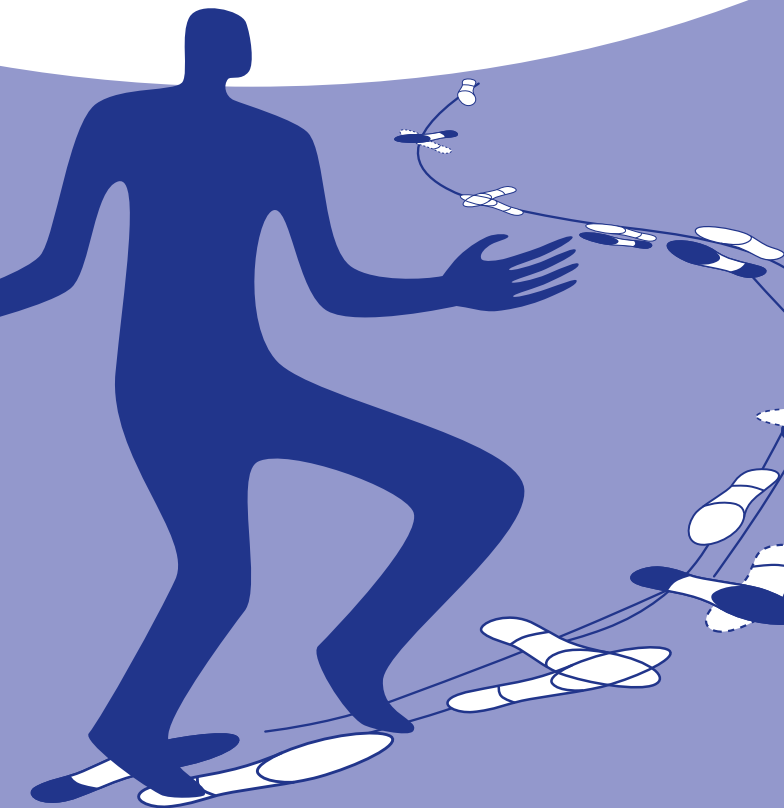


A guide for people who've just found out they have HIV

# Your next steps

Terrence  
HIGGINS  
TRUST



01	Introduction
03	Health issues
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23	Life goes on
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This booklet is part of a range of publications produced by Terrence Higgins Trust to support you in living well with HIV. Most of these publications are designed to be suitable for you whatever your race, nationality, gender or sexuality.

This project has been made possible as part of the Pan-London HIV Prevention Programme.

**This booklet is for you if you've just found out you have HIV. You might also find it helpful if you've known for a while, but have not wanted to think about it much until now.**

**The booklet covers things that we often want to know about at this time. There's straightforward information about what HIV is and how we can look after our health. The booklet talks about having sex when you have HIV, and whether or not it's a good idea to share your news with other people.**

When we find out that we have HIV, some common feelings include fear, worry, embarrassment, shame, sadness, loneliness, blame, hopelessness, dirtiness, anger at ourselves, anger at others and guilt. Some of us just feel numb, and some of us even feel relieved.

Different people have different ways of dealing with feelings like these. Some of us carry on as if nothing has happened, some of us search out lots of information, and some of us prefer to keep our thoughts to ourselves.

We may find it difficult to tell anyone at all about what's happened, or we may choose to get the support of a few trusted friends. Some of us don't mind if everyone knows.

The booklet also talks about those professionals, organisations and support groups who are there to help. Although it can be a difficult step to talk about our situation with other people, talking to someone we can trust may help. It may become easier to understand what is going on and to work out ways of dealing with the situation. We may also get specific information that's particularly relevant to us.

Finding out that you have HIV can be upsetting. This booklet may help by giving clear, factual information, and reassuring you that life does go on.

# Health issues

**04 What is HIV?**

**05 Keeping an eye on your health**

**06 Do I need to take treatments?**

**08 How HIV progresses**

**09 How do treatments work?**

**10 Looking after your health**

## What is HIV?

If you are "HIV positive" this means that you have a virus called HIV in your body.

It doesn't necessarily mean that you are ill, or that you have AIDS, or that you are dying.

HIV slowly attacks the immune system, which is the body's natural defence system against infections. If the immune system is weak, there is a risk of getting ill from different infections.

At some stage you may need drug treatments to stay in good health. They can stop HIV reproducing, and so limit the damage to the immune system.

The initials in HIV stand for  
**Human Immunodeficiency Virus**  
AIDS stands for **Acquired Immune  
Deficiency Syndrome**

"AIDS" is different from HIV. AIDS is an advanced stage of infection when the immune system is very weak. Thanks to medicines, few people now get AIDS, and they can often recover from it.

## Keeping an eye on your health

From someone's physical appearance, you can't tell if they have HIV or not. And you can't always know how good their health is.

But blood tests can show how HIV is affecting your health. Even if you're not taking treatments, it's important to have two blood tests done regularly.

The first is called the CD4 count and is a measure of the strength of your immune system. When the immune system is strong, the CD4 count is higher.

The second is the viral load test. It's a measure of the number of copies of HIV in a sample of blood. The lower it is, the better.

You'll probably be asked to have these tests done every few months. They will help you and your doctor make decisions about your health.

Aim for  
a **HIGH**  
CD4 count

Aim for  
a **LOW**  
viral load

## Do I need to take treatments?

The drugs used to treat HIV are often called 'combination therapy'. That's because people usually take a combination of three drugs at the same time.

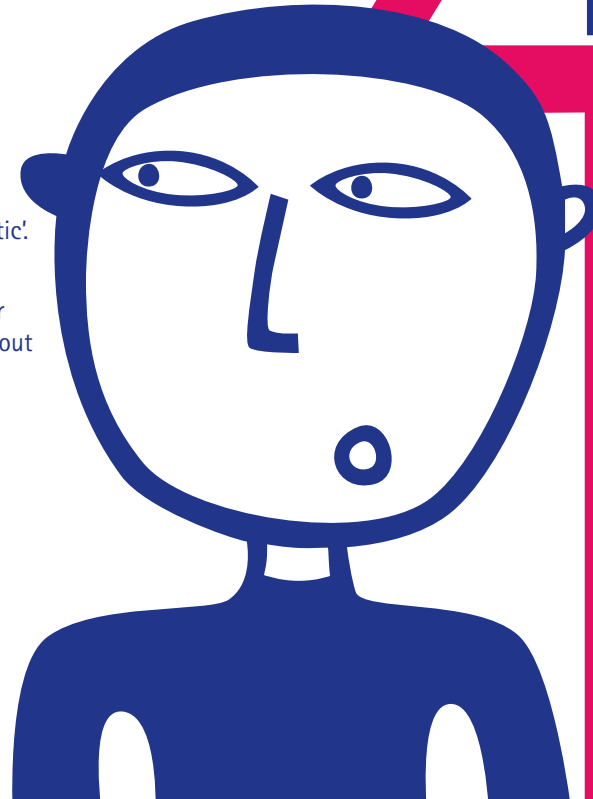
Not everybody with HIV needs to take combination therapy straightaway.

It's different for different people:

- If your CD4 count is above 350 and HIV is not making you ill, then treatment may not be recommended.
- If your CD4 count is below 350 or HIV is making you ill, your doctor may recommend that you start treatment.

If HIV is making you ill, doctors call this 'symptomatic'. If it's not making you ill, it's 'asymptomatic'.

Deciding to start treatment also depends on your feelings. Give yourself enough time to find out about your options and make your own mind up.



## How HIV progresses

After being infected with HIV, we don't usually get ill straightaway. There may be a short illness, a bit like a flu, in the first few weeks, but after that, our health is usually pretty good for anything between two and ten years. The average is around seven years.

But we don't usually get diagnosed with HIV immediately after getting infected. There's often a gap of months or years.

If you were infected quite recently, you'll probably have good health for several years, without needing to take treatments.

On the other hand, it may be that you have only just found out, but have already had HIV for many years. This could be the case if you had an HIV test after getting ill and going to hospital. In this situation, your doctor may recommend that you start combination therapy straightaway.

Being ill, finding out you have HIV and being asked to make decisions about treatment can be a lot to deal with all at the same time.

## How do the treatments work?

Combination therapy usually involves taking tablets once or twice a day. They work by slowing down the spread of HIV inside your body, so that you have a lot less HIV.

If there is less HIV, there is less damage to your immune system, and you are less likely to get ill.

But combination therapy isn't a cure. At the moment, no drug can totally wipe out HIV from your body.

It only works well if they are taken exactly as prescribed. This is often called 'adherence', and it means taking the drugs:

**at the right times**

**at the right dose**

**strictly following any advice about food and drink.**

You should only start taking the drugs when you feel ready to take them in this way, every single day. Taking combination therapy may mean that you have to alter how you live, when you wake up and go to sleep, what you eat and when you eat it.

## Looking after your health

Taking care of your health involves more than popping pills.

It will also help if you can:

- **Get rest and sleep so that you can wind down and recuperate.**
- **Eat a balanced diet to maintain a healthy weight, give you energy and get the nutrients your body needs.**
- **Get some exercise, which is good for the heart, lungs, circulation and mobility. It's also good for you mentally, and can help relieve stress and depression.**

Taking care of yourself in this way will mean that you are putting your body and your immune system under less strain.

### Alcohol and Drugs

During difficult times, you may find that you use more alcohol or drugs. They may help you to forget, or to stop thinking about things. This might work in the short-term, but problems don't just go away when they are ignored for a while. Also too much drink or drugs will probably bring their own problems.

# Clinics & support

- 12 **Registering with a doctor and clinic**
- 13 **Confidentiality**
- 14 **Getting support from your clinic**
- 16 **Other sources of support**

## Registering with a doctor and clinic

Most of us have our HIV monitored and treated at a specialist hospital clinic. We are usually treated as outpatients – in other words, we don't stay in the hospital overnight.



HIV clinics are “open access”. This means that you don't need a referral from your GP (family doctor) or anyone else to use one. You can simply phone up and ask to register as a patient. You choose which HIV clinic to use.

To get details of HIV clinics in your area call **THT Direct (0845 12 21 200)** or go to **[www.tht.org.uk](http://www.tht.org.uk)**.

Regular appointments with your doctor will be used to keep an eye on your health, especially the results of your blood tests (see page 5). This is also your opportunity to ask any questions you have about HIV. If you see the same doctor regularly, you'll have a better chance of building up a good relationship.

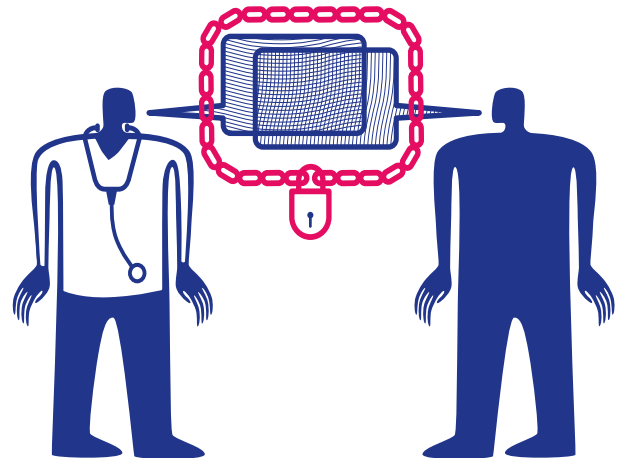
**“Your doctor can answer any questions you have about HIV.”**

## Confidentiality

It's a basic rule that medical information should be kept confidential. This means that nobody can be given information about your health or see your medical records without your permission. The HIV clinic will not pass on information to government agencies or to members of your family.

In fact, confidentiality rules are stricter for HIV than for other conditions. Because of this, your GP (family doctor) will not be told that you have HIV, unless you give permission.

On the other hand information may be shared within the team at the HIV clinic. Also, if your HIV doctor sends you for tests or treatment in another hospital department, the staff you see will normally know that you have HIV. This is mostly so that the right decisions about treatment can be made.





## Getting support from your clinic

Clinic staff are not just there to deal with a virus. Many parts of our lives can make a difference to our health, and clinic staff are often able to help.

If you've just found out that you have HIV, it's possible that you are feeling confused and upset. The clinic should have health advisers and psychologists who can talk to you about things that are on your mind, and to help you to find a way forward. These staff will be available later on, too.

If you want to understand more about HIV or about treatments, you can talk to your doctor or a nurse specialist (a senior nurse). If you're taking treatments, the pharmacists can give specific advice for the drugs you're taking.

Practical problems like housing, money and immigration can get in the way of looking after our health. The clinic may be able to put you in contact with social workers who can help.



## Other sources of support

As well as the help from your clinic, there are many other services available for people with HIV.

They may be provided by:

- local HIV groups
- charities, including Terrence Higgins Trust
- the social services department of your local council.

You should be able to get information and advice on everything from treatments to housing. Practical help may be available if you're ill.

Or you may just want to talk to someone about what you're going through.

**“You may just want  
to talk to someone.”**

There may be support groups where you can meet other people with HIV. It may be reassuring to talk to other people who are in a similar situation, or to meet people who have had HIV for several years and are living well.

The services available vary from place to place. To find out what's available in your area go to [www.tht.org.uk](http://www.tht.org.uk) or call THT Direct (0845 12 21 200).

# 3

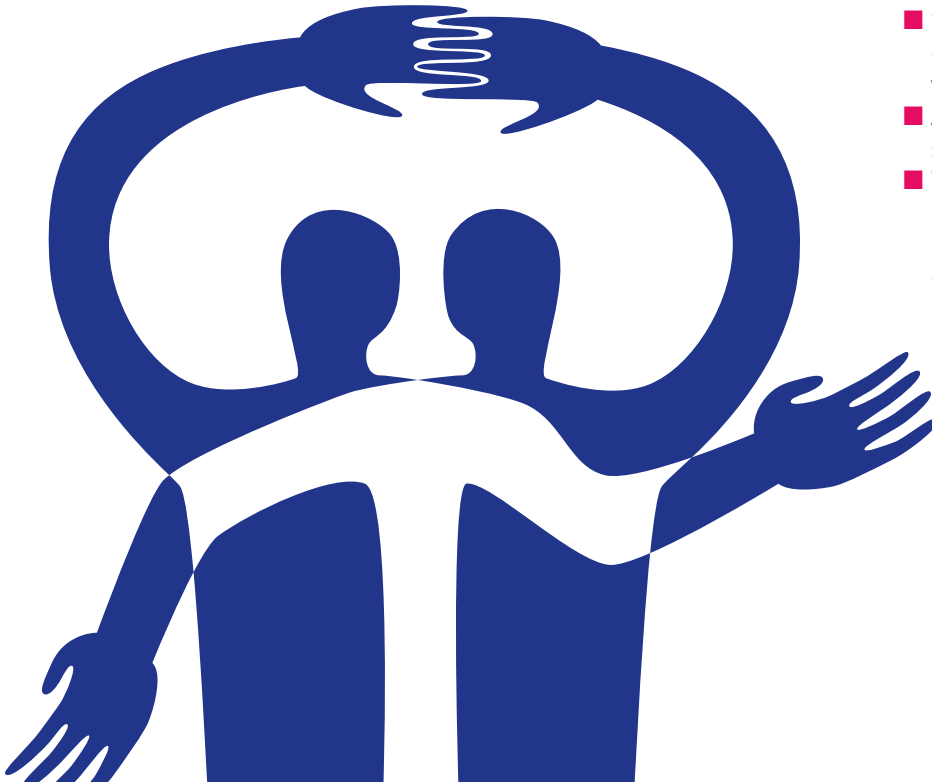
## Sex

- 18 Sex when you have HIV
- 20 Transmission facts
- 21 Post Exposure Prophylaxis (PEP)
- 22 Prosecutions

## Sex when you have HIV

Having HIV can affect our feelings about sex in many different ways.

For some, it can make us anxious about passing HIV on, or we may feel less desirable. While some people go off sex altogether, others look for it more and more. Moments of intimacy and pleasure may become more important than ever.



It's worth knowing that:

- **Most people with HIV do continue to have sex and form relationships.**
- **Safer sex will protect both you and your sexual partner(s) from infections.**
- **Many people with HIV are able to have healthy children (see page 28).**

To look after your own health:

- **Condoms will protect you from many sexually transmitted infections.**
- **Some, like syphilis and hepatitis C, can be more difficult to treat when you have HIV.**
- **Ask the clinic about having a regular sexual health check-up.**
- **When choosing a contraceptive method, HIV treatments may need to be considered. Some anti-HIV drugs can interact with the pill and other hormonal contraceptives.**

## Transmission facts

In terms of sex, it's worth being clear about when there is and when there isn't a risk of passing HIV on to someone else.

Vaginal and anal sex without condoms are the most common ways that HIV is passed on. Condoms provide an effective barrier for preventing infected fluids passing from one partner to the other during penetrative sex. Using a water based lubricant makes condoms even safer.

There is less risk of HIV being passed on during oral sex, but it does happen. If you are a man with HIV and someone sucks your penis, HIV can be transmitted - especially if you have a high viral load, or you ejaculate in their mouth.

There's a much lower risk if you are a woman with HIV and someone performs oral sex on you.

HIV is not normally passed on through:

- **vaginal sex, with condoms**
- **anal sex, with condoms**
- **someone with HIV performing oral sex on ("going down on") someone who doesn't have HIV**
- **mutual masturbation (rubbing each other's penis, vagina or anus)**
- **kissing, cuddling or stroking.**

People around you may be worried about getting infected with HIV. You can reassure them that there is no risk during normal social contact.

No-one has ever picked up HIV from:

- **sharing household items like cups, plates and cutlery**
- **using the same toilet**
- **breathing the same air as someone with HIV.**

### PEP (post exposure prophylaxis)

If you're worried that you might have just passed HIV on to someone (for example if a condom broke), an emergency treatment called PEP is available.

PEP is a course of anti-HIV drugs that must be started very soon after the risk has been taken - the sooner the better and definitely within 72 hours (three days). It can prevent HIV being passed on.

PEP is available from HIV and sexual health clinics, and some Accident & Emergency departments.

## Prosecutions

You might have already heard about people being prosecuted for passing on HIV. While it's important to be aware of this, you should know that so far this has only happened to less than 20 people.

In England and Wales, you could be convicted if, at the time you had sex:

- **you knew you had HIV**
- **and you understood how HIV is transmitted**
- **and you had sex with someone who didn't know you had HIV**
- **and you had sex without a condom**
- **and you transmitted HIV to that person.**

But it's not against the law simply to have 'unsafe sex' or to have sex without telling your partner that you have HIV. A conviction can only happen when HIV is passed on.

### Thinking about going to the police?

If you are thinking of making a complaint about the person you think gave you HIV, it's important to be aware of the possible consequences for you. It's worth getting advice from an organisation that has experience of these situations, and giving yourself time to think through what's best for you.

If you do go to the police, they will closely examine your sex life and may contact your previous partners. This may lead to other people finding out that you have HIV. The process can take a lot of time, and it can become difficult to withdraw a complaint.

For more information and advice, call THT Direct on **0845 12 21 200**.

# 4

## Life goes on

**24 Should I tell?**

**25 Telling people**

**26 Quality of life when you have HIV**

**27 Working when you have HIV**

**28 Having a baby when you have HIV**

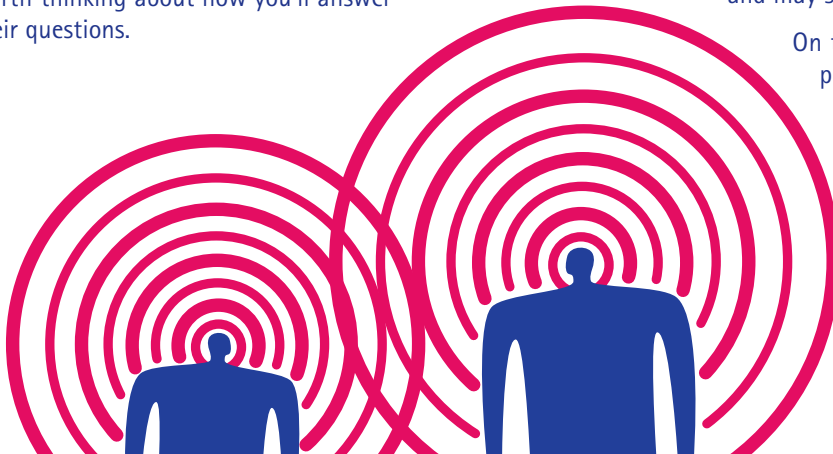
## Should I tell?

If you've just been told you have HIV, you may be feeling upset or confused. You may want to share that with other people. But it's probably not a good idea to rush into telling people that you have HIV before you've got used to the news yourself.

Although you will still be able to tell people later on, you can never 'un-tell' someone.

For each person who you are thinking of telling, ask yourself what you are hoping to achieve by telling them. Try thinking about how they will feel on hearing the news. Imagine the best way they could react – and the worst.

You may also want to think about the best time and place to raise the subject, and make sure that you only tell people you can trust to keep it to themselves. Did you tell anyone that you were going to have an HIV test? If you did, it's worth thinking about how you'll answer their questions.



## Telling people

Telling an employer is very different from telling a parent, and different again from telling a friend. Talking to a sexual partner is nothing like any of the above.

**You don't have to tell everyone, and certainly not everyone at once.**

**You don't have to tell anyone at all if you don't want to.**

Some people you tell may not know much about HIV, or may have lots of questions. You might find it useful to have factual leaflets about HIV to hand to provide reassurance.

Generally, people's reactions will depend on what they know, or think they know, about the subject. There are lots of fears and myths associated with HIV. Some people you tell may be hostile or unkind, and may spread gossip.

On the other hand, telling the right person can be a very positive experience. It can help you to get support when you most need it, and it can sometimes make relationships stronger.

## Quality of life when you have HIV

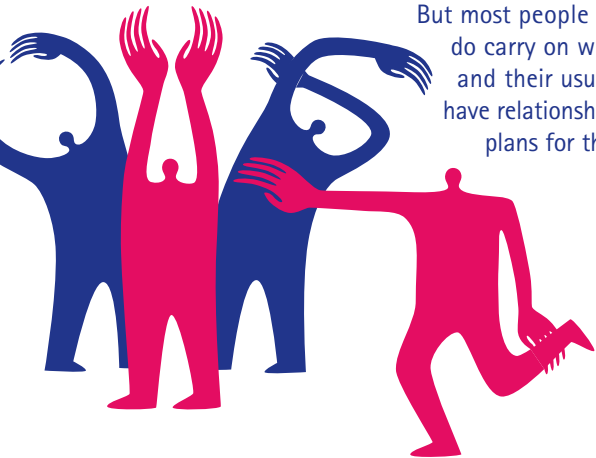
Back in the 1980s and early 1990s, effective HIV treatment didn't exist, and many people with HIV died at a young age.

That's no longer the case, and many people with HIV can now expect to have a near-normal life expectancy.

With currently available treatments, most of us can expect to live into our 60s and beyond. What's more, it's likely that new drugs will be discovered in the future, and those drugs may keep us healthy for longer.

HIV doesn't have to stop you from carrying on with the rest of your life. Many of us do take more care of our health. We may go through a period of adjustment, and reconsider our priorities.

But most people with HIV do carry on with their jobs and their usual activities, have relationships, and make plans for the future.



## Working when you have HIV

If you're currently in work and are feeling healthy, there's no reason why you should stop work because you have HIV. Treatments mean that most of us are in good enough health to continue with our work or studies.

As a general rule, your employer doesn't need to know about your HIV status. If you're worried about gossip being spread, you may want to keep the news to yourself. On the other hand, if your employer knows, it may be easier to have time off for appointments or to deal with periods of sickness.

By the way, it's illegal for an employer to discriminate against employees (or potential employees) because they have HIV.

**“There's probably no reason why you should stop work”**

## Having a baby when you have HIV

If precautions aren't taken, there is a risk of a mother passing HIV on to her baby during pregnancy, childbirth and breast feeding.

But many women with HIV have given birth to healthy children, by taking the following precautions:

- taking anti-HIV drugs during pregnancy
- making a careful choice between caesarean section and vaginal delivery
- not breastfeeding
- giving the new baby an anti-HIV drug for a few weeks.

If you follow all of these safety measures, it's extremely unlikely that your baby will be HIV positive.

Taking anti-HIV drugs during pregnancy will protect your baby from HIV, and you may also need them for your own health. Although a planned caesarean section is often recommended, if your health is very good, a vaginal delivery may be possible.



If you're thinking about having a baby, but aren't pregnant yet, it's worth speaking to your doctor first, so that he or she can check if you are in good enough health to have a baby safely.

Your doctor can also tell you about how to get pregnant without putting your partner at risk of infection.

### Becoming a father

HIV can be passed on from mother to baby during pregnancy, but it cannot be passed directly from the father to baby.

Nonetheless if your partner does not have HIV and you have unprotected sex, there is a risk that she will be infected with HIV. To allow you to have children safely, a process called 'sperm washing' may be available.





## Getting more help, information and support

Terrence Higgins Trust publish a range of booklets, which go into more detail about all the subjects mentioned in this leaflet.

There are also several HIV organisations who are there to help if you're looking for information, want to talk through your questions and concerns, or need practical help.

THT Direct is a good place to start. This is Terrence Higgins Trust's helpline where you can get advice, information and support over the phone. They can also give you details of all the services that are available in your area, whether they are provided by Terrence Higgins Trust or another organisation.

**THT Direct: 0845 12 21 200**

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

[info@tht.org.uk](mailto:info@tht.org.uk)

Some of the other large HIV organisations include:

**NAM** provide reliable information about treatments and other HIV issues. They publish the free monthly newsletter *HIV Treatment Update* and the Aidsmap website.

**020 7840 0050**

[www.aidsmap.com](http://www.aidsmap.com)

**HIV i-Base** provide treatments information through publications and a phoneline.

**0808 800 6013**

(Monday to Wednesday, 12 – 4pm)

[www.i-base.org.uk](http://www.i-base.org.uk)

[info@i-base.org.uk](mailto:info@i-base.org.uk)

**Positively Women** is a charity run by and for women with HIV.

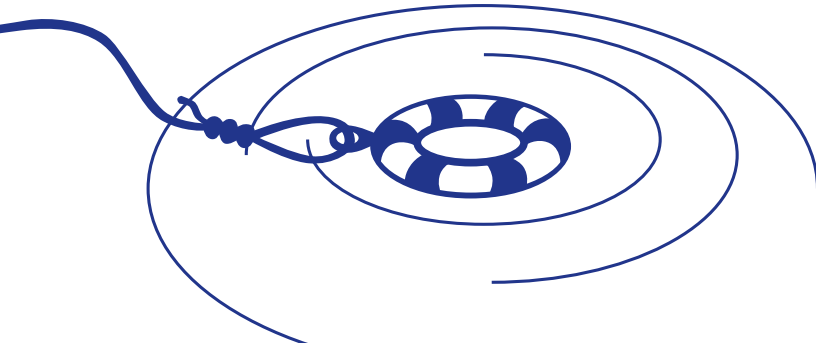
**020 7713 0222**

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

**GMFA** is a charity for gay men, and their website includes information for gay men with HIV.

**020 7738 6872**

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



## What did you think of this booklet?

Terrence Higgins Trust and NAM want to make sure this booklet is useful to you. We would be grateful if you could take a minute to provide us with some valuable feedback.

The questionnaire is anonymous and confidential.

### 1. As a result of reading this resource have you learnt anything about HIV, your health and treatment?

- I have learned nothing new
- I have learnt something but it's not particularly useful to me
- I have learnt something that is useful to me
- I have learnt something that seems vitally important to me

### 2. Please tell us in your own words what you have learnt:

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### 3. As a result of reading this resource I am more likely to:

- Discuss my treatment and care with my healthcare team
- Feel more confident talking to my healthcare team
- Feel better equipped to take decisions regarding my treatment and care
- Feel more informed about HIV treatment and living well with HIV
- Find other information and support, if I need it
- None of the above

### 4. Please tell us in your own words what you are more likely to do as a result of using this resource:

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We have a few more questions on the next page. You don't have to answer these, but if you do, it will help us make sure our information is relevant and useful to our readers.

Please tear off this page and post it to us using the freepost address: **NAM, FREEPOST LON17995 London, SW9 6BR**. Alternatively you can complete the questionnaire at [www.aidsmap.com/feedback](http://www.aidsmap.com/feedback) On this webpage you can also complete our HIV treatments and health knowledge quiz, which will help ensure you have all the basic information you need to get the best out of your healthcare or treatment.

**1. I am:**

male  female  transgender

**2. I live:**

in London  
 in the UK but outside London  
 outside the UK (please specify)

---

**3. My ethnic background is:**

White  Indian, Pakistani or Bangladeshi  
 Black-Caribbean  other Asian or oriental  
 Black-African  other or mixed  
 Black – other

**4. My HIV status is:**

positive  negative  unknown

**5. (If positive) I think I got HIV as a result of:**

sex between men  
 sex between men and women  
 injecting drugs  
 from blood or blood products  
 mother-to-child transmission  
 other  
 don't know  
 rather not say

**6. I work:**

in the HIV field  
 not in the HIV field  
 I do not work at the moment

**7. I got this booklet from:**

nurse  support group  
 doctor  NAM  
 clinic  friend  
 Terrence Higgins Trust  family member  
 Terrence Higgins Trust's Health Support Service  other (please specify)

---

Thank you very much for taking time to fill in this questionnaire. NAM really values your feedback. It helps make the information we provide better.

For details of local services, information,  
advice and support, contact us:

THT DIRECT  0845 12 21 200

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

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us go to [www.tht.org.uk/howyoucanhelpus](http://www.tht.org.uk/howyoucanhelpus)



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**Website:** [www.aidsmap.com](http://www.aidsmap.com)

The HIV and sexual health charity for life

**Website:** [www.tht.org.uk](http://www.tht.org.uk) **THT Direct:** 0845 12 21 200

**Registered office:** 314-320 Gray's Inn Road, London WC1X 8DP

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