



# YOUR VOICE

**A GUIDE TO DISCLOSURE AND HIV**

## Important note:

This guide contains useful information but not legal advice. If you are experiencing difficulties you can find a list of organisations that offer direct support to people living with HIV at the end of this guide. We would recommend that you seek specialist advice about your particular situation if you have concerns over any aspect of disclosure and the law.



# CONTENTS

INTRODUCTION .....	5
DO I HAVE TO DISCLOSE? .....	6
At work .....	8
Receiving healthcare .....	14
Getting insurance .....	16
Travelling abroad .....	19
Playing sports .....	19
In education .....	19
IS THERE A RIGHT WAY TO DISCLOSE?.....	20
INFORMATION AND SUPPORT .....	26
ACKNOWLEDGEMENTS.....	30

“DISCLOSING,  
FOR ME, WAS  
THE MOST  
REWARDING  
AND FREEING  
EXPERIENCE I  
HAVE HAD IN MY  
LIFE.

**It has created bonds with people who admire that I am real and honest. I have been able to touch many lives through my story as well, and still do. This does not mean everyone has been supportive, some boys who were hitting on me would hear of my status and disappear. It's disheartening but I focus on the reason I went out in the first place: to ensure that every girl going through what I went through would not feel alone.”**



## INTRODUCTION

A person's HIV status is private. It is your right to choose whether to tell someone (or 'disclose') that you have HIV. However, there are some situations where you are legally required to share your status. This guide explains what those situations are so that you can have a greater understanding of what to expect and your rights and responsibilities.

This guide also contains some practical hints and tips to support you if you do want to tell others (or not) that you have HIV. We have included real-life examples throughout this guide, to show the diversity of people's experiences, along with advice from people who have themselves disclosed.

# DO I HAVE TO DISCLOSE?

**You do not have to tell a sexual partner that you have HIV, as long as you take appropriate precautions to prevent sexually transmitting HIV.**



## IN RELATIONSHIPS

People living with HIV are entitled to an active, healthy sex life. You do not have to tell a sexual partner that you have HIV, as long as you take appropriate precautions to prevent sexually transmitting HIV.

What is considered appropriate will depend on your personal circumstances and the advice you've been given by healthcare professionals, but it could include things like using recommended precautions (e.g. condoms with lubricant) and following medical advice (e.g. adhering to treatment so you have an undetectable viral load).



**“I started seeing someone just after being diagnosed and he was very understanding. We have been together now for 18 months, he is negative.”**



**“My motto is tell a person before you invest heavily both emotionally and psychologically then have them leave when you are already too deep down in the relationship and they feel betrayed, it's not fair.”**

Your HIV doctor or nurse can advise you about protecting your sexual partners, and what precautions you should take. If you cannot get the information you need, ask to speak to a peer supporter (another person who has HIV and is trained to give support). They can help you talk to your health team if you're not feeling confident or your questions aren't being answered.

If you don't take precautions and don't disclose, then you could potentially be charged with a criminal offence if you transmit (or, in Scotland, risk transmitting) HIV to a sexual partner. If you would like more information about HIV and prosecution, details of resources are included at the end of this guide.

The thought of telling a sexual partner may make you feel anxious, but there could be advantages to being open about your HIV status with them. It might make you feel more relaxed, less inhibited and it could bring you closer together. If you have any doubts, speaking with an HIV healthcare worker or peer supporter can be really helpful in planning how to tell partners your HIV status.

If you've been diagnosed with HIV you may want to tell previous sexual partners so that they can get tested too. If you do not feel able to tell them yourself, a sexual health clinic can help and even do this for you without mentioning your name.

**The thought of telling a sexual partner may make you feel anxious, but there could be advantages to being open about your HIV status with them.**

# AT WORK



In most cases, it is completely your choice whether or not to tell your employer you have HIV. Many people don't because they don't think it's relevant to their job. However, a small number of professions (described on page 12) do have particular requirements and you would have to disclose or take an HIV test to meet those.

## RECRUITMENT

HIV is considered a disability from the point of diagnosis under anti-discrimination law in the UK. This means that people diagnosed with HIV are protected from discrimination at all stages of the employment process, including recruitment. If an employer rejects a job applicant solely because they have a disability, it is direct discrimination and is unlawful.

Generally in Great Britain, it is unlawful for an employer to ask you about your health or disability before they've offered you a job. This also means they can't refer you to an occupational health practitioner until a job offer is made. However, questions about health and disability can be asked in a few specific circumstances during the initial stages of recruitment, e.g. you could be asked about your ability to carry out a task which is required for the job, such as lifting heavy objects.

**“It is all very well disclosing when you're employed but you've also got to think about the best time to disclose before your employment - do you tell them at the interview stage? Because, if you don't get the job, is it because of your ability or because of discrimination?”**

Many people will feel that HIV has made no difference to their health at all, whereas others may at times be unable to carry out certain tasks.

*“In my interview I was asked if I have any medical conditions that would affect me doing manual lifting. I said ‘no’ because my HIV hasn't caused me any problems.”*

*“I was asked if I had any health issues that would affect me working on a production line. My HIV usually wouldn't but I had just started treatment and my doctor mentioned it could make me need to go to the toilet more often, so I told them I need to use the toilet regularly but I didn't mention HIV.”*

Once an employer has made a job offer they may ask questions relating to health or disability. Often job offers are conditional following satisfactory pre-employment checks, including medical checks and references. If there is a genuine requirement, an employee could be turned down for a job on health and safety grounds.

However, to turn someone down just because they have HIV (when it has no relevance to their ability to do a job) would be discriminatory, and you could take the employer to a tribunal.

Except in very limited circumstances (see page 12 on healthcare workers) there is no reason why an HIV test should be included in any medical questionnaire/examination. If you are asked to disclose your HIV status on a medical questionnaire after a job offer, you can ask before completing the questionnaire what the information will be used for, who will have access to it and why specific questions are necessary for the role. Failing to respond honestly could be considered by an employer as grounds for termination of employment, though this could be challenged as discriminatory and/or unfair dismissal.

## MANAGING HIV AT WORK

Employers cannot dismiss or treat a person unfairly because they have HIV, or need a short time off work because of symptoms or the side effects of treatment.

*"My employers do not need to know as I manage my appointments around work."*

Although you are under no obligation, there can be advantages to disclosing your HIV status at work, particularly if you want to request reasonable adjustments to help you do your job. Reasonable adjustments could include things like time off for hospital appointments, flexible working hours to fit in with any side effects of treatment, or privacy to take medication. If you do disclose, your employer must keep this information confidential and the people you work with do not need to know what your condition is (see the confidentiality guide for more information).

## SEEKING REDRESS

*"I told my line manager who was very supportive to begin with but once I started to have a medical problem I was managed out."*

If you think an employer has discriminated against you, you can contact the Equality and Human Rights Commission (EHRC), Equality Commission for Northern Ireland, or local Citizens Advice Bureau (see page 27). If you belong to a union, your union representative can also support you. If necessary you can make a discrimination claim in the employment tribunal.



## Challenging discrimination at work

### CASE STUDY

Josh had a good relationship with his manager and disclosed his HIV status to him. However, it soon became apparent to Josh that his manager had told his co-workers. His colleagues began to isolate him by excluding him from discussions and social events. Josh became unwell and on returning to work was dismissed from his post. He felt this was a clear case of discrimination and sought advice from his Union. He also spoke with a solicitor and they decided to take the employer to a tribunal. During this time, Josh was asked to provide documentation about his health and employment - fortunately he had kept detailed records of events. His HIV doctor was very supportive and provided all the medical evidence needed for the case. Just prior to the tribunal hearing, Josh's previous employer apologised and offered him compensation, meaning the matter was resolved out of court. Josh is still angry about how he was treated, but is pleased that he stood up to discrimination and the behaviour of his manager.

# JOBS WHERE THERE MAY BE A REQUIREMENT TO DISCLOSE

## CASE STUDY

### HIV IN THE MILITARY

Conor was diagnosed with HIV while working in the army. He was very anxious about disclosing but wanted to be honest about his status so he could receive appropriate medical treatment if he needed it. Upon disclosing to the medical officer, Conor was surprised by how positive a response he got. The medical officer thanked Conor for his honesty, and reassured him that he could still have a fulfilling career in the army. They talked about the different tasks that Conor undertook and ways to safeguard his health should any problems arise.



#### HEALTHCARE WORKERS

All healthcare workers who are new to the NHS are offered a voluntary HIV test, and for workers who will perform 'exposure-prone procedures' this test is compulsory. Exposure-prone procedures are those where a worker's blood could come into contact with a patient's open tissues. This includes surgery, midwifery and dentistry, where a worker's gloved hands may be in contact with sharp instruments, needle tips or sharp pieces of bone or teeth.

Healthcare workers with HIV can undertake all procedures if they are on effective treatment. They must also have an undetectable viral load of HIV, and be regularly monitored. There is official guidance in this area which is listed on page 28.



#### MILITARY PERSONNEL

The Army, Royal Navy and Royal Air Force do not accept applications from people who are HIV-positive. This is the same for many health conditions such as diabetes. The military's policy is that although you cannot join the military with HIV, if someone is diagnosed after they have joined they are able to remain in service. Guidance will be given from a military occupational viewpoint about the most suitable placements and roles within the military.



#### AVIATION WORKERS

There are restrictions for HIV-positive pilots and air traffic control officers. These restrictions are intended to ensure that illness/medication does not affect work capability or judgment, and vary depending on whether a person shows symptoms related to HIV or medication. UK Civil Aviation Authority guidelines detail the various assessments that are required of HIV-positive pilots and air traffic control officers, and the types of restrictions that might be put in place.



# RECEIVING HEALTHCARE

There is no legal requirement for you to disclose your HIV status before undergoing any type of medical examination or treatment.

All healthcare professionals use 'universal precautions' to prevent the transmission of blood-borne viruses like HIV to and from patients. However, telling healthcare workers about your status could help them to provide you with better care.

*"Telling your dentist, your optician, or your GP, is actually really useful because they will be able to tell you if need to get something checked. I worked with dentists and they all were really au fait with HIV; they knew what they were looking for in the mouth and might notice something quite early on as an indicator of someone's declining health."*

Disclosure to healthcare workers can be particularly important as HIV medications can interact with other types of medication, and other conditions may be affected by HIV. If you have any doubts, you can ask your regular HIV specialist whether disclosure to other health practitioners could be beneficial.



**"I think there is more benefit to disclosure than not. You might not get on with your GP or whatever, but if they know about your condition they can treat a given ailment with HIV in mind and issue the appropriate medication without the risk of interaction or interference."**

If you disclose your HIV status to a medical practitioner, then this information, like other medical information, is protected by various laws. If you do not want other healthcare providers, such as your GP, to know your status, be sure to make this clear to your HIV specialist. See the accompanying Choice guide on confidentiality for more details.

**"I disclosed to my GP. I respected myself and my GP and decided to speak to her about it. I always see the same GP, she's lovely, and she didn't treat me as a statistic or a number... she treated me as an individual and she spoke to me like she always spoke to me, and I really respected that."**

We are all entitled to fair and respectful treatment when accessing healthcare and it is illegal to treat someone less favourably because they have HIV.

You can find out more about your rights in our accompanying Rights guide.



# GETTING INSURANCE



When taking out insurance, you have a legal obligation to disclose all relevant information and answer any questions as honestly as possible. Whether your HIV positive status is considered 'relevant' depends on the type of insurance you are applying for.

HIV status is unlikely to be relevant for home and contents insurance or car insurance. On the other hand, it will be relevant if you are taking out insurance cover on yourself. On all applications for life assurance, critical illness cover and income protection insurance, you will be asked if you have tested positive for HIV or are awaiting the results of a test. If the answer is yes, you must say so. If you don't disclose when taking out these kinds of insurance policies, then the insurance company won't have to pay out for any claim you make.

*"I went to a bank to get a life insurance policy, so my son would be supported if I became unwell. They asked me if I was HIV positive so I left the bank and said I would finish it afterwards. I then went to another bank and they asked me the same question. I even found somebody online who advertised that they don't ask you medical questions but when I called them they did. I don't know what to do now as I don't want to disclose..."*

When considering life assurance for people living with HIV, insurers will consider factors such as your CD4 count, viral load and time on medication. The criteria can vary between insurers so it's important to speak to a professional. The policies available are likely to be restricted to term assurance policies - this means you would be covered for a fixed period of time such as 10 or 25 years rather than whole of life assurance policies.

Life assurance is available to people living with HIV but you will have to disclose your status to be covered. Here are some real-life examples of people living with HIV who successfully received life assurance from specialists in finding life assurance for people living with pre-existing medical conditions.

## SAME SEX COUPLE

"Ian, 32, is HIV positive and his partner Peter, 30, does not have HIV. Ian was initially declined cover due to his status, but advisors at the specialist agency were able to get him the cover he needed. Ian had been diagnosed eighteen months before he was provided with cover and had a CD4 count of 584 and an undetectable viral load."

## YOUNG COUPLE WITH NEW BABY

"Lisa aged 32, living with HIV, and Patrick aged 29, who does not have HIV, were asked to take out life assurance by the bank for their new mortgage, but felt intimidated by the HIV questions they were asked on their application form. Through a specialist insurance company for people living with long-term conditions, their application was approved. Lisa had been diagnosed six years previously, has a CD4 count of 827 and an undetectable viral load."

**You should always make sure you read and understand the small print on insurance agreements prior to disclosing or entering into a contract.**

You may also be asked about your HIV status when you take out travel insurance. Policies that cover medical expenses usually exclude claims arising from pre-existing conditions, and some companies may refuse to provide travel insurance at all. If you are having problems with finding insurance, there are a range of companies that can provide HIV-specific cover.

When filling out an insurance application, you might have to sign a form confirming that you consent to your GP disclosing health information about you. For example, an AMRA (Access to Medical Records Agreement) that will allow the insurance company to approach both your GP and consultant for information.

If your doctor is contacted by your insurer, they will have to provide all relevant information, including your HIV status. You can find out more about this in our confidentiality guide.

You should always read the small print on insurance agreements prior to either disclosing or entering into a contract. You can also contact insurance companies anonymously to ask them questions about disclosure in advance.



**TRAVELLING ABROAD**

Most countries allow visitors who are living with HIV, but some do restrict people who are HIV positive from entering the country or staying for long periods of time. If a visa application form asks you about your HIV status, you are legally required to disclose. If you don't disclose when asked, and the authorities in your destination country find out, you could run the risk of a fine or even imprisonment for making a false declaration.

Before you travel internationally, you should always make sure you are aware of the laws in the countries you plan to visit. This information is usually available from the consular offices of each country.



**PLAYING SPORTS**

There is no requirement to disclose your status when participating in the vast majority of sports. However, certain contact sports such as boxing may require participants to undergo a medical examination, including an HIV test, in order to compete professionally.



**IN EDUCATION**

If you are a student or you have children with HIV, there is no requirement to inform the school, university or college. Education providers cannot lawfully discriminate against someone because of their HIV status. There is also a legal duty on education providers to make reasonable adjustments for people living with HIV, if they need them, to allow them to take part in education.

# IS THERE A RIGHT WAY TO DISCLOSE?

**If you want to tell someone, make sure to tell someone you trust.**



Deciding whether or not to tell someone you have HIV can be a difficult decision.

Many people fear the impact that disclosing will have on their relationships with partners, friends, family and colleagues. However, telling people you have HIV can also be a rewarding experience: the burden of keeping a secret can be lifted, people can be brought closer together, and better support can be offered.

There is no right or wrong way to tell someone that you have HIV, and no set of rules that should always be followed. How you wish to disclose is personal to you. Remember, you have control over who you tell, and when and how you tell them. You may decide you don't want to tell anyone at all. Consider your own needs first and say only what feels comfortable. Below are some points and tips about disclosure that you may find useful to consider.

Think carefully about who you want to tell, and why you want them to know.

It could be helpful to write out a list of the advantages and disadvantages of telling a particular person to help you decide. For each person you want to tell, ask yourself if the person needs to know now or if it's better to wait.

*"I am normally a very open person so have struggled to keep it from family, but I now feel there is no rush. I will tell them when I'm ready. So remember: do what's right for you, in your own way, with support, in your own time."*

If you want to tell someone, make sure to tell someone you trust. You can never take a disclosure back and telling others means you have less control over how that information is shared. You should be careful about disclosing to people who might not respect your privacy.

*"If you don't want to disclose to certain people, that's OK. It's whatever is right for you, whatever is going to help you feel happy and safe. Once you have told someone you can't un-tell them, so just be sure."*

Think about how they may react. Remember the emotions you felt when you found out and be prepared for others to have their own reactions. Think about whether you are confident that you can deal with their reaction. Disclosing your status can be a huge relief. Although some people will experience rejection, many people find that friends and family are extremely supportive. Be prepared for a variety of reactions: what's the best you can hope for and worst you might have to deal with?

*"I've got two sisters and disclosed to both of them on the same day. My youngest sister was first and she burst into tears. But my other sister, she was the exact opposite, she was really practical. When I told her, she asked how I'd got it and that was it. She was supportive and open with her kids about it as well. Both were positive experiences but it just shows you, within your own family, how two people can react totally different from one another."*



**Get support. It may help to talk to support services, a peer supporter, or a healthcare professional you trust, before disclosing to family, friends and partners.**

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*"The main reaction I got from friends was concern, they wanted to know I was getting the right support and that my health was improving."*

*"Chatting about HIV with people around you first, and getting to know their level of understanding and reasoning on the subject, can be really helpful before disclosing."*

Make it clear that knowledge of your status is something you're trusting them with, and that it's confidential. Be clear whether it is okay for them to tell other people - you may want to tell them to ask your permission before they tell anyone else.

*"Be certain that people you want to disclose to have an understanding about HIV, and that they won't discriminate against you or use the information against you in the future."*

Be prepared for questions. If you are the first person they know who has HIV, they will be on a learning curve. Be prepared with answers to the most likely queries - they may have questions on the basic facts or worries about prevention and testing. Giving them written information about HIV that they can look at later could be helpful. Places where you can access information and support are listed at the end of this guide.

*"I had newspaper articles that I would have someone read if it was too hard to talk face to face, or I would bring them to advocacy forums with me so they could hear me speak."*

*"Don't wind yourself up about it, and if the subject comes up unexpectedly, don't get quiet or embarrassed. You're in a position to educate people from your personal experience."*

**"Knowing the facts and educating myself helped me, so when I told someone and they had questions, I had some basic answers. It helped me feel more confident."**





You should also consider which questions you're comfortable answering. People may ask you how you got HIV and if you don't want to share that information it could be helpful to have a reply ready in advance.

Get support. It may help to talk to support services, a peer supporter, or a healthcare professional you trust, before disclosing to family, friends and partners. They can offer you support to tell people, help you clarify what you want to say and prepare you for any questions. They could also link you to support groups or other people who can help you in the disclosure process. Remember to make yourself a priority. Have a support person lined up to call afterwards or even bring the person with you for the discussion.

*"I don't have to do it alone, I can have someone with me if I need them... The fact that I can talk to a counsellor too about how I feel about disclosure has been helpful. It has helped me discuss any anxieties or fears."*

**"I always say to people, if they are feeling worried about anything, to talk to someone. There are people there to give support. I also try to talk to people about my own positive experiences as it's reassuring to have peer support - to talk to someone who has been through it already."**



**Know your rights. You have the right to be treated fairly and equally, and your HIV status must not be used as a reason to discriminate. You cannot be refused a service because of being HIV positive, or because someone thinks you might be. See our rights and confidentiality guide for more details.**

**"Educate yourself, and know your rights too"**



# INFORMATION AND SUPPORT

## **Equality and Human Rights Commission (EHRC)**

Protects people against discriminatory treatment and holds organisations, such as businesses and Government, to account for what they do.

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

In Scotland:

☎ 0141 228 5910

@ scotland@equalityhumanrights.com

## **Equality and Advisory and Support Services (EASS)**

Advice and support about discrimination and human rights.

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

☎ 0808 800 0082

## **Equality Commission for Northern Ireland (ECNI)**

Provides protection against discrimination on the grounds of age, disability, race, religion and political opinion, sex and sexual orientation.

☎ 028 90 500 600

@ information@equalityni.org

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

## **Citizens Advice**

Provides free, confidential and impartial advice on a range of issues including money, benefit, housing and employment problems.

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

England call 03444 111 444

Wales call 03444 77 20 20

## **Citizens Advice Scotland**

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

☎ 0808 800 9060

## **Acas**

Help and advice for employers and employees.

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

☎ 0300 123 1100



#### THE LAW AND HIV TRANSMISSION

See the information booklet Prosecutions for HIV and STI Transmission or Exposure Guide by HIV Scotland, National AIDS Trust and the Terrence Higgins Trust, available on the HIV Scotland website.

#### TRAVEL

For information on HIV-specific travel and residency restrictions visit: [www.hivtravel.org](http://www.hivtravel.org)

#### JOB-SPECIFIC INFORMATION

##### **Civil Aviation Authority**

The UK's specialist aviation regulator.  
[www.caa.co.uk](http://www.caa.co.uk)

Look for 'Aeromedical certification for HIV+ applicants'

##### **Healthcare Workers**

Look for 'The Management of HIV infected Healthcare Workers who perform exposure prone procedures: updated guidance, January 2014' by Public Health England

#### HIV SUPPORT

To find support services in your area visit:

##### **NAM E-atlas service finder**

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

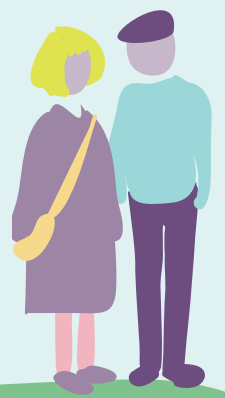
☎ 020 7837 6988  
@ info@nam.org.uk

Or:


##### **HIV Scotland service finder**

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

☎ 0131 5583 713  
@ info@hivscotland.com



**“I don't  
have to do  
it alone...”**



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