talk to you about whether they need testing.
- Unprotected sex (that is, without a condom or femidom) with someone who is HIV-positive.
- Being given a blood transfusion or blood products containing HIV. Blood and blood products have been tested for HIV in the UK since 1985, but might not have been tested in other countries around the world.
- Sharing needles or equipment for injecting drugs with someone who is HIV-positive.
- Using unclean needles in body-piercing, tattooing or for medical reasons outside the UK.
- Being scratched by used needles and other sharp items which might have blood on them (sometimes called a 'needle stick injury').

HIV is not passed to other people through everyday social contact, for example, going shopping, being with friends and family, eating meals together or kissing.

You can get more information about being HIV-positive from the following.

- The hospital midwife who specialises in antenatal screening or the hospital doctor (obstetrician).
- Your nearest NHS sexual health clinic, listed in the phone book under GUM (genito-urinary medicine).

- You can phone your local hospital and ask for the GUM clinic.
- You may want to talk to other women who have HIV, and the Terrence Higgins Trust can help arrange this.

The Terrence Higgins Trust

Terrence Higgins Trust Cymru
435-451 Cowbridge Road East
2nd Floor Canton House
Canton
Cardiff
CF5 1JH
Phone: 02920 666 465
E-mail: info.cymru@tht.org.uk
THT Direct: 0845 12 21 200 (national helpline)

National AIDS Helpline

24-hour Freephone helpline
0800 567 123
All calls are taken by trained staff.
If they cannot answer your question straight away, they will research it and contact you with the answer.

Positively Women

347-349 City Road
London
EC1V 1LR

Phone: Helpline staffed by HIV-positive women: 10am to 4pm Monday to Friday
020 7713 0222
E-mail: info@positivelywomen.org.uk

AVERT

4 Brighton Road
Horsham
West Sussex
RH13 5BA
E-mail: www.avert.org

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