



## HIV - Some Key Things You Should Know

This leaflet gives some basic general information about HIV.

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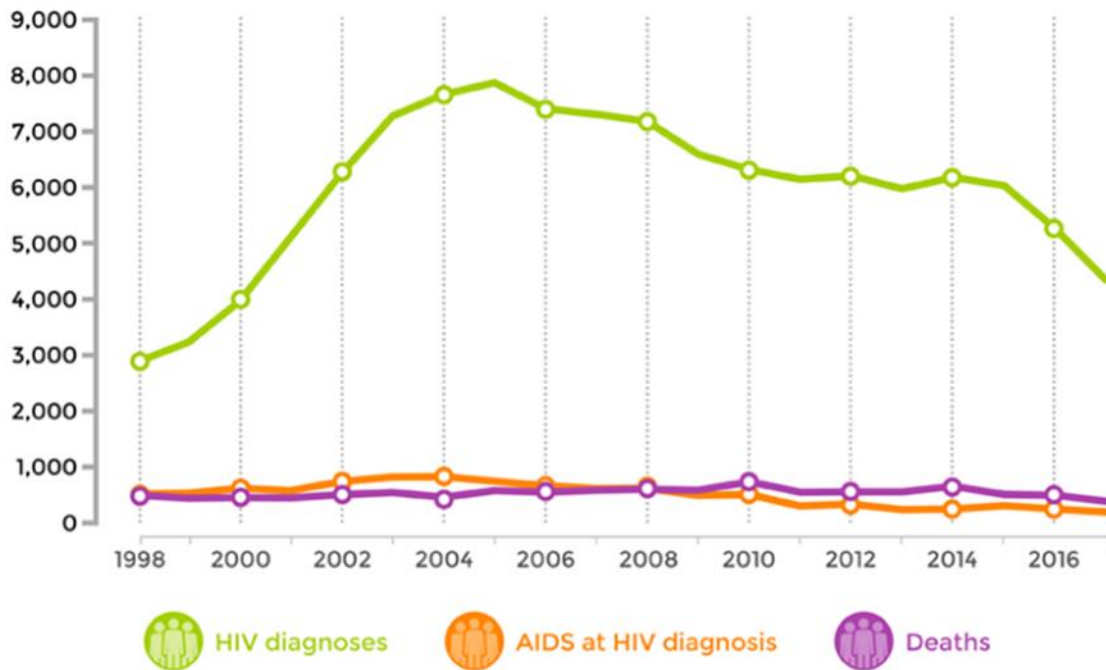
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### 1. What is HIV?

HIV stands for Human Immunodeficiency Virus. HIV has been passed on between humans for many decades but was only identified in the early 80s. When someone acquires HIV, if not treated, over time, the virus will weaken and damage the immune system so that it can't fight off infections. They may then develop one or more serious infections and illnesses known as an AIDS defining illness. AIDS stands for Acquired Immune Deficiency Syndrome but the term AIDS isn't used very often now. Late-stage or advanced HIV is sometimes used instead.

**FACT-People living with HIV who are diagnosed early enough and have effective treatment won't go on to develop an AIDS-defining illness. They can live long and healthy lives on treatment, with a normal lifespan.**

## New HIV diagnoses, AIDS at HIV diagnosis\* and deaths: UK, 1998 to 2017



\*AIDS defining illness within three months of an HIV diagnosis

Source: Public Health England (2018)

Avert) [www.avert.org](http://www.avert.org)

## 2. How is HIV Transmitted?

**HIV is found in blood and some bodily fluids, most notably semen, vaginal or anal fluids.** The most common route of transmission is through sexual transmission - by having unprotected vaginal or anal sex. There are other ways of getting HIV. One is by sharing needles or other injecting equipment. This is a risk for injecting drug users. Another is passing HIV from a mother to her baby during pregnancy, birth, or breastfeeding. Again, this is rarely seen now in the UK and shouldn't stop you considering starting a family. There are very effective ways to start a family safely when living with HIV which your clinic can support with

**MYTHS- You can't get HIV from sweat, saliva or urine. You can't get HIV from hugging, kissing, sneezes, coughs, sharing baths or towels, from swimming pools, toilet seats or from sharing toothbrushes, razors, cups, plates or cutlery. You can't get HIV from animals or insects, including mosquitoes. HIV isn't transmitted through spitting or biting.**



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### 3. How is HIV Treated?

At the moment, there's no cure for HIV. However, there are very effective drug treatments known as Anti-Retroviral Therapy (ART) that are easy to take. **Thanks to ART, people with HIV in the UK can now live long and healthy lives.**

The aim of treatment is to lower and keep the amount of HIV, or Viral Load, in your blood to levels that are so low, they can hardly be detected. This is known as an undetectable viral load and is the best result you can get from treatment. An undetectable viral load means that the virus is not replicating in your body, and is not damaging your immune system. ART can be effective even if you were diagnosed late, didn't realize you had HIV or didn't start ART for some time after diagnosis.

**ART means taking tablets every day.** Often, this is just one pill, once a day. Most people do not experience any side effects, or they are mild and go away after a few weeks. However, if you do have problems and/or side effects, there are usually other options for ART that might be easier for you to take. Discuss this with your clinical team.

**It is important to take your ART on time, every time.** This is called adherence. Missing doses often may lead to the regime becoming ineffective. Without ART, your viral load will quickly increase and you will again be at risk of serious illness in the future.

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### 4. U=U (Undetectable equals Untransmittable)

**If your viral load becomes undetectable through taking your ART as prescribed by your HIV clinician for more than 6 months, you cannot pass HIV on through sex. This is called untransmittable.**

To be classed as undetectable, the viral load actually just needs to be at such a low level (less than 200 copies/mL) so that there is not enough of the virus in sexual fluids for infection to occur. ART typically reduces the viral load to less than 50 copies/mL. You can't tell if you have an undetectable viral load simply by how well you look or feel. The only way to know that your viral load is undetectable is by having a simple blood test done by your clinical team. Your HIV clinician is the only person who can confirm that you are undetectable.

U=U only prevents transmission through sex - it doesn't prevent HIV being passed on by sharing needles, for example.

**It also does not prevent the passing on of other sexually transmitted infections (STIs),** such as hepatitis C. Using condoms and lube is still the best protection against other STIs.

There is a helpful printable factsheet about U=U from i-Base:

<https://i-base.info/wp-content/uploads/2018/09/A5-factsheet-UU.pdf>



## 5. Other Methods of HIV Prevention - PrEP and PEP

If you are living with HIV, the most effective way of preventing HIV being passed on to a sexual partner is through U=U - being undetectable on ART. This is sometimes called "Treatment as Prevention" or TasP. Other methods of prevention such as condom use are also effective.

If you do not have HIV, then you should know that you cannot get HIV from someone who is living with HIV and is undetectable - U=U. Condoms will protect you from HIV and other STIs.

Another HIV prevention method for someone who is HIV-negative is PrEP (Pre-Exposure Prophylaxis). **PrEP is a pill containing antiretroviral drugs that needs to be taken before and after sex, as directed. It is available free on the NHS. When taken properly, PrEP virtually eliminates the risk of getting HIV.** It works for everyone - men and women, cisgender and transgender, heterosexual or gay. While PrEP can prevent HIV, it does not prevent other sexually transmitted infections or pregnancy.

PrEP may be something you want to consider if you are at higher risk of HIV - for example, if you have an HIV positive partner who is struggling to take regular ART, if you have had a recent STI or used recreational drugs for Chemsex. PrEP should be prescribed by a doctor and taken under medical supervision. You need to take an HIV test before you start taking PrEP.

PrEP will not affect contraception and vice versa. Likewise if planning a pregnancy then PrEP can help making sure you don't become HIV positive. If you become pregnant, speak to your GP or clinician about PrEP usage. Breastfeeding is safe around PrEP.

There is a helpful printable factsheet about PrEP from i-Base:

<https://i-base.info/guides/wp-content/uploads/2019/11/UK-guide-to-PrEP-Nov-2019-FINAL.pdf>

**If you think PrEP might be something for you, please call our main clinic number to discuss the options, timescales for taking PrEP and more information**

PEP stands for Post Exposure prophylaxis. It is also sometimes known as PEPSE - Post Exposure Prophylaxis after Sexual Exposure. **It means taking HIV drugs after sex if there has been significant risk of exposure to HIV. For example, if you are HIV positive and have a detectable viral load and experience condom break during sex.**

To work, PEP must be taken within 72 hours (three days) after potential exposure, and ideally should be taken within 24 hours. Most guidelines have a cut-off for PEP after 48 hours. Even though you can get it, it is much less likely to work when it is used this late. The longer you delay, the less likely PEP will work. The medicines should be continued for four weeks (28 days). **The longer you delay, the less likely PEP will work.**

**You can get PEP at any accident and emergency (A&E) department of a hospital 24 hours a day. You can also access PEP from a GUM clinic during working hours.** However, before you are given it, your risk of exposure will be carefully assessed, to make sure that PEP is the right choice for you at this time.

There is more information about PEP and when it might be considered here:

<https://www.aidsmap.com/about-hiv/post-exposure-prophylaxis-peg>



**To discuss treatments, side effects, concerns and other queries, please contact us**

## 6. Discrimination and Stigma

Discrimination is when you are treated differently from others in a way that is unfair – for example, treating you less favorably just because you have HIV. It's about actual behavior. Depending on the situation in which discrimination occurs, it may be unlawful.

Although most people living with HIV would not consider themselves to have a disability, the legal protection comes from HIV being defined as a disability for the purposes of the Equality Act (2010). This protects against discrimination at work, when renting or buying property, in education and when using shops, businesses and services. **All people living with diagnosed HIV are protected by the law, in the same way as people who are discriminated against because of their race, sex, age, sexual orientation or religion.**

However, that doesn't mean that there is no stigma associated with HIV.

Stigma means different things to different people. If people are stigmatized, they are marked out as being different, and are blamed for that difference. Stigma leads to people not being treated with dignity and respect and is one of the main reasons that some people end up having quite negative feelings about themselves in relation to their HIV diagnosis.

Stigma is often attached to things people are afraid of. Ever since the first cases of AIDS in the early 1980s, people with HIV have been stigmatized. A lot of people aren't well informed about HIV in the UK today, and still have some of the unfounded fears from those early days in the 1980s.

Dealing with stigma can be difficult. A lot of people with HIV come from groups who may already be stigmatized for other reasons – such as being gay or transgender; being a sex worker; being an injecting drug user or being from an ethnic minority.



If you have concerns about stigma, get in touch with a member of the healthcare team. They may be able to support and help you, or put you in touch with peer support where you can share your experience with other people living with HIV. This can also be very helpful.



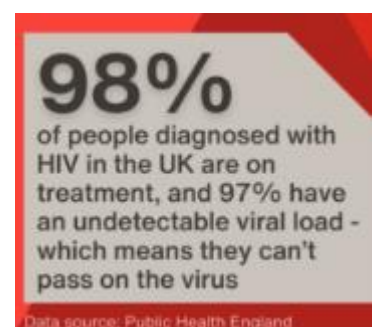
## 7. Telling other people

Telling other people about your HIV status (sometimes called disclosure) can be really helpful, and your friends and family may be a good source of support. However, it is up to you to decide who you tell and you should never feel pressured into doing this.

Unfortunately, in many communities, there is stigma attached to HIV. People may not understand how it is passed on, be afraid, or judgmental. This means you may get some negative reactions.

**If you are thinking of telling others about your HIV, you should carefully consider who you want to tell, why you want to tell them, and when, where and how you will tell them.** You may find it helpful to talk to your healthcare team, or get some peer support, before sharing your status with other people. Peer support is where you can share your experience with others living with HIV in a safe, confidential and helping environment. Peer supporters or mentors can give you information, and help you think about your own circumstances.

**There are only a very few cases where you have an obligation to tell someone that you have HIV.** In most instances, HIV will make no difference to your employability or affect your ability to do your job. Therefore, there are very few jobs where there is an obligation to tell your employer that you have HIV. However, there are some roles where you need to tell your employer - for example, healthcare workers who perform procedures



that involve exposure to blood (such as surgeons, dentists and midwives).

Some countries still have restrictions on HIV-positive visitors.

**Although you are not obliged to tell your GP or healthcare workers other than those in your HIV clinic about your HIV status, it is best that they know so that they can provide you with the best healthcare and support.**

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## 8. HIV and the Law - Criminalization

**There is no law in the UK saying you must tell your partners that you have HIV.**

**It's your choice whether you tell them or not.**

In England, Wales and Northern Ireland, it is possible you could have legal action taken against you if **all** of the following apply:

- You suspect or know you are HIV positive
- You suspect or know you have a detectable viral load
- You still have sex without a condom without telling your sexual partner about your HIV status
- Your partner acquires HIV as a result.

Several people in England, Wales and Northern Ireland have been charged with committing an offence because their sexual partners acquired HIV through sex without a condom, and they had not told them they were HIV positive. (The term often used in the law is 'reckless' transmission.) However this is now quite rare. It is technically very difficult to prove that someone's HIV came from a specific person.

**If you are being investigated, or you think that someone may make a complaint against you, it's important you get good advice and support from an HIV support organization. You need to find an experienced lawyer straight away, before you make any statement to the police.** In the UK, the Terrence Higgins Trust helpline, THT Direct, can help you find both these; you can speak to them in confidence on 0808 802 1221.

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## 9. HIV and Work

Deciding whether or not to tell your employer you are living with HIV can be a difficult. While many employers will be understanding and willing to make accommodations, you may still encounter stigma and discrimination in the workplace.

In most instances, HIV will make no difference to your employability or your ability to do your job. Therefore, there are very few jobs where there is an obligation to tell your employer that you have HIV (**See 7. Telling other people**)

According to the Equality Act (2010), it is illegal to discriminate based on HIV status.

**The Equality Act requires an employer to make reasonable adjustments to prevent you being disadvantaged at work.** For this, you would need to disclose your HIV status for reasonable adjustments to be made. Reasonable adjustments could include:

- time off for clinic appointments
- flexible working arrangements
- taking medication at work

The Data Protection Act 2018 also states that records of your HIV status must be kept confidential.



# TRAVELING WITH HIV

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## 10. HIV and Travel

Many people living with HIV travel regularly for work, business, study, and for pleasure. **In most cases, HIV is not a barrier to travel and holidays. HIV is a globally known lifelong condition however perceptions around living with HIV can change from country to country, and you might not know if disclosure is safe in the country you are visiting. Consult GOV.UK or speak with us if you are concerned by any part of travelling.**

As for other long-term health conditions, it is sensible to consider your health and medication when you make your travel plans. It might be very difficult, or even impossible, to get supplies of your medication once you've left home. Therefore, **make sure you take enough of all your medicines with you to last the full duration of your trip.** It might be wise to count out your medicines before you travel and to take a few additional days' worth just in case you are delayed. **If you run out while away, it can be tricky to access the same level of care and service as you will get in the UK. There may be high costs and extra appointments needed in this case. Allow plenty of time to arrange this**

It's best to carry your medication in your hand luggage, as this is less likely to get lost. If you are travelling to another country it makes good sense to **have a copy of your prescription or a letter from your healthcare team explaining that your medicines are for a chronic medical condition.** It does not need to mention HIV.

**Taking a break from HIV treatment to go on holiday (or for any other reason) is not recommended.** There are serious risks if you do this, including developing resistance to your drugs so that they no longer work effectively. This can mean you are more vulnerable to health problems in the future. And there will be fewer HIV treatment options available to you if you develop resistance.

**Travelling across time zones will affect the time at which you take your medication. Generally, it's best to adapt to the time zone of your destination as quickly as possible.** If you are stable on treatment with an undetectable viral load, then taking one dose of your drugs a few hours early or late, because of a change in time zones, will not usually cause problems. You can get more advice from your healthcare team.

People living with HIV are able to travel to most countries of the world. **But some countries have restrictions on entry for people with HIV,** most often for people applying for a work or resident's visa. Restrictions can change quickly and with very little notice. Talk with your healthcare team, or check on:

[www.hivtravel.org](http://www.hivtravel.org).

Depending on where you are travelling, you may need vaccinations or other preventive medicines for other infections or diseases such as yellow fever or malaria. You need to be sure that these are safe for you to have. Tell your GP or travel clinic about your HIV and these inoculations to check for any interactions.

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## 11. HIV and Healthcare

**HIV prevention, testing and treatment is free across the UK, regardless of your immigration status.**

In the UK, it is almost certain that you will receive your HIV care from a specialist HIV clinic. You can use the HIV clinic of your choice - it does not have to be the one nearest to you, but that might be easier for you to get to.



**As mentioned previously, it is a good idea to tell other healthcare professionals, such as GPs, dentists and pharmacists, that you are living with HIV so that they will be able to provide you with the most appropriate care.** It is particularly important if your GP is prescribing medication for you, because there are interactions between some HIV treatments and drugs used to treat other conditions (for example, anti-histamines and oral contraceptives). Your HIV clinic needs your permission before it can discuss your health with others. Your GP will not get involved in deciding on HIV treatments - that is left to the HIV specialists at the HIV clinic.

Please contact us if you need assistance navigating or getting information on any healthcare services in the UK

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## 12. The Future of HIV in the UK

There are about 110,000 people living with HIV in the UK. Most of these people are on ART, and most have an undetectable viral load. However, there are still about 6000 people in the UK who have HIV but do not know it. This is a concern for their own health, which will get worse over time if they do not get HIV treatment, but also, for transmission.

Every year, there are still a large number of new HIV diagnoses in the UK. The number has been coming down in recent years, but is still around 4000 new cases of HIV every year.

The UK Government has pledged to reduce HIV transmissions in England by 80% by 2025, and to reduce it to zero new transmissions by 2030 making England the first country to do so. A key part of this will be by increasing the amount of HIV testing that is done, and by making HIV testing more accessible in a wide range of situations and locations.

You can read about the full plan to achieve this goal here:

<https://www.hivcommission.org.uk/2020/11/30/final-report-and-recommendations-out-now/>



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## 13. Other Issues and Further Information

You may well have many more questions about how HIV might affect aspects of your life. These might include more detail or issues around:

- HIV testing and diagnosis
- HIV treatment options
- Dealing with multiple health conditions (co-morbidities)
- Having a healthy and enjoyable sex life
- Contraception, or starting a family

- Psychological and emotional well-being
- Physical health - exercise; diet; nutrition
- Ageing with HIV
- Getting the best care out of the health system

There are lots of organisations and websites that give information on all of these issues and more, which we list below.. Please also call and ask to speak with our Wellbeing and Support Team or with Peer Mentors (where you can share your experiences with others who are living with HIV and have knowledge and experience in these areas).

**You may have many questions and queries relating to living with HIV: please contact one of the  
HIV Team at YorSexual Health today**

### **Information sources:**

1. BHIVA Standards of Care for people living with HIV.

<https://standards.bhiva.org/home>

The BHIVA Standards of Care for People Living with HIV were published in 2018. It aims to tell you about what you should expect when getting your HIV care. There is some useful general information in the Foreword; and there are 8 Standards that cover all aspects of HIV care in the UK throughout your HIV journey such as testing and diagnosis; starting HIV treatment; sexual health; mental health and emotional wellbeing; ageing and more.

2. HIV i-Base

<https://i-base.info>

HIV i-Base provides accurate and up-to-date information about all aspects of HIV treatment. They have a wide range of non-technical publications. They also provide a confidential Q&A service (by phone, email or online) to address any questions about HIV treatment that you may have.

3. NAM Aidsmap

<https://www.aidsmap.com>

NAM Aidsmap has a large range of leaflets in everyday language giving clear information about a wide range of topics related to HIV. They also provide the latest news and information about HIV prevention, treatment and cure from around the world.

4. AVERT

<https://www.avert.org>

Avert provides information and engages with the general public and professionals, challenging stigma and other drivers of HIV and poor sexual health. They focus on digital communication, and have a global perspective.

5. National AIDS Trust (NAT)

<https://www.nat.org.uk>

NAT is the UK's HIV rights charity. They work to stop HIV from standing in the way of health, dignity and equality. They focus on policy issues and deal with the Government on things like rights, equality and discrimination, immigration and asylum issues, and healthcare legislation.

#### 6. THT (Terence Higgins Trust)

<https://www.tht.org.uk>

THT is the UK's leading HIV and sexual health charity. It supports people living with HIV and is the largest voluntary sector provider of HIV and sexual health services in the UK. They campaign on a range of issues and also run community projects.

#### 7. Positively UK

<https://positivelyuk.org>

Positively UK provides peer-led support, advocacy and information to everyone living with HIV to effectively manage any aspect of their diagnosis, care and life with HIV. They are passionate about peer support and provide training and support for peer mentoring.

#### 8. Sexwise

<https://www.sexwise.org.uk>

Sexwise give honest advice about contraception, pregnancy, STIs and pleasure.

#### 9. Yorkshire Mesmac

<https://www.mesmac.co.uk/about-us/who-we-are>

Yorkshire MESMAC is one of the oldest and largest sexual health organizations in the country. They offer services to various communities across Yorkshire, including men who have sex with men, people of colour and other marginalized races, people misusing drugs, sex workers and LGBT+ young people and adults.

 **YorSexual Health**  
Free and confidential services across North Yorkshire and York

[www.yorsexualhealth.org.uk](http://www.yorsexualhealth.org.uk)

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