

Information for pregnant women who are HIV-positive

This leaflet is for you if you are pregnant, have had a test for human immunodeficiency virus (HIV) and have been told that you are HIV-positive.

We need to double-check this result by taking another blood sample from you. It is very unlikely that this result will be any different.

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

Your 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).

What is HIV?

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 very effective treatment available which means you can expect to live as long as anyone else.

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.

How did I catch HIV?

HIV can be caught in the following ways:

- 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.

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 ART – Antiretroviral Therapy. The drugs do not kill the virus and will not cure HIV. However, they can prevent the growth of the virus so they reduce the amount in your bloodstream (the viral load). A blood test measures the viral load. People with undetectable viral loads stay healthier longer. They are also less likely to pass HIV infection to others.

When you are offered treatment with ART 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 ART.

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 ART. 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.

How will having HIV affect my baby?

If you did not know that you have HIV, you will not have been able to take steps to try to 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

You will be recommended treatment at some time during your pregnancy and when you give birth.

2 Delivery

If your HIV is well controlled near the date your baby is due, it may be possible to plan for a normal vaginal delivery. If you have any medical problems, a planned Caesarean section may be suggested. 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. It is recommended that free formula milk is available to HIV positive women in Wales. 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.

If your baby has tested negative to the blood tests done soon after birth, and at six weeks of age and 12 weeks of age, and you are not breastfeeding, your baby should be free of HIV. But the doctors cannot say for certain that babies are 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 that I am HIV-positive?

For you and your baby to have the best care, it is necessary for you to receive 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. However, your GP will be aware of other health issues you may have and medicines you take. If they know that you have HIV, this can avoid interactions between HIV medication and other drugs they may prescribe.

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.

Where can I get more information?

- The hospital midwife who specialises in antenatal screening or the hospital doctor (obstetrician).
- Your nearest NHS sexual health clinic - you can phone your local hospital and ask for the sexual health clinic.
- You may want to talk to other women who have HIV. The Terrence Higgins Trust can help arrange this.

The Terrence Higgins Trust

Phone: 0808 802 1221 (national helpline)

Website: www.tht.org.uk

Terrence Higgins Trust Cymru

Phone: 02920 666 465

Phone: 01792 477 540

Email: cymru-wales@tht.org.uk

National Sexual Health Helpline

24-hour Freephone helpline

Phone: 0300 1237123

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 UK

Phone: 020 7713 0444 (10am to 4pm Monday to Friday)

Email: info@positivelyuk.org

Website: www.positivelyuk.org

AVERT

Phone: 01403 210202

Email: info@avert.org

Website: www.avert.org

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