

HIV & You

Being diagnosed HIV positive does not mean that you are going to become ill or that you will develop AIDS. Fortunately treatment and care is available in Sheffield which can keep you healthy and well for many years.

However, to ensure you stay well you will need to attend a specialist HIV Clinic regularly for check-ups, blood tests, and to monitor your drug treatment

CD4 Count & Viral Load

- HIV infects a particular part of your immune system known as CD4 cells. The HIV virus uses the CD4 cell to make more HIV and in the process the CD4 cells are destroyed. In time the immune system becomes weak and it is unable to fight off infections.
- A CD4 count is a measurement of the concentration of CD4 cells in your blood, a normal CD4 count is between 600 and 1,500 in a cubic millimetre of blood (a drop).
- A CD4 count below 350, indicates a weakened immune system. This is the time when anti-HIV drug treatment is needed.
- If a CD4 count drops below 200, the patient is vulnerable to serious infections.
- Therefore the higher the CD4 count the less your immune system has been damaged by HIV.

Viral Load

- Viral load is the amount of HIV in the blood. It estimates the number of HIV particles circulating in the blood.
- E.g. A viral load of 20,000 would be described as 20,000 copies/ml.
- Therefore the higher your viral load, the more HIV you have in your blood.

Routine Tests

Resistance Test

There are many different strains of HIV. All patients get a blood test called a resistance test done when they are first diagnosed. This is to see if the anti-HIV drugs will work on the strain of virus you have.

If you are on anti-HIV treatment your HIV viral load will be monitored regularly and if the viral load has risen above 200 copies/ml a resistance test will sometimes be performed to see if the strain of HIV that you have is resistant to any of the anti-HIV treatment you are taking.

Other Blood Tests

Haematology

This test gives information about the number, shape, size and oxygen carrying power of your red blood cells. We also look at the quality and number of white blood cells (these are involved with defence against infection) and also the number of platelets involved in the initial process of clotting your blood. ESR test is used to detect inflammation which can occur in a range of other conditions and illnesses.

Kidney Function

The kidneys dispose of toxic waste into the end product (urine) whilst retaining useful components. These include sodium, potassium, chloride, urea, and creatinine. Any deviation from the recommended range may require further assessment.

Your kidneys will have to cope with processing any drugs you may be prescribed, for example Anti-HIV medications, so your doctor will want to ensure that these are monitored closely and that there are no problems.

Liver Function

The liver is very important and does a number of vital jobs. Albumin and protein are produced by the liver. Excess alcohol may trigger a rise in some liver function enzymes like gamma GT (which is the amount of liver enzyme in your blood). Other measures of liver function include bilirubin and the transaminases (AST and ALT). These may give important information about liver function.

Your liver will have to cope with processing any drugs you may be prescribed, for example anti-HIV medication, so your doctor will want to ensure that these are monitored closely and that there are no problems.

Uric Acid

This is the substance which, if occurring in high levels in the blood can cause gout or kidney stones.

Glucose

This is a measurement of the sugar in the blood. Being an essential nutrient it should be kept in a narrow range and any raised glucose usually requires further assessment to exclude the presence of diabetes.

Thyroid test

This hormone helps control the metabolic rate of the body.

Calcium and Phosphate levels

These can indicate abnormalities of bone and kidney function.

Cholesterol

High cholesterol (blood fat) can lead to heart disease and strokes. People without HIV can get high cholesterol. Some of the anti-HIV drugs can also cause high cholesterol. The amount of cholesterol in your blood will be monitored.

Drug Treatment

Finding out you are HIV positive does not necessarily mean that you will have to start taking tablets. However at some point it will be advised by your Doctor to start HIV treatment. For some people this may be very soon and others may be able to wait for many years.

HIV drugs are often called combination therapy, this is because you will need to take a combination of drugs or it may also be called HAART, **H**ighly **A**ctive **A**nti-**R**etroviral **T**herapy.

HAART is highly effective and aims to reduce the amount of virus in your body to tiny amounts but it does not get rid of the virus completely. HAART works by stopping the virus from making more of itself. Each drug from a combination you will take will interfere with the different stages of this process, therefore reducing the viral load in your blood. If the viral load is low, your immune system and your CD4 count will have the chance to get stronger again. Your Doctors at your clinic will advise you to start taking HAART if your CD4 count has fallen below 350, A CD4 count below 350, indicates a weakened immune system. If a CD4 count drops below 200, the patient is vulnerable to serious infections. Also the Doctors may recommend that you will benefit from taking HAART due to another reason such as another infection you may have at the time.

HAART is essential in keeping you well and once started, is life long, and taking a break from treatment is not recommended as the virus can grow stronger and the drugs can stop working.

The Doctors and Specialist Nurses in the Clinic you attend will discuss the recommendation of starting HAART and together you will decide on which of the medicines will suit you best. It is very important for you to share your wishes and concerns with your team. They will also discuss the importance of adherence to the treatment with you. HAART must be taken at the right time, thus ensuring that all the drugs in the combination are at high enough levels to keep the HIV viral load down constantly. Your team will help you develop a routine or daily schedule.

It is extremely important that you let your doctor know if you take any other drugs including medication from your GP, dentist, over the counter, herbal remedies, recreational drugs and any bought from the internet. This is because many other drugs can affect the anti-HIV drugs and may stop them from working.

We know all medicines have side effects and unfortunately HAART is no different. The side effects of HAART vary in their severity from person to person and some patients do not experience any side effects. After a few weeks, most people find that taking HAART gets easier. Most side effects are usually mild and transient in nature. Anti- sickness or anti- diarrhoea medicines may be prescribed to take alongside HAART to ease the side effects in the first few days or weeks.

There is only a small risk of serious side effects, and these should be picked up by careful monitoring. Your Doctors and Specialist nurses will ensure that you are aware of how to manage side effects and to seek medical advice/care should you need it. You will also be given a clinic / doctor contact details card to take home.

Post-Exposure Prophylaxis - PEP

This information may be particularly useful to share with partners, family and friends of people living with HIV

What is PEP?

PEP or Post Exposure Prophylaxis is used as a treatment for people who may have been exposed to HIV. This includes people who have had unprotected sex, shared drug injecting equipment or healthcare workers who may have been exposed to the virus (e.g. through needle stick injury).

When HIV first gets into someone's bloodstream it can take time before the virus permanently infects them. PEP can prevent this happening, but it's important to act quickly.

Timing of PEP:

In order to be effective PEP needs to be given within 72 hours of the possible exposure to HIV, although it has a better chance of working and preventing HIV infection if treatment is started within 24 hours.

In Sheffield PEP is available from a number of services:

i. Sexual Health Sheffield – Hallamshire Site (formerly known as GUM Clinic)

Within normal clinic hours by appointment only. Telephone 0114 226 8888 to book an appointment (you will be offered an appointment within 48 hrs).

ii. Department of Infection and Tropical Medicine at the Royal Hallamshire Hospital (E-Floor)

Within normal clinic hours please contact the nurse specialist on 0114 271 1882 or reception on 0114 271 3560

At weekends and bank holidays in order to access PEP within the recommended 72 hours of exposure, advice and "starter packs" are available via the Accident and Emergency Department at the Northern General Hospital.

What happens next?

The medical staff will determine whether you are eligible for PEP by discussing how you think you may have been exposed to HIV. If you are eligible and staff think you may have been put at risk, then you will be asked to come into the hospital for review, a blood test and to begin treatment. You will need to remain on treatment for four weeks, and will need to attend the hospital for check- ups and blood tests during this period, and for the following three months after exposure.

You will also be monitored for side effects as PEP can make you feel sick and give you diarrhoea.

Further information:

For further information and advice regarding PEP, please contact the specialist nurses on E floor on 0114 271 1882 or one of the Health Advisors at Sexual Health Sheffield on 0114 226 8888

Children & Young People

Issues they may face on first diagnosis

Every child and young person will respond differently to first diagnosis. Their response is often based on their prior experience and knowledge of HIV and whether or not they have lost a close family member to the virus.

There can be a lack of understanding about HIV on first diagnosis which can increase fear and anxiety. In this way, it is essential that children and young people are supported in their comprehensive understanding of HIV. Children and young people need to know that HIV is a manageable condition. It can be helpful for health care professionals to relate HIV to other chronic illnesses to assist in them in this.

Issues children and young people may face on first diagnosis include the following:

- Shock
- Anger
- Loss
- Fear
- Worry
- Concerns and questions with regards to future health and life.
Am I going to die?
- Questions around relationships and children. Will I be able to have a boyfriend? Will I be able to have a baby?
- Questions around how the child or young person contracted HIV. Family support is vital here in enabling children and young people to be informed

Issues regarding sex and relationships

A positive HIV status is considered to be a barrier to sex and relationships for young people. It can add to a normal anxiety for teenagers negotiating this part of their life.

Disclosure

Who do I tell and how?

Fear and Anxiety:

How will my boyfriend / girlfriend react to my HIV?

Shame and Embarrassment:

What will my boyfriend / girlfriend think of me if I tell them I have HIV?

Confidentiality and Extended Disclosure:

If I disclose will my boyfriend / girlfriend keep my status confidential?

If we break up will he keep it to him / her self?

Contraception and Condom Use:

Positive young people need to be aware of the legalities around the responsible use of condoms during sex and of cases where positive people have been prosecuted as a result of having unprotected sex whilst knowing that they are HIV positive.

Peer and / or partner pressure to have sex: The need for HIV specific sex and relationship education for positive children and young people

Issues regarding friendships

Disclosure:

Who do I tell and how? Do my friends need to know?

Fear and Anxiety:

How will my friends react to my HIV?

Shame and Embarrassment:

What will friend(s) think of me if I tell them I have HIV?

Confidentiality and Extended Disclosure:

If I disclose will my friend(s) keep my status confidential?

If we fall out will they use it against me?

Secrecy and the weight of this for children and young people:

It's a part of me that I keep to myself.

Managing Medication:

I need to take my tablets but I don't want my friends to see.

Sleep over's with friends

I don't want my friend to see me taking my medication and to start asking questions.

Body Image:

Body shape can change as a result of medication.

Issues they may experience in school / college – who if anyone needs to know and how info may be stored

It is **not** a requirement that schools and colleges are informed of a child or young person's HIV status. Informing school / college nurses is recommended, however, but is not compulsory.

It is recommended that schools and colleges use universal procedures to clean cuts / wounds of HIV positive children and young people and that if school / college staffs are concerned over serious blood exposure that they contact their local hospital.

It is recommended that children and young people who are aware of their positive status take care if they cut themselves at school.

Sex education in schools may not cover HIV wholly. It is recommended that children and young people take any specific HIV related questions they may have to other professionals involved in their care and support as they may not feel comfortable speaking up during these classes at school.

Disclosure of status

- Who do I need to tell?
- Who do I want to tell?
- Fear and anxiety of reactions of friends, family, partners and professionals
- Shame and/or Embarrassment on disclosing
- Confidentiality and concerns over extended disclosure

Managing HIV within the family

Secrecy and Denial:

In some cases parents feel unable to disclose their positive status to children and/or wider family members and/or they withhold testing for children and/or young people for fear and/or denial of the possibility of HIV.

Whilst recognising the complexity of disclosure within families, it is recommended that families seek support to enable them to disclose and foster open honest communication around the issue of HIV. This can encourage a stronger support system for children and young people within families as well as impacting positively on the adherence of medication, negating secrecy related tension and in some cases saving the lives of children and young people who may be unaware of their HIV status until tested.

A lack of knowledge of HIV within the family:

This can inform the amount and quality of support and information available for children and young people within their families.

Discordance amongst family members:

Why me?

Spin off issues as a result of a positive diagnosis of parent(s) or self:

Anger and Blame.

Spin off issues as a result of one sibling having a positive status, others not:

Jealousy, Rivalry and Competition for Attention.

Death and Bereavement;

as a result of loss of family member(s) to an AIDS related illness.

Displacement:

Children and young people living with extended family as a result of loss of immediate family member(s) to an AIDS related illness.

Role models within families for children and young people:

The importance of honest open communication around HIV and medication adherence so that children and young people can lead by example.

The importance of making treatment as easy as possible for children and young people

- **Timing:** Supporting them and their parents / carers to encourage children and young people to take medication on time. Suggesting the use of alarms on mobile phones to manage this.
- **Tablet Training:** Showing children and young people how to swallow large tablets and ways in which it can be made more palatable by using a sugary drink or candy immediately afterwards.

Adherence

Supporting adherence as highlighted above. Supporting children to have confidence in their medication by enabling them to understand its importance for maintaining their health and wellbeing. Encouraging children and young people to be honest about missing doses *“If you don’t take it, talk about it”*

Useful Documents and Resources

World Health Organisation Guidelines on HIV Disclosure for Children Up to 12 Years of Age – http://whqlibdoc.who.int/publications/2011/9789241502863_eng.pdf

CHIVA Guidelines – Talking to Children About Their Health and HIV Diagnosis – <http://www.chiva.org.uk/professionals/health/guidelines/followup/talking.html>

The Children and Young People HIV Network – Just Normal Young People: Supporting Young People Living With HIV in Their Transition to Adulthood – http://www.ncb.org.uk/media/517556/hiv_network_-_young_people_s_transition_report.pdf