

Making decisions about telling people you have HIV

Your Decision

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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.

The previous edition of this booklet, entitled 'Should I Tell?', was highly commended in the British Medical Association's Patient Information Awards in 2007.

This project has been made possible as part of the Treatment Information Providers Initiative, which is funded by the London HIV Commissioning Consortium.

Is it a good idea to tell other people you have HIV?

Even though you may feel you are the only person to be faced with this situation, many other people with HIV have been through something similar before. This booklet has been written using many people's thoughts and experiences. It won't tell you what to do, but will suggest some things you might want to think about.

Disclosing your HIV status (as it's often called) is a complex topic. 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.

There are lots of fears and myths associated with HIV. People's reactions will depend on what they know, or think they know, about the subject. You may find telling people stressful, frightening, or embarrassing.

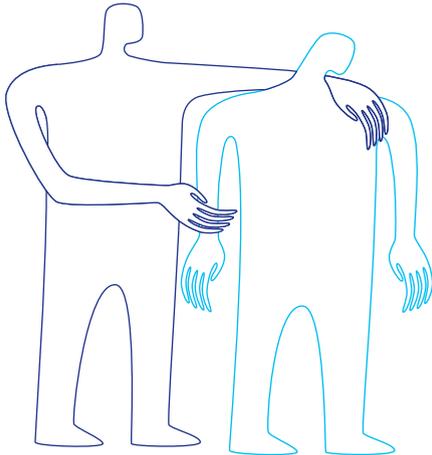
On the other hand, telling the right person can be a very positive experience. It can enable you to get support when you most need it, and it can sometimes make relationships stronger.

Telling people can be a good idea because...

- You can get love and support to help you deal with things.
- You can tell people about issues that are important to you.
- You don't have the effort of hiding your status.
- You can get appropriate health care and services.
- Your sexual partners will be able to make informed decisions.

Telling people may be difficult because...

- You may get unkind or hurtful reactions.
- You may suffer discrimination or rejection.
- You may be asked intrusive questions about your health and feelings.
- The people you tell may be upset, and you may need to reassure and support them.



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Should I tell?

04 Four questions to ask yourself before you tell someone

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Four questions to ask yourself before you tell someone

1 Why do you want to tell them?

It's easier to be sure that telling someone is a good idea if you have a clear idea about what telling them could achieve – what benefits are you hoping for? You might think that if they knew, they could give you some help or support. Think about whether these expectations are realistic.

There may be some people you are very close to who you feel 'should' know. But think through the next two questions, and check that it still seems a good idea.

2 How will they react?

Try thinking about how this person will feel on hearing the news. Imagine the best way they could react – and the worst.

You might find yourself needing to reassure someone who is upset. You could be asked how you got HIV, and the news could tap into someone's prejudices about sexuality, morality or illness. You might find it helpful to have factual leaflets about how HIV is transmitted at hand to provide reassurance. A useful leaflet would be *Understanding HIV*, published by Terrence Higgins Trust.

Or you may want to tell this person because you are confident that they will be calm, supportive and trustworthy.

3 Can they keep it to themselves?

When you tell people, it may be worth telling them clearly who they can and cannot talk to about your HIV status.

Is this a trustworthy person who understands the importance of confidentiality? Although you can ask someone not to tell others, once you've told them, you won't have much control over what they do with the information.

People you are close to might find the news worrying or upsetting. They may want to get support for themselves. But if they're not allowed to talk about it with anyone at all, this will be hard for them.

4 How will you tell them?

You might want to think about how you'll bring the subject up, as well as the best moment to do so. Choose a time and a place where you'll be as comfortable as possible.

It may be easier to find your own answers to these questions with the help of someone at your HIV clinic, a local support group or by phoning **THT Direct** on **0845 12 21 200**.



If you've just been told you have HIV

If you're feeling upset or confused, you may want to share that with other people. But remember that although you will still be able to tell people later on, you can never 'un-tell' someone.

It's probably not a good idea to rush into things before you've got used to the news yourself. Most people find making decisions easier when they've had the time to think things through and consider their options.

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.

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.



Family and friends

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People you live with

It may be difficult to keep doctor's appointments, medicines or periods of illness a secret from people you live with.

If you tell them, they may have needless worries about the risks of infection. To reassure them, you could give them written information about how HIV is transmitted. Or you could suggest that they talk to someone at THT Direct.

Transmission basics

The most common ways in which HIV is passed on are through unprotected sex, sharing drug injection equipment, and from mother to baby (during pregnancy, childbirth and breastfeeding).

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.

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Sexual partners

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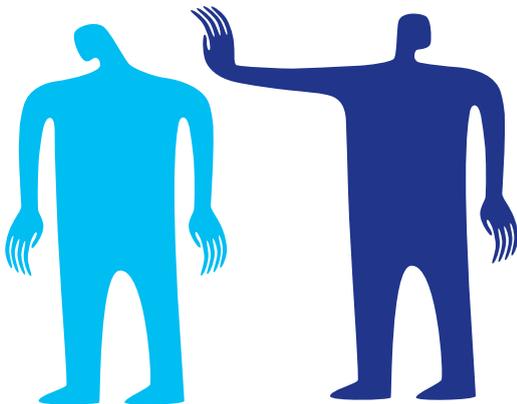
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A complex decision

Telling a sexual partner can feel particularly stressful as you or the person you tell may be concerned about the risks of HIV being passed on. Many people with HIV have faced rejection from sexual partners because of this, and so don't find disclosing their status easy.

Your sexual partners might have unrealistic expectations about sex and HIV. They may imagine that all people with HIV will disclose their status. They may not be confident about the safety of condoms and lubricant, despite the scientific facts.



The law

There's also a legal side to disclosing to a sexual partner. Since 2003, a small number of people with HIV have gone to jail for transmitting HIV, when they hadn't talked about their status and then had sex without a condom. At the time of writing (October 2007), the law is still unclear, but it seems that a conviction is only likely if:

- your sexual partner doesn't know you have HIV
- *and* you don't tell them
- *and* you don't use a condom for all penetrative sex
- *and* your partner becomes infected during sex
- *and* your partner complains to the police
- *and* you are the only person who could be responsible for transmitting HIV.

So it appears that if you don't tell partners you have HIV but always use condoms for penetrative sex, you are unlikely to be prosecuted.

Also, it's very unlikely that you would be prosecuted just because you didn't disclose your status – transmission of HIV needs to take place.

But this situation could change and you are strongly recommended to get up to date advice. Detailed information is on our website (www.tht.org.uk/prosecutions) or you can phone THT Direct on 0845 12 21 200.

Telling a new sexual partner

As with telling any other person, it's worth thinking about why you want to tell a sexual partner. The reasons you have for telling (or not telling) may depend on the kind of relationship you want to have. Will you see this person just once, or are you hoping for a longer term relationship?

It may also depend on the kind of sex you want to have. If the risk of passing on HIV will be very low, many people see no reason to tell someone. But others tell partners so that it's easier to make informed decisions together about sex. And some people tell because of recent changes in the law.

Despite the legal implications, many people with HIV feel that they don't need to tell all their partners. They think that each HIV negative person should be taking responsibility for their own health.



With sexual partners, timing can be important. It can be difficult to talk about HIV when you have only just met someone, but putting it off may cause problems later. If your partner does find out later on but can't accept it, it may be more upsetting for both of you.

If you've just met someone, you might not feel that you know enough about them to anticipate their reaction, or to judge whether they'll respect your privacy. You might be in a bar, a party or another place where it feels out of place to talk about HIV. Some people go to a more neutral environment, arrange to meet up later or decide to talk about HIV once they've got to know the person better.

Other people drop HIV into the conversation very early on, in a very casual and matter of the fact way, so that if the other person can't accept it, no time is lost.

Some people drop hints about HIV or try to guess the status of their partner. But these judgements are not always accurate.

Current and previous partners

Telling your current partner

If you've just been diagnosed with HIV, and you are already in a relationship, there will be the question of telling (or not telling) your partner. The news could introduce new concerns and pressures into your relationship. Your partner may be worried about his or her own health, and may want to have an HIV test or re-think the sex you have.

Some people face particularly difficult situations. You may live with your partner and be worried about losing your home. Or you may be afraid of domestic problems or violence. You may want some help or support to think these issues through. This will be available through your clinic, a local support group or **THT Direct (0845 12 21 200)**.

Telling previous sexual partners

Whether or not you tell previous sexual partners can depend on a number of factors, such as what your relationship was like, the kind of sex you had, whether you think they would want to know and whether you want them to know.

You can ask staff at your HIV clinic to contact your ex-partners and sexual contacts for you. They'll do this without giving any of your details away.

Telling past sexual contacts yourself can be difficult. You might believe that you picked up HIV from this person, but they may think that you put their health at risk. It's not always clear who is right or wrong.

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Medical professionals

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Dentists

Most dentists will ask you if you have HIV. According to the Disability Discrimination Act (and professional guidelines), dentists should not refuse treatment, give a worse service or otherwise discriminate because you have HIV.

In fact dentists frequently refuse to treat people with HIV. Dentists say this is to protect themselves and other patients from HIV. But standard sterilisation procedures are enough to prevent HIV being passed on. If you experience discrimination, you could take it up with:

- your local NHS Primary Care Trust – contact their Patient Advice and Liaison Service, or
- the Commission for Equality and Human Rights (www.equalityhumanrights.com).

Your HIV clinic may be able to recommend a good dentist.

The benefits of telling a dentist are that he or she can check for HIV related gum problems, and make sure that medicines used don't interact with anti-HIV drugs.

“It’s illegal, but dentists frequently refuse to treat people with HIV”

Doctors

There are good medical reasons to tell your GP or family doctor. When treating you and making prescriptions, your doctor needs to know about other health issues you have and other medicines you are taking.

Doctors are not allowed to refuse to treat you because you have HIV, or discriminate because of your lifestyle, sexuality, religion or race.

You may be worried about confidentiality, particularly if other people you know have the same doctor, or are friends with people working at the clinic.

But doctors' rules say that they cannot show your records or talk about your health to your family, friends, or anyone else. These rules also say that it is the doctor's responsibility to ensure that personal information remains confidential.

One important exception is that information will normally be shared within the healthcare team and with other health workers who give you care. But you could ask your doctor not to do this, and unless it would put another worker in danger, the doctor must respect your wishes.

Also, if you apply for life insurance or a mortgage that requires life insurance, your GP may be asked about your HIV status. He or she needs your consent to answer, but has to respond honestly. See page 30 for more information on insurance.

Confidentiality in the NHS

The NHS rules on confidentiality apply to everyone working in the NHS, including receptionists and administrative staff. They're as relevant in doctor's and dentist's surgeries as in hospitals.

The general principle is that your personal information must be kept private. But it's important to remember that information will be shared within the healthcare team and with other health workers who give you care. This is mostly so that the right decisions about treatment can be made.

NHS rules say:

- Staff shouldn't show your medical records or discuss your health with family, friends or anyone else without your permission.
- Staff shouldn't discuss your case where they can be overheard (especially if someone could work out that it's you they are talking about).
- Confidential information (like "HIV positive") should never be written on the cover of your medical notes where other people could see it.
- Doctors can only complete medical reports for insurers and employers with your permission.

Under the specific rules for doctors, there are a few situations when the normal rules of confidentiality may be broken. These situations are extremely uncommon.

- If a court forced a doctor to give evidence, he or she would have to answer all questions honestly. This could happen if someone is prosecuted for transmitting HIV (see page 15).
- If the police were investigating a crime and asked a doctor for information, the doctor might co-operate. However many doctors would refuse.
- If a doctor believes that someone with HIV is putting the life of another person in danger, the doctor has the right to disclose information to the person in danger. This can only be as a last resort, and after telling the person with HIV that confidentiality will be broken.

Otherwise, health workers must make sure that your medical information remains private.

Your doctor will probably note your HIV status in your medical records. Under the Data Protection Act, you have the right to see your medical records and have anything inaccurate changed. If there's something in your notes which is accurate, but you are still unhappy with, you can ask if the doctor would be willing to modify it.

Electronic records

The same NHS rules of confidentiality will apply to the 'summary care record'. This is a new, national system of electronic records that will soon be introduced.

- These records will contain basic information like your name and date of birth.
- They will also mention allergies and the medicines you take, including HIV medicines.
- Health workers involved in your care will be allowed to access your records.
- You can refuse to have your details stored on this electronic record, and you can ask for information about HIV medication to be left off.

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Officials and organisations

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Employers

As a general rule, employers do not need to know about your HIV status.

Disclosure may not be a good idea if you are not sure that your employer will treat the issue sensitively. The danger is that personal information may be made public, you may suffer discrimination, or your bosses may simply lose confidence in your ability to do the job.

On the other hand, if your employer is supportive, it could be easier to make changes to your workload, to have time off for appointments, or to deal with periods of sickness.

If you want your employer's support, you could ask to speak in confidence to your manager or human resources representative. You could explain that you have a medical condition, without naming HIV. It may help to bring a letter from your doctor explaining that medication keeps your condition under control and that you are able to do the job. You can stress that you want this personal information to be kept secret.

It's worth knowing that all people with HIV are protected under the Disability Discrimination Act. This says that you cannot be refused a job because of your HIV status, and that an employer has to make 'reasonable adjustments' to make it possible for you to do your work. This could include changing work schedules, for example.

Job applications

When you apply for a job, there may be questions on the application form about medication or having a medical condition. If you lie, and are found out, you could lose the job. Alternatively, you could try, as tactfully as possible, to avoid answering the question.

- You could leave that part of the form blank, and wait to see if they come back to you for an answer.
- You could decline to give sensitive personal data which is protected by the Data Protection Act. To be consistent, you could withhold your ethnic group as well as health information.
- You could say that you will answer personal questions later, if the application is successful.
- If pressed for more information, you could ask your doctor to write a letter confirming that you will be able to do the job, despite your unnamed health condition.

To be protected by this law, your employer needs to know about your HIV status. But you can tell them when you want – you don't have to tell them when you apply for the job.

If you work in healthcare, you are obliged to inform your occupational health physician, and avoid performing invasive procedures.

Immigration and government officials

Government policy says that having HIV can never be used as a reason to refuse applications for visas, leave to remain or asylum.

If you apply for asylum, the application must be based on a fear of persecution for reasons of race, religion, nationality, membership of a social group, or political opinion.

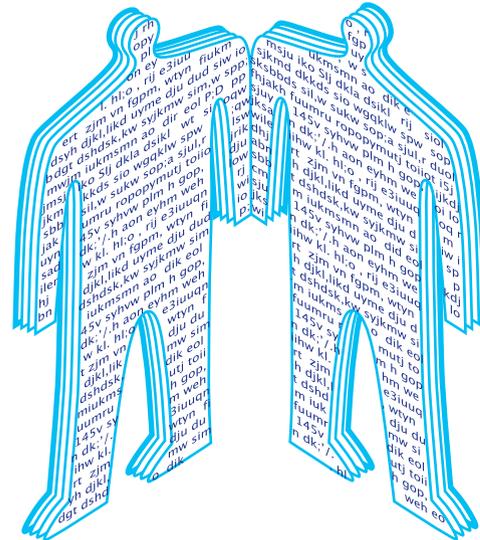
If you are applying for leave to remain solely on human rights or compassionate grounds, the Home Office will consider several factors together, often including HIV. The relevance of this will depend upon the extent and severity of your health problems and symptoms. A good immigration lawyer can advise you on the likelihood of you being granted leave to remain in the UK.

In either of these cases, disclosing your HIV status to officials may help you get accommodation and financial support. This may be available from the local authority of the area where you are resident. To apply, speak to a social worker or the social services department of the local authority.

A second alternative for asylum seekers is support from the National Asylum Support Service (NASS). The disadvantage is that NASS may try to 'disperse' you to another part of the country. However current NASS policy is that if they know you are HIV positive, they must consult your doctor to make sure there will be appropriate health care in the place you will be sent to.

If you are applying to stay in this country, appealing against a refusal or have leave to remain, you probably have the right to free NHS treatment. The rules are complex and change frequently, but you can get more information from **THT Direct (0845 12 21 200)**.

This information was correct in October 2007.



Insurers

If you apply for life insurance or a mortgage that requires life insurance, they will ask both you and your GP about your HIV status. If you lie, and the insurance company finds out, they will cancel the policy.

Insurance industry guidelines say that you can be asked about:

- testing HIV positive
- having a sexually transmitted infection in the last five years
- living or travelling abroad
- having blood transfusions or surgery abroad
- injecting drugs.

But you can't be asked about your sexuality, how many sexual partners you have or how long relationships have lasted.

Getting more help and support

This booklet suggests four questions to ask yourself each time you think about telling someone that you have HIV.

Why do you want to tell them?

How will they react?

Can they keep it to themselves?

How will you tell them?

Your answers will depend not only on the people you might tell, but also your own personal values. Deciding whether to tell someone is, in most cases, your own choice. Thinking carefully about your needs, fears and expectations will help you work out what is right for you.

It may be easier to think through the issues with the help of other people with HIV or a professional with experience in the area. Or you may need more detailed information. You could talk to someone at your HIV clinic, a local support group or THT Direct.

THT DIRECT  0845 12 21 200
www.tht.org.uk

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

THT DIRECT > 0845 12 21 200

www.tht.org.uk

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The HIV and sexual health charity for life

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