

Useful support services

The [Healthy Living Team's](#) overall aim is to make a significant, on-going contribution to the improvement of the physical and mental health, wellbeing and quality of life of the people of St Helens: healthysthelens.co.uk

The [Smokefree St Helens](#) service can offer you advice and support to quit smoking.

In St Helens, a free and confidential drug and alcohol service is provided by [CGL](#) (Change, Grow, Live), this service is for adults only

HIV specific support local

[Sahir House](#) support services are for people living with HIV in the Merseyside area.

HIV specific support Nationwide

[Terrence Higgins Trust \(THT\)](#) provides a My HIV webpage that offers advice and support for people living with HIV. Alternatively, you can receive direct support from THT direct on 0808 802 1221.

[George House Trust](#) provides services to people living with, and affected by HIV ght.org.uk

[HIV I-base](#) is a treatment activist group, providing timely and up to date information about HIV treatment to HIV positive people and to health care professionals.

Whiston Hospital
Warrington Road,
Prescot, Merseyside, L35 5DR
Telephone: 0151 426 1600

St Helens Hospital
Marshall Cross Road,
St Helens, Merseyside, WA9 3DA
Telephone: 01744 26633

 /sthknhs  @sthk.nhs
www.sthk.nhs.uk

Living my life

Patient Information leaflet

This leaflet can be made available
in alternative languages / formats on request.

如有需要，本传单可提供其他语言/版式
此單張的其他語言/格式版本可按要求提供

Na żądanie ta ulotka może zostać udostępniona
w innych językach/formatkach.

Author: Health Improvement
Department: Sexual Health
Document Number: STHK1485
Version: 001
Review Date: 31 / 08 / 2023

Introduction

Finding out you are HIV positive can be a shock for some people. It is likely to take some time to come to terms with this change in your life. HIV treatment, keeping your appointments and positive lifestyle changes enables many people with HIV to lead long healthy lives. This booklet aims to help you understand what changes you may need to make after your diagnosis and offer some advice on certain lifestyle changes while also covering topics such as disclosure and sexual health.

This pack will discuss:

- Understanding HIV
- Transmission
- U = U
- Viral Load
- Treatment for HIV
- The HIV clinic and appointments
- Disclosure
- Lifestyle
- Sex and Relationships
- Planning a baby
- Women's Health
- Men's Health
- Signposting

Cervical screening

The Cervical Screening Programme invites women for screening at 25 years every 3 years, and then every 3-5 years depending on age. However, for women that are HIV positive, it is recommended that they are screened every 12 months. Cervical screening can be carried out at the Sexual Health Clinic, which is confidential and no information will be given to your GP practice or any other healthcare provider with your consent. Further information on the cervical screening programme can be found at:
www.cancerscreening.nhs.uk/cervical.

Breast screening

Women that are HIV positive will be screened the same as women that do not have HIV. There is no difference in the screening programme between women with HIV and those who do not have HIV. Currently, the National Breast Screening Programme (NBSP) invites women aged 50 and over for screening but is phasing an extension of the age range to include women aged between 47-73 every 3 years.

Your HIV team

Sexual Health Clinic
Lower Ground Floor
St Helens Hospital
WA9 3DA

Email specialist.nurse@sthk.nhs.uk

HIV nurses: 01744 646 482

HIV Support worker: 07341 795 401

Websites: Contraceptive and Sexual Health website and St Helens www.getiton.org.uk

However, some HIV medication may cause certain methods to be less effective, such as the contraceptive pill, patches, implants, and vaginal ring. It's important to talk to your Sexual Health practitioner about your current HIV medication and how it may interfere with your contraception choices.

Emergency contraception

If you have not used contraception or you think your normal method has failed, you can take emergency contraception up to 5 days after unprotected sex, however, it is more effective the earlier it is taken. Free emergency contraception is available from Sexual Health Clinics and some pharmacies, but it is important to let the health care practitioner or pharmacist know what medication you are currently taking. HIV medication may interfere with how emergency contraception works and may limit the amount of time you have to take the emergency contraception pill and the dose that you may need for it to be effective.

Termination

Unplanned pregnancies are common but you do have the option to terminate the pregnancy. This can be a very difficult decision to make but talking to family, friends and healthcare professionals can help to you to make the right decision for you. Abortions can be carried out up until the 24th week of pregnancy. There are two methods of abortion that are used, a medical abortion and surgical abortion. Both methods are safe for HIV positive women and are carried out in the same way. For more information and advice, please talk to your healthcare practitioner.

Long Acting Reversible Contraception e.g. IUD, IUS, injection, or implant may be more suitable for women that forget to use other methods of contraception as required. Once inserted, these methods can last between 12 weeks to 10 years depending on contraceptive method.

Understanding HIV

HIV stands for Human Immunodeficiency Virus. Once someone is infected with HIV the virus will remain in their body for the rest of their life. There is currently no cure for HIV and no vaccine to prevent people from becoming infected. However, treatment can help most people with HIV to live much longer and feel well.

Transmission

It is important for you and others around you to understand how HIV is transmitted. This knowledge can help challenge myths and misconceptions about HIV which can lead to discriminatory behaviour. There may be a lot of myths about how HIV is passed on; most of these are not true. HIV **cannot** be passed on through: kissing, hugging, or shaking hands, sneezing or coughing, sharing cups, plates, or toilet seats.

The only way HIV can be transmitted is through:

- Bodily fluids (semen, vaginal and anal fluid, blood, breast milk) - HIV can be transmitted through semen, vaginal, and anal fluid during sex (this may include anal, or vaginal sex) if you or your partner is HIV positive and is not on [undetectable](#).
- Sharing of injecting equipment and/or drug paraphernalia – HIV can be transmitted by using needles, syringes or equipment that is contaminated with HIV.
- Mother to baby - HIV can be transmitted from mother to baby through pregnancy, childbirth, and breast feeding. However, with the correct treatment, many HIV positive women deliver HIV negative babies.

U=U Undetectable = Untransmittable

What is U=U?

U=U stands for Undetectable = Untransmittable. It means that someone with an undetectable HIV viral load on Antiretroviral treatment (ART) cannot transmit HIV, even without using condoms or Pre Exposure Prophylaxis (PrEP).

What does U=U involve?

This protection from ART depends on:

- Taking ART every day.
- Having undetectable viral load for at least 6 months.
- Continuing to take your meds every day.

How can U=U not be a risk?

The quick answer is when HIV viral load is undetectable there is too little virus in sexual fluids for an infection to occur. Any risk of sexual HIV transmission relates to viral load and being undetectable reduces this risk to zero.

Women's Health

Menstrual Cycle (Periods)

HIV may interfere with the menstrual cycle due to the effects that HIV can have on the hormonal system. Changes could include long intervals between periods or missed periods without pregnancy. It's important for you to speak to a health care professional should you notice any changes in your menstrual cycle.

Menopause

It is more common for women with HIV, especially women with a low CD4 count, to start menopause earlier than women without HIV. GPs can offer Hormone Replacement Therapy (HRT) which can help with some symptoms of menopause and can be taken with HIV medication. However, it may be a good idea to speak with your healthcare practitioner as there may be interactions between HRT and the current HIV medication you are taking. Exercising and eating healthily is important for everyone with HIV, yet it is even more important for women with HIV that are experiencing the menopause. This is due to the fact that menopause, as well as HIV medication, can cause bone loss and lead to osteoporosis.

Osteoporosis is a condition that causes the bones to become thin and weak, often causing the bones to become fragile and more likely to break/fracture easily. The National Osteoporosis society (NOS) offers information and advice on www.nos.org.uk

Contraception

All methods of contraception, except the diaphragm and cap, are suitable for women with HIV.

Men's Health

Erectile dysfunction

Erectile Dysfunction (ED), a common condition that is estimated to affect half of all men between 40-70 years old, is the inability to attain or maintain an erection for sexual satisfaction and performance. Causes of ED can be physical, psychological, or both. Physical causes include diabetes, high blood pressure, high cholesterol or heavy smoking. ED can also be a sign of a more serious health condition such as heart disease, so it's important to speak with your health care provider if you are experiencing any erectile dysfunction.

Testicular Cancer

Testicular cancer is most common in men aged between 15-45 years, but has a cure rate of up to 95%. The most common symptom is a lump or swelling in the testicle, feeling of heaviness in the scrotum, discomfort or pains the testicles or scrotum. All men should check their testicles on a regular basis, at least once per month.

There are 5 simple steps to self examination: (Best time is during a warm bath or shower) Hold the scrotum in the palm of your hands and feel the surface and weight of the testicles. It's normal to have one testicle larger than the other. Examine each testicle by rolling it gently between your finger and thumb, they should feel smooth with no lumps. You should be able to feel a tube like section at the back of each testicle (this is the epididymis and it's normal to feel tender). If you notice any swelling or lumps on the testicle or have any pain or discomfort in the testicles or scrotum, you should go and see your GP.

Treatment for HIV

Once HIV is diagnosed, you will be given a number of tests to monitor the stage of the infection and to show if or when treatment should be started. People with HIV may be supported and treated by a specialist team of people at a HIV clinic.

At the moment, there is no cure for HIV but there are drugs known as antiretroviral treatment (ART) or combination therapy that reduce the level of HIV in the blood, and prevent or delay the development of late stage HIV infection. Most people with HIV benefit from these treatments and live longer and have better health than if they had not taken them. There are also treatments available that can help prevent or treat many of the illnesses that people with HIV are more likely to get. Your doctor or specialist can give you full information about treatment options, side effects and long-term effects of treatment.

Quick Starting medication right away may be recommended for some people who are experiencing seroconversion or who are pregnant.

Late Diagnosis

Late diagnosis means that you've tested positive for HIV after the virus has already started to damage your immune system. If you're diagnosed when your CD4 count has dropped below 350 (or it reaches this point within three months of your diagnosis) this is considered a late diagnosis.

If you've been diagnosed late, your doctor will may want you to start treatment straight away, unless they need to treat any other conditions you have first.

Treatment protects your immune system (even if it has been damaged) and if you are taking it and have an undetectable viral load you cannot pass on HIV.

Get to know your Viral Load levels

Once you have been diagnosed as HIV positive, your initial CD4 and viral load will be monitored to check progress and manage treatment.

Viral Load indicates how much HIV there is per cubic ml of blood. In general, the lower the viral load the better as this indicates that there is less HIV in the body. Your healthcare practitioner will monitor your viral load and keep you informed of any changes.

A viral load between:

- 100,000 to 1,000,000 or more – high viral load
- 10,000 or less – low viral load
- 50 or less – undetectable. It is the aim of HIV treatment to get viral load down to this level.

CD4 count indicates the strength of your immune system and in general the higher the CD4 count, the stronger the immune system. CD4 counts can fluctuate and may be lower in the morning and may become higher after exercise. Your CD4 level will be monitored every two years once you are undetectable.

Planning a baby

Can I still have a baby if I and/or my partner have HIV?

If you or your partner has been diagnosed with HIV, you may be worried that you cannot have children. HIV can be transmitted from mother to baby during pregnancy, birth and breastfeeding. However, with the correct care, it is possible for a HIV positive woman to give birth to a child without passing on HIV to the baby with the right treatment and support.

It is important that you speak with a medical practitioner before you conceive as they can offer advice and support on how to get pregnant while reducing the risk of transmission to the baby and partner. There are ways to reduce the risk of transmission of HIV to a partner, but it is important that you follow medical advice even before conception. Please discuss with your healthcare practitioner the safest way to get pregnant.

Is there anything that I need to know before I get pregnant?

Before you get pregnant it is important to understand that HIV can be passed on from mother to baby through breast milk, therefore it is not recommended that HIV positive women breastfeed their babies.

Are there any other options for having a baby?

Adoption may be an option if you are unable to conceive naturally or for gay men who want to become parents. Being HIV positive does not mean that you cannot adopt, but it will be taken into consideration during the adoption process.

Pre and Post exposure Prophylaxis (PEP and PreP) Post Exposure Prophylaxis (PEP)

Post Exposure Prophylaxis (PEP) uses antiretroviral drugs after a single high risk event to prevent HIV infection. PEP must be taken as soon as possible after exposure, normally within 72 hours. If you think your partner has been exposed to HIV infection, contact your healthcare practitioner as soon as possible.

Pre Exposure Prophylaxis (PrEP) is used daily to reduce the risk of HIV transmission for people who are at substantial risk, such as anyone in a relationship with a HIV positive partner who is not on treatment. For people who want to use PrEP, regular HIV and other STI testing is required.

What are our options if we want to have unprotected sex?

It is important to understand the risk factors of HIV transmission.

The higher the viral load means the higher risk of infecting another person with the HIV virus, so it's important to keep up to date with viral load. Different types of sexual activity carry different risks. Oral sex may be lower risk than anal or vaginal sex, but it is still advisable for condoms or dams to be used during oral sex.

If you have an undetectable viral load, research has shown that there is no risk of transmission. (This is known as U=U) however you can still catch other STIs. Your partner may be able to access PreP for more information about this, please speak to your healthcare professional.

Taking your HIV medication

HIV drugs stop the virus making copies of itself. This reduces your viral load to very low levels. Your CD4 count then has a chance to grow stronger again. As long as you do not develop a drug resistance, the same drugs can work for years. These four points are important:

- To take your drugs on time.
- To follow advice on taking with or without food.
- Do not miss doses.
- Check in with your doctor for any potential drug interactions when starting new medication.

By following this guidance, regular testing and keeping appointments; the aim is to get your viral load to undetectable (less than 50 copies/ml) this means you cannot pass on the virus.

Side effects of medication

Many people experience some mild side-effects, particularly in the first few days and weeks of starting treatment. For example, you might feel sick or have a headache. Although unpleasant, most side-effects should improve and go away altogether as your body gets used to taking the drug. Some side-effects may be less obvious to you. For example, the commonly used drug TDF (tenofovir) can cause problems with the kidneys. Your healthcare professional will check a sample of your urine to look out for early signs of kidney problems.

If you think you are experiencing a side-effect, the best thing you can do is talk to a healthcare professional about it.

Getting my medication

In the past you would have had to go to clinic to collect your medication and perhaps also to be trained on how to use the medication. We use a company called Health Care at Home; they are a leading provider of clinical care in the home. Your clinical team will arrange for Health Care at Home to manage, dispense and deliver your medication.

Your responsibility: it is your responsibility to inform the clinic as soon as you open your last bottle of medication (you must always have a month's supply). This is to ensure that you never run out of medication. The HIV clinic does not keep a supply of HIV medication and all prescriptions go through Health Care at Home. It can sometimes take a few weeks from offering a prescription to you receiving it at home

Visiting the HIV Clinic and Appointments

You may initially be asked to attend appointments at the HIV clinic regularly. Once your viral load is undetectable and you have no outstanding concerns, appointments will usually be every six months although you can be seen more regularly if you need to be. During your appointment you may see a variety of people, a nurse, doctor and you have the opportunity to see support workers should you choose to.

Getting the most from your consultation

We understand that it may be difficult to get the most out of your consultation in a short space of time; here we provide just a few tips to help you get the most out of your next appointment.

Make a list of the questions you want to ask before your consultation. Take a pen and paper with you to your appointment to write down important notes you want to remember. Make sure you know all the medication you are currently taking, you could either make a list or bring them with you to your appointment.

pregnancy, so an effort should always be made to practice safer sex. If you are going to have sex, using condoms or internal (or female) condoms correctly is a very effective way of preventing HIV, sexually transmitted infections (STIs) and unplanned pregnancies.

Sexual Health

Sexual Health clinics provide free condoms and other types of contraception, as well as confidential information and advice. There are other ways of preventing unplanned pregnancy, including the contraceptive pill, implant and injection. If you are on HIV treatment and the level of HIV in your body is undetectable there is no transmission risk.

It is important to tell your healthcare professional if you are taking HIV treatment and contraceptive drugs together, as some antiretroviral interact with them and make the contraception less effective.

Safer sex

Regardless of HIV status, if you are in a relationship or have multiple sexual partners, it is always important to practice safer sex. Making sure that a condom is used during sex, including oral sex; helps protect both yourself and partner from Sexually Transmitted Infections (STI) and unintended pregnancy.

Condoms offer protection during vaginal, anal, and oral sex. Dams (a thin latex sheet) can be used for oral sex and caution should be made during mutual masturbation and sharing of sex toys. Free condoms are available from the Sexual Health clinics and can also be delivered by post, please visit our website for more information on the Sexual Health clinics and Condoms by Post.

Sexual Health testing and Condoms by Post is a scheme that allows people 16+ living in St Helens to access free sexual health testing and condoms that are delivered by post.

Exercise

Regular exercise can offer many benefits to people that are HIV positive such as keeping the heart and immune system healthy, relieve stress, and improve fatigue and sleep. It's recommended 30 minutes of exercise 5 days a week will help keep the heart healthy and provide essential energy. However, it is important to start slowly and progress at a suitable level e.g. 30 minutes doesn't have to be one 30 minute session, it could be broken down into two 15 minute sessions. The Healthy Living Team offer a range of physical activity classes to suit all abilities including a variety of exercise classes, guided walks and activities for those with long term health conditions. For further information, see the back page of this booklet.

Drugs and Alcohol

Alcohol can damage your health if you drink more than the recommended guidelines state. The damaging effects of alcohol most often relates to the amount of alcohol that is consumed, so the more you drink the more likely it is that it may be damaging your health. Some of the damaging effects include liver problems, high blood pressure, fertility problems and heart disease. Alcohol and drugs can lower inhibitions and make people likely to engage in risky behaviour, including unprotected sex. Knowing the recommended guidelines may help to reduce the risk of alcohol on your health.

Sex

A HIV positive diagnosis does not mean that sex has to be a thing of the past. Many people who are HIV positive enjoy healthy sex lives, but it is important to understand how to practice safer sex to help protect yourself and your partner(s).

Sex with or without a HIV positive diagnosis carries risks such as Sexually Transmitted Infections (STI) and unintended

HIV support

We understand that you may be overwhelmed by the amount of information you are being given at appointments and particularly since your diagnosis. You may have pre-conceived ideas of what it is like to live with HIV. For this reason we offer a range of support to suit your needs. We have a support worker who works closely with the HIV team who you can contact and discuss any worries etc. We also have access to Sahir House.

Sahir House Support Service is for people living with and affected by HIV in Merseyside. You can self-refer or be referred via a health and social care provider. All support is confidential and after an assessment with a case worker they will direct you to the available support to help you live well, informed and independently with HIV.

Support includes information, advice and guidance, community outreach, counselling, wellbeing activities and referral to welfare and benefits advice, social work, housing assistance and the HIV community nursing team. Contact details are at the end of this booklet in the help section.

Clinical Psychologists we have a clinical psychologist that works alongside the HIV team and they can refer to them should your health condition start affecting your psychological wellbeing.

HIV Support worker we have a support worker who can help you with any concerns you may have. They can be contacted should you have any queries outside of your hospital appointments.

For **Online support**, please refer to the back of this document.

Telling people you are HIV Positive (Disclosure)

After your diagnosis, one of the most difficult decisions you may make is about which people you choose to tell about your HIV diagnosis. You may be very open and honest about your diagnosis and do not feel under pressure to keep your diagnosis private. However, for many people, choosing the right person to tell can be difficult, but remember that it is a personal decision.

Although you don't have to disclose your diagnosis to anyone, it is still advisable to tell someone you can trust so they can offer you support. You may also want to inform your past sexual partners so that they can get tested for HIV.

Current sexual partners

Telling someone you are HIV positive can be a positive experience, but it is important to be prepared when you disclose your diagnosis to others, as reactions can differ. Some people may react badly if they do not know the facts around HIV, hopefully the facts in the transmission section may help dispel myths and offer reassurance. Be prepared for a variety of reactions, everyone will react differently and sometimes it may not be in the way you may have hoped. You may first think about disclosing your diagnosis to someone that may offer you emotional support when disclosing this to others.

Telling healthcare providers

It is standard practice for us to inform your GP so that you get the best possible care. They cannot tell friends or family and only discuss your care with other health professionals.

Please tell us if you have any objection to this.

Telling your employer

You do not have to tell your employer that you are HIV positive unless stated otherwise e.g. some healthcare workers may be asked to disclose their HIV status. If you do decide to disclose your diagnosis then your employer may be able to make suitable adjustments for you e.g. allowing time off for hospital appointments. However, it is a personal decision whether to tell your employer and you should consider the pros and cons before disclosing this information to your employer.

Life Insurance

Another important note is that when applying for life insurance, you may be asked about your HIV status. If you lie about your diagnosis then your policy may be cancelled.

Lifestyle

In addition to complying with medication that is prescribed for you, it is important to look after your body. A healthy lifestyle can help prevent other potential health complications of HIV such as obesity, heart disease, and cancer. Maintaining a healthy lifestyle should be a long term goal of all people living with HIV.

Smoking

Stopping smoking can improve your health and reduce the risk of smoking-related illnesses whether you're HIV positive or not. However, smoking can be even more damaging to your health if you have HIV.

Smoking has not been shown to make HIV progress any faster than in non-smokers; however, HIV positive smokers are at a higher risk of smoking related illnesses than HIV negative smokers, Readytostopsmoking.co.uk can offer you advice and support to quit smoking. For further information, see signposting at the end of this booklet.