



Human Immunodeficiency Virus (HIV)

This information sheet from Great Ormond Street Hospital explains the causes, symptoms and treatment of HIV and where to get help.

HIV (Human Immunodeficiency Virus) is a blood-borne virus that attacks the body's immune system. It is a life-long condition that can lead to AIDS (Acquired Immunodeficiency Syndrome).

Once inside the body, HIV hunts down CD4 helper lymphocytes (a kind of white blood cell that usually help the body fight infection) and uses them to make copy itself. In the process of multiplying it kills the lymphocytes which causes weakening of the immune system.

HIV can stay in the body for many years without showing any outward symptoms. However, gradually the number of T-cells in the blood will fall, increasing the risk of developing AIDS.

You might think in the UK we don't need to worry about HIV and AIDS any more, particularly as far as children are concerned. It's true that in Western countries the number of people living with HIV is increasing at a slower rate than 20 or 30 years ago but there is no room for complacency. There is still no cure for HIV.

Over the past 15 years, around 250 children in the UK have died from HIV. Around 1,300 children in Britain today are known to be HIV-positive, having been infected from birth.

What causes HIV?

HIV can be passed between people in blood and bodily fluids through:

- having unprotected sex
- sharing used needles (for example, drug users or tattoo artists)
- blood transfusions if the blood isn't carefully screened

Women with HIV can also pass it on to their babies either at birth (especially vaginal delivery) or through breastfeeding.

However, it's possible to drastically reduce the risk of transmitting HIV from mother to child if precautions are taken. These involve taking anti-HIV drugs towards the end of the pregnancy, opting for birth by planned caesarean section, and the baby receiving anti-HIV medication for a short time after birth and not breastfeeding.

This depends on a woman being aware of her HIV status before giving birth.

HIV testing is offered to all pregnant women in the UK but it is a woman's choice to opt out of the test. Some pregnant women refuse to have an HIV test because they do not think it is relevant to them. Yet if a woman knows that she has the HIV virus, the risk of passing it on to her child can be reduced from 30 per cent to below two per cent.



Although 17 per cent of children born to HIV positive women since 2000 are currently described as 'indeterminate' (still pending test results), 98 per cent of these children are likely to be uninfected.

What are the signs and symptoms of HIV?

Some babies will show flu-like symptoms about six weeks after infection – a sore throat, aches and a rash, for example. But others do not have any symptoms at all for many years.

This is indicative of the variety of courses HIV can take. Occasionally doctors see a baby at three months already very sick with PCP – a form of pneumonia uniquely associated with HIV – but it is equally likely that we may not see children until they are much older.

It can take from one to 10 years for HIV to develop into AIDS. Then there are periods of illness as the immune system is very weak. These can include mouth infections, herpes and shingles, cold sores and genital warts.

Once this happens, your child will start lose weight quickly and can catch diseases like tuberculosis, cancer and rare infections. By this time, their immune system can't fight back and they will die.

How is HIV normally diagnosed?

HIV can be diagnosed by a blood test although, after infection, it can take up to three months for the blood test to turn positive. Also when babies are born with

HIV, more specialised tests trying to find the HIV virus in the babies' blood may be needed. If you think a child is at risk, it's vital that they visit a GP, a sexual health clinic (GUM clinic) or a specialist HIV testing centre as soon as possible.

The sooner the HIV virus is detected the better. A child can be offered ongoing health monitoring and medicines that will help to ensure good health for longer.

How is HIV treated?

There are now over 15 different anti-HIV drugs available for children compared to just one in 1991. Used in combination, these drugs are highly effective. They work by keeping the HIV under control at very low levels in the body, which allows the immune system to recover. Although these medicines control the HIV virus, they do not cure the infection.

The combination therapy children need to keep them well means taking three different medicines once or twice a day. Side effects have been seen in those who are on it for many years. For example, diabetes has been recognised as a side-effect in adults.

Children metabolise some medication more quickly than adults, so when they are very young may need higher doses proportionally of anti-HIV drugs to achieve the same effects.

There are many aspects to caring for a child with HIV. Breathing difficulties, infections, skin conditions, developmental delay, dental problems, and difficulties with feeding leading to poor weight gain are common.



Emotional and social support

Of course, there are also many emotional and social implications of an HIV diagnosis. The stigma associated with HIV is still evident. Here at Great Ormond Street Hospital NHS Children's Trust (GOSH), we run a large family clinic where healthcare professionals offer medical, psychosocial and other support to children and their families.

Many of the families we see live in secrecy and isolation. They may agonise over what or whether to tell friends and family. It can be helpful to tell schools but is not mandatory.

Not surprisingly, parents often find it difficult to explain the diagnosis to their child and can put it off for months and even years. However older children and teenagers need to be able to talk about their HIV status, to be involved in decisions about treatment and safer sex issues.

Other family members may also be affected. As well as dealing with having HIV themselves, children often find themselves in the role of carer when a parent becomes ill or dies.

What happens next?

The outlook for children with HIV in Britain today is very good, a lot better than it was even 10 to 15 years ago. HIV is now considered a chronic life-long disease that must be controlled. We see

the evidence of this at our clinic, where children in their teens are well and show every likelihood of living into their thirties and beyond. Only one child has died with AIDS at Great Ormond Street Hospital in the last four years. Compare this to the 13 deaths we had in 1997 and you can see how things are getting much better.

Studies continue to be carried out across Europe, Africa and the USA, and it is hoped that in the future medication will be further improved.

Further help and advice

Talk to the child's doctor or health visitor.

The following organisations offer support and advice to children living with HIV/AIDS:

CWAC - Children with AIDS Charity

Tel: 020 7033 8620

Web: www.cwac.org

AVERT

Tel: 01403 210202

Web: www.avert.org

The Terrence Higgins Trust has a booklet about being pregnant and having HIV called Thinking about pregnancy. For a copy call THT on 0845 1221 200 or visit www.tht.org.uk.

The following organisations have useful websites:

- National AIDS Manual
- National AIDS Trust
- British HIV Association

Compiled by the GOSH web team

Great Ormond Street Hospital for Children NHS Foundation Trust, Great Ormond Street, London WC1N 3JH
www.gosh.nhs.uk