

Human Immunodeficiency Virus (HIV): information for families

HIV (Human Immunodeficiency Virus) is a blood-borne virus that attacks the body's immune system. HIV is considered to be a life-long condition for which there is currently no cure, leading to AIDS (Acquired Immunodeficiency Syndrome) if left untreated. AIDS is an "umbrella term" which describes the number of potentially life-threatening infections and conditions which occur when the immune system has been severely damaged by HIV. However, with appropriate management, HIV is no longer regarded to be a life-threatening or a life-limiting condition, rather it is referred to as a chronic condition. This information sheet from Great Ormond Street Hospital (GOSH) describes HIV and how it can be managed.

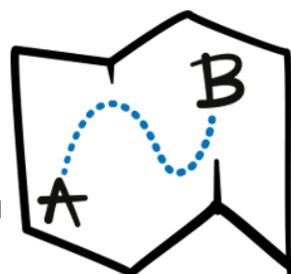
Once inside the body, the HIV virus targets CD4 helper lymphocytes (referred to as CD4 cells). The CD4 cells are particularly important because they are regarded as "captains of the body's immune cell team", instructing the rest of the immune cells on what to do in the event of an infection. In the process of multiplying, the virus kills the CD4 cells which causes weakening of the immune system. Therefore if the CD4 cells become compromised this will affect the rest of the immune system.

As the number of CD4 cells gradually declines, the risk of developing serious infections, including those associated with AIDS, is increased. However, with appropriate management, there is no reason why a person living with HIV shouldn't live a "normal" life if they take their medication as prescribed and have regular clinical reviews. In developed countries where there is access to treatment and healthcare services, the number of people living with HIV is increasing at a slower rate than it was 20 or 30 years ago, but in the absence of a cure, there is no room for complacency.

What causes HIV?

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

- Having unprotected sex, unless the person living with HIV is on treatment and has an undetectable virus level in their body
- Sharing used needles, syringes or other injecting equipment (for example, drug users or tattoo artists)
- Blood transfusions if the blood isn't carefully screened - this mainly occurs in countries without a robust Blood Transfusion Screening Programme
- Female Genital Mutilation (FGM)
- Male Circumcision in some countries if there are unhygienic practices
- Women with HIV can also pass it on to their babies either at birth (especially vaginal delivery) or through breastfeeding.



In the UK most children and young people living with HIV had it passed on from their mother.

For a mother living with HIV if their pregnancy is appropriately managed, the risk of transmitting HIV from mother to child is reduced. Data published in the UK and other European countries have shown vertical transmission rates (mother to child) of <0.5% in women on antiretroviral medications, irrespective of how they give birth (caesarean section or vaginal delivery). The appropriate precautions include taking anti-retroviral medications before, during, and after the pregnancy, and ensuring the baby receives antiretroviral medication following birth.

With the support of specialist teams, some women living with HIV have been able to successfully breastfeed without passing on HIV to their baby, although formula feeding is still the preferred method. Breast feeding should only be done with the proper support in place. 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 a woman has the choice of opting 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.

Misconceptions about HIV transmission

It has been proven that a person living with HIV who takes their medicine regularly and has an undetectable virus level cannot pass on HIV to their partner during unprotected sex. This is known as “U=U” which stands for “Undetectable = Untransmittable”.

You CANNOT pass on HIV through regular daily contact. This includes through saliva (that is, through kissing or sneezing), sweat, or urine.

What are the symptoms of HIV?

In the UK, most babies and children who are potentially exposed to HIV are appropriately screened, diagnosed, and treated so they remain well.

In settings where the health infrastructure is lacking, or where a family is not engaging with health providers, babies born with HIV may present already very sick with illnesses associated with Acquired Immune Deficiency Syndrome (AIDS).

Sometimes children living with HIV and not on treatment present with repeated or serious infections (some uniquely associated with HIV) at a later stage. These can include mouth infections, herpes simplex (cold sores) and herpes zoster (shingles). Eventually a child may lose weight and become susceptible to conditions like tuberculosis, cancers and other rarer infections (such as toxoplasmosis). If HIV is left untreated, the immune system might not be able to fight back at all, potentially resulting in death.

Many people are completely unaware they are living with HIV until they are tested or become unwell with an illness not associated with healthy people.

How is HIV diagnosed?

In the general population, HIV can be diagnosed by a blood test although, after a potential exposure, it can take up to three months for the blood test to turn positive.

Babies born to mothers living with HIV need to be screened after birth, and will have blood tests at regular intervals until they are at least 18 months old.

Rapid HIV tests are available in the community and can give a result within 15 minutes, with results being confirmed by a laboratory test with results taking 24 to 72 hours.



At GOSH, some specialties (including BMT and Rheumatology) include HIV screening as part of specific treatment protocols which will be discussed with you and your child if applicable.

How is HIV treated?

There are now more than 30 medications in six drug classes available to treat HIV. Some are not licensed for or they are not well tolerated by children. Each class of drug attacks HIV in a different way. Of these, there are over 15 different anti-HIV drugs available for children compared to just one in 1991, and new medications continue to be developed. 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 current PENTA, WHO and NICE guidelines state that for all who are tested and are found to be living with HIV, it is good practice for them to be commenced on treatment. Research has shown that early treatment is beneficial.

People who are not taking treatment could become unwell quite quickly or they may not develop symptoms for many years (referred to as long term non-progressors), but over time the immune system and other systems of the body are quietly being affected.

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 GOSH, we run a multidisciplinary clinic where healthcare professionals offer medical, psychosocial and other support to children, young people 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 this is not mandatory.

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.

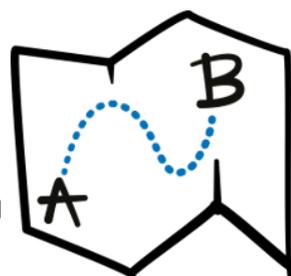
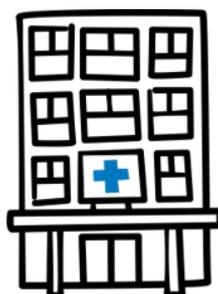
HIV and stigma

This can be described as the disapproval or discrimination against anyone on the basis of 'difference'. This difference can be visible or perceived, and can affect someone's self-esteem and all areas of daily life, such as socialising or working. Other people may have misconceptions about the person, using dismissive, offensive or hurtful language to them and about them. This is particularly distressing from family, friends and colleagues or people in authority such as the police or healthcare staff. More information about stigma is available from Mind, the mental health support organisation.

As well as stigma from other people, it is common to stigmatise themselves. This can make someone feel negatively about the thing making them 'different' so they talk themselves down and generally feel worthless.

It can be difficult to talk to about HIV especially if a child and young person is HIV positive. How they manage their diagnosis depends of how they are told about it and when. The attitudes of their family and anyone else that matters to them will impact on their body image as well as their sense of belonging both within the family and wider society.

Children and young people living with HIV must feel good about themselves and have 'resilience'. If they see HIV as a shameful secret, then the way families disclose the diagnosis can put extra pressures on them to not mention it outside the family. In extreme cases, children and young



people may be discouraged from mentioning it outside of clinic visits. Not being able to talk about their diagnosis can have far-reaching consequences. While their diagnosis shouldn't be the only thing that defines them, they should feel able to raise concerns and ask questions as they arise.

Children's HIV Association (CHIVA) and WHO recommend telling children about their HIV at the age of six, and that most children should be told by the age of nine. This should be undertaken in an age-appropriate way at an age when children are less likely to know what HIV is already. This is an opportunity to share information and build hopes for their future, before they access any misleading information or hear about any stigma towards HIV. With other chronic illnesses of childhood, it has been shown that most children's ability to cope with their condition is best supported if they are given knowledge about it as they grow older.

A child or young person growing up living with HIV may have many questions, especially about what it is like to grow up with HIV, but may feel like they don't have someone they can approach. It is important to help children and young people understand that any reluctance of parents or carers to talk about HIV may be due to their own anxieties and experiences of living with HIV.

The CHIVA website has films for families to watch together to help children or young people to bring up the subject. They also have annual family conferences.

Most recent data on the number of people living with HIV

In 2019, 38.0 million people globally were living with HIV of whom 1.8 million were children aged up to 14 years.

The most recent estimate suggests there were 105,200 people living with HIV in the UK in 2019. Of these, around 6,600 are undiagnosed so do not know they are HIV positive.

According to Collaborative HIV Paediatric Study [CHIPS], in 2020 a total of 2,210 of children were reported to be living with HIV in the UK.

Please note that this data is collected and reported annually – for the latest figures, please visit the WHO and CHIPS websites.

What is the outlook for children and young people living with HIV?

The outlook in Britain today is very good - a lot better than it was even 10 to 15 years ago. 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.

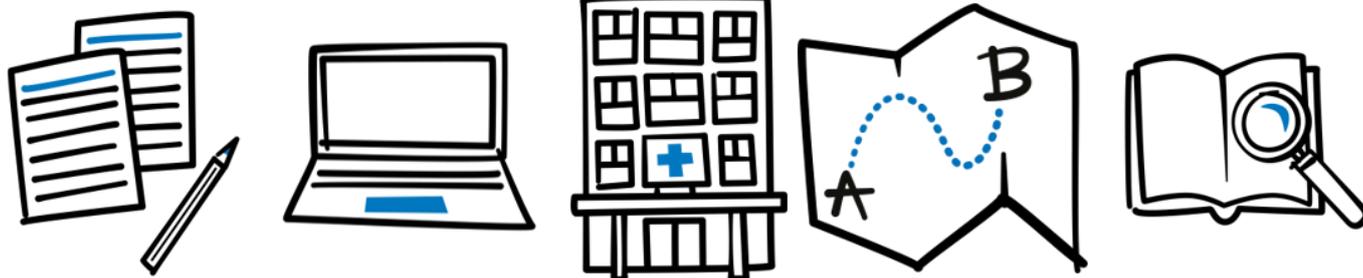
Further information and support

The following organizations offer support and advice to adults and children living with HIV.

The **Children's HIV Association (CHIVA)** contains lots of helpful information:

"Life Growing Up" video at www.youtube.com/watch?v=HHfW_uVzx8g&feature=emb_title

You can also call CHIVA on 0117 905 5149 or visit their website at www.chiva.org.uk/



AVERT is another organisation supporting children and young people living with HIV and also produces helpful information about sexuality and puberty. Call them on 01273 947 749 or visit their website at www.avert.org

Alongside You (East London) is a local organisation for families – call them on 020 7473 5050 or visit their website at www.alongsideyou.org.uk/

The **Terrence Higgins Trust** is probably the best known HIV organisation in the UK. Call their helpline on 0808 802 1221 or visit their website at www.tht.org.uk

The following organizations have useful websites:

- National AIDS Trust - World AIDS Day “Rock the Ribbon” Campaign – the 2020 campaign will be addressing the issue of “Stigma” - <http://www.nat.org.uk/>
- British HIV Association - <http://www.bhiva.org/>
- National AIDS Manual - <http://www.aidsmap.com/>
- Positively UK - <https://positivelyuk.org/>
- The Well Project - <http://www.thewellproject.org.uk/>
- Integrated Screening Outcomes Surveillance Service (Previously NSHPC) - <https://www.isoss-online.org/>
- Collaborate HIV Paediatric Study (CHIPS, soon to be CHARs) - <http://www.chipscohort.ac.uk/about/background-and-funding/>

