

HIV, stigma & discrimination

2012 Third edition



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HIV, stigma & discrimination

This booklet is for people living with HIV and is about stigma and discrimination. The booklet explains what stigma and discrimination are, makes some suggestions for how to deal with these problems and gives information about your legal rights.

Throughout the booklet are short quotes from real people living with HIV about their experiences of stigma and discrimination and the way that they've responded. You may find them useful, but people respond to situations in different ways, so don't think that you have to react in the way suggested by these examples.

Some of the quotes were collected from feedback to NAM, others by the People Living with HIV Stigma Index (www.stigmaindex.org) during their research in the UK. NAM is grateful to Stigma Index for permission to reproduce these quotes.

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HIV in the UK today

Living with HIV now is a very different experience to living with HIV ten or twenty years ago. And living with HIV in the UK is quite different to living with HIV in some other parts of the world.

For those able to access it, HIV treatment has brought a longer, healthier life to tens of thousands of people. The UK's medical services for people with HIV are among the best in the world.

There have been legal changes too. Since 2005, it's been illegal to discriminate, in areas like health care and employment, against a person because they have HIV. It's also illegal to

discriminate against a person because of their race, sexuality or gender.

Public attitudes are also changing. In most social groups, it's no longer considered acceptable to display prejudice against people because of their disability, ethnicity, gender or sexuality.

People with HIV are living full lives and there are very few things that you can't do just because you have HIV. Crucially, most people with HIV find that they are loved, accepted and supported by those close to them.

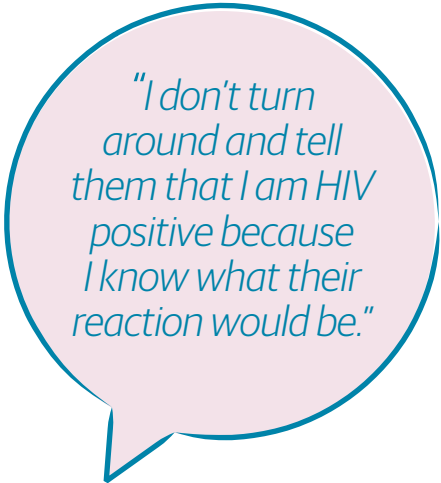
But we don't live in a perfect world. People with HIV do still come across stigma, prejudice and discrimination. This can often be the worst part of living with HIV.

HIV in the UK today

It's worth knowing that stigma and discrimination are taken seriously by the organisations that work for the rights and wellbeing of people with HIV. There has been progress tackling these issues, although more needs to be done.

To deal with stigma and discrimination, it can be helpful to understand what causes them, to work out ways of responding to them, and to find out where you can go for help and support.

You've made a good first step dealing with these issues by reading this booklet.

A light pink speech bubble with a blue outline, containing a quote in blue cursive text.

"I don't turn around and tell them that I am HIV positive because I know what their reaction would be."

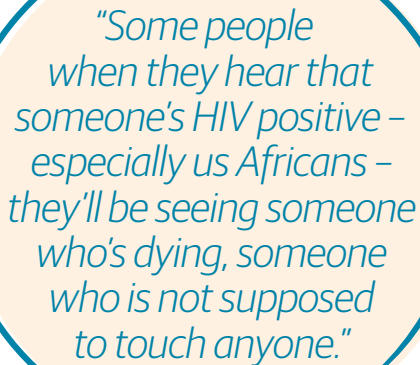
What is stigma?

Stigma means different things to different people.

This is one dictionary's definition: *"The shame or disgrace attached to something regarded as socially unacceptable."*

There may be a feeling of 'us and them'. People who are stigmatised are marked out as being different and are blamed for that difference.

HIV is an infection which many people have fears, prejudices or negative attitudes about. Stigma can result in people with HIV being insulted, rejected, gossiped about and excluded from social activities.



"Some people when they hear that someone's HIV positive – especially us Africans – they'll be seeing someone who's dying, someone who is not supposed to touch anyone."

What is stigma?

Fear of this happening can lead to people with HIV being nervous about telling others that they have HIV or avoiding contact with other people. They may end up suffering in silence instead of getting the help they need.

Stigma can also result in people with HIV believing the things that other people say about HIV. For example, they may think it's true that HIV is a death sentence or that most people with HIV are immoral or irresponsible.

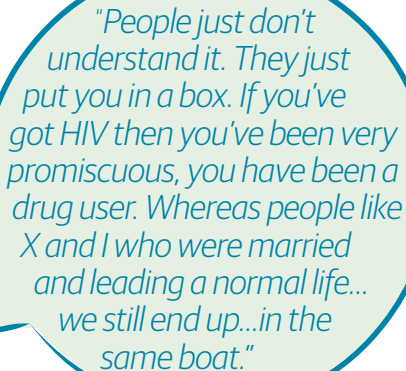
Stigma is often attached to things people are afraid of. Ever since the first cases of AIDS in the early 1980s, people with HIV have been stigmatised. There are a number of reasons for this:

- HIV is a serious, life-threatening illness. There is a long history of illnesses being stigmatised – cancer and tuberculosis are two other examples.
- People who don't understand how HIV is transmitted may be afraid of 'catching' it through social contact.
- Some people have strong views about sexual behaviour. They may think that there are situations in which sex is wrong or that certain people shouldn't behave in particular ways.
- The way people think about HIV depends on the way they think about the social groups that are most affected by HIV. Some people already have negative feelings about

What is discrimination?

women, gay men, immigrants, black people, drug users and others.

Stigma leads to people not being treated with dignity and respect.



"People just don't understand it. They just put you in a box. If you've got HIV then you've been very promiscuous, you have been a drug user. Whereas people like X and I who were married and leading a normal life... we still end up...in the same boat."

What is discrimination?

While stigma is sometimes hard to pin down (it may be found in people's attitudes or beliefs), discrimination is a little easier to describe. It's about actual behaviour.

Discrimination means treating one person differently from another in a way that is unfair – for example, treating one person less favourably simply because he or she has HIV.

Depending on the situation in which discrimination occurs, it may be against the law. The *Equality Act* protects against discrimination at work, in education and when using shops, businesses and services.

What is discrimination?

The *Equality Act* applies in England, Wales and Scotland. In Northern Ireland, similar protections are given by the *Disability Discrimination Act*.

Here are some examples of things which would normally be against the law:

- A dental surgery which refuses to register people with HIV as patients.
- A company which pays a lower salary to employees with HIV.
- A sports club which, because of unjustified fears of HIV transmission, excludes people with HIV.

All people 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.

For the purposes of these laws, people with diagnosed HIV are defined as having a 'disability'. Some people with HIV don't feel disabled and would prefer not to be described in this way. Whether or not you agree with the definition, you can still benefit from the protection of the law.

Myths and facts

When thinking about stigma and discrimination, a good place to start might be to consider how irrational and wrong they are.

Stigma and discrimination are usually based on ignorance and prejudice. There are some common misconceptions about HIV, and it's worth reminding yourself that these views are factually incorrect.

Myth X People with HIV are a public health risk

In fact, HIV is difficult to catch. It cannot be picked up during day-to-day contact and good hygiene practices are enough to protect healthcare workers.

You can prevent passing on HIV to sexual partners by using condoms. Mother-to-child transmission of HIV can be prevented in nearly all cases with the right treatment and care.

Myth X HIV is a death sentence

Yes, untreated HIV can be fatal and people do still become ill because of HIV. But HIV treatment is highly effective.

Most people who receive HIV treatment at the right time, take it as prescribed, and look after their health will live a long and healthy life.

Myth X HIV treatment is too expensive for the NHS

HIV treatment is highly cost-effective and enables people to live full and productive lives.

Myths and facts

Without treatment, people with HIV will eventually become extremely ill. They will then need medical care that is much more expensive than HIV drugs.

Myth X 'Health tourists' come to the UK to take advantage of free NHS health care

If people moved to the UK because of the free health care, they would probably start to use health services soon after they arrived. In fact, the average length of time between a person arriving in the UK and getting care from an HIV clinic is five years.

Also, HIV rates are lower in people moving to the UK than in the countries they come from.

Myth X Finding out you have HIV is the end of the world

Being diagnosed with HIV will change your life. Some people with HIV experience health problems, loneliness, exclusion, poverty or unhappiness. All too often, such experiences are related to the discrimination that people with HIV experience from others, the fear of being rejected, or because they blame themselves for the situation they are in. But in time, many HIV-positive people maintain and form new close relationships, have the support of their families, have children without putting others at risk of HIV, have fulfilling love and sex lives, maintain and develop careers, and make plans for the future.

What people think about HIV

This booklet focuses on problems. But it's worth knowing that the majority of adults living in the UK say that people with HIV should be treated with respect.

According to a 2010 survey of the general public:

- Two-thirds of those who answered the survey would feel comfortable working with a colleague who had HIV.
- Two-thirds agree with laws protecting people with HIV from discrimination.
- Three-quarters believe that people with HIV deserve the same support and respect as those with cancer.

More information on the survey is available on the National AIDS Trust website:

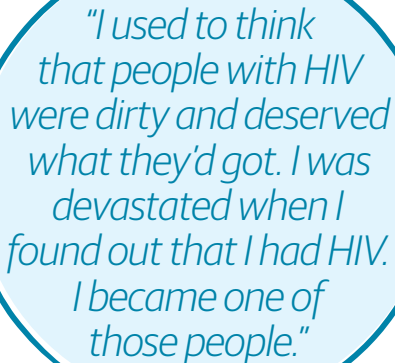
www.nat.org.uk

Your own feelings about HIV

Stigma is one of the reasons that some people end up having quite negative feelings about themselves and about having HIV.

In society, a lot of negative and inaccurate ideas are spread about HIV. It can be difficult for anybody, including people with HIV, to ignore all these ideas and not be influenced by them.

Before you found out that you have HIV, perhaps you looked upon people with HIV in a rather negative way yourself. Or perhaps HIV wasn't a topic that you had thought too much about. But without realising it, you may have taken on board some of those inaccurate ideas.



"I used to think that people with HIV were dirty and deserved what they'd got. I was devastated when I found out that I had HIV. I became one of those people."

Your own feelings about HIV

When you find out that you have HIV, it can be difficult to shake these ideas off. For example, some people with HIV believe that they deserved to get it, that they are not worth looking after, or that having HIV is a death sentence.




"Sometimes I just want to be myself without HIV. Before I was open but nowadays I'm closed; I'm closing my doors and windows."

If you feel this way, it's important to question and challenge these thoughts and feelings. HIV support organisations can help you do this.

If you think carefully about all the things you've ever heard about HIV and then compare that with what you know about your own life, you may find that a lot of what you've heard was just plain wrong.

Some people find it useful to meet other people with HIV and to hear their experiences. This may give you a better idea of how people live with HIV and what it means to them. There are some ideas about how you can do this in the next section.



"My main feeling when I first found out that I had HIV was 'Why me?'. I blamed myself for getting it, for not being careful, but eventually I realised it wasn't my fault."

Connecting with others

You don't need to deal with problems on your own. Talking to someone close to you about how you feel about HIV and its effect on your life can really help. But if you don't feel able or ready to tell friends, family or loved ones that you have HIV or about your feelings, there is support available from organisations which can help.

Some good places to start are THT Direct (0808 802 1221) or I Do It Right (0800 0967 500), where there are trained staff who you can talk to in confidence about your feelings and concerns.

These helplines can also give you details of other organisations that can help. Staff at your

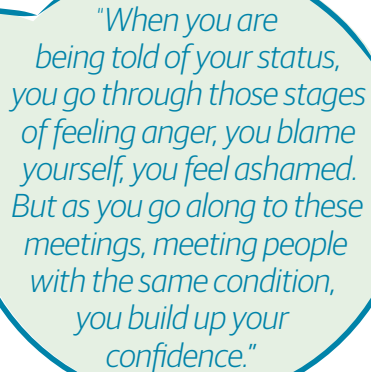
Connecting with others

HIV clinic will also know about local support organisations.

Even if your family and friends are supportive, you may find it helpful to meet other people who are living with HIV. It may be good to talk to someone who's going through similar things to you or has been through them before.

Many HIV organisations host groups for people with HIV to meet, talk, and provide mutual support. Some people find it helpful to dip into a group when they're feeling under pressure or dealing with a particular problem. Others use them as a source of long-term support and feel they are part of a positive community. Some groups are open to all people with HIV, while others are only open to people from certain communities.

Some organisations also offer courses for people who have recently found out they have HIV or for people who want to learn more about living well with HIV. These are also good opportunities to meet other people with HIV.



"When you are being told of your status, you go through those stages of feeling anger, you blame yourself, you feel ashamed. But as you go along to these meetings, meeting people with the same condition, you build up your confidence."

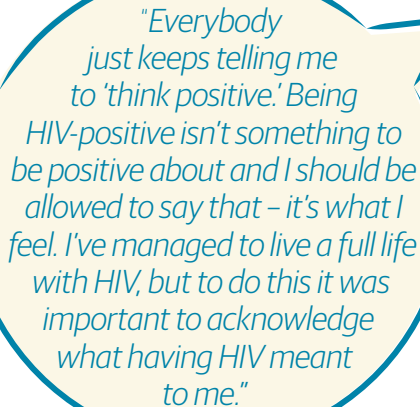
Connecting with others

Not everybody finds these courses and groups useful, so don't think that there's something wrong with you if you try one and it doesn't suit you. There is nothing to stop you trying another one, or coming back at some stage in the future.

Support groups have strict rules about confidentiality, so you shouldn't have to worry about people finding out that you're going to one.

On the internet, you can also get support and information from other HIV-positive people. There are some specialist websites which have discussion forums and which aim to create an online community. There are other websites which will put you in touch with other people with HIV, either for dating or for friendship.

While most of the people you contact through these websites will be genuine, it's advisable to take care when exchanging personal information or arranging to meet in person.



"Everybody just keeps telling me to 'think positive.' Being HIV-positive isn't something to be positive about and I should be allowed to say that – it's what I feel. I've managed to live a full life with HIV, but to do this it was important to acknowledge what having HIV meant to me."

Other people's stories

There are also some websites in which people with HIV have written first-hand accounts of their experiences and feelings. On other websites, you can watch videos of people with HIV telling their stories. You may find some of these websites encouraging or helpful:

- ➔ www.aidsmap.com/inyourownwords
- ➔ www.myhiv.org.uk
- ➔ www.healthtalkonline.org/chronichealthissues/HIV
- ➔ www.hivaware.org.uk/be-aware/real-stories.php
- ➔ www.avert.org/stories.htm
- ➔ www.positivelyuk.org/personal_stories.php (women's stories)

- ➔ www.livingstories.org.uk (stories from people with haemophilia)

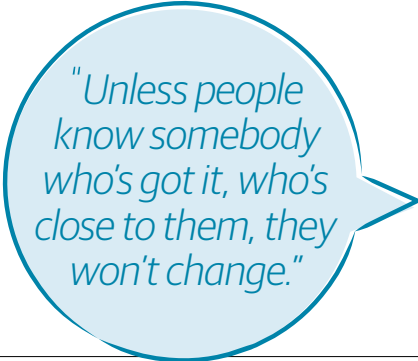
Deciding whether to tell people that you have HIV

Because of stigma, many people with HIV think quite carefully about whether to tell people that they have HIV or not. One way that some people avoid experiences of stigma and discrimination is by not telling others that they have HIV.

In a great many situations, HIV simply isn't relevant and is unlikely to come up in conversation. Many people with HIV decide that the majority of people they come into contact with have no need to know about their health status.

On the other hand, disclosing their HIV status may be the single most powerful thing that a person with HIV can do to fight stigma.

Deciding who to talk to about HIV is a very personal decision, and what is right for one person won't necessarily be right for another person.



"Unless people know somebody who's got it, who's close to them, they won't change."

Deciding whether to tell people that you have HIV



"I've been very careful as to who I tell. I don't think I have been discriminated against or stigmatised in any way, but I think that's because of who I've chosen to tell."

There can sometimes be advantages to telling people you trust or people who will be able to help in some way. If they understand what you

are going through, they may be able to give you the love and support you need. Sharing a confidence can sometimes make a relationship stronger and you won't have the effort of hiding your HIV status.

Sometimes people who are told respond in an unkind or hurtful way. But this probably happens less often than many people think. Most people with HIV find that most of the people they tell react well.

Telling people that you have HIV is more likely to be a positive experience if you are careful about who you tell and how you tell them. Here are five questions to ask yourself each time you think about telling someone that you have HIV.

Deciding whether to tell people that you have HIV

"The person I would never, ever tell in my life is my mum. You know back home, they are highly ignorant of HIV. They don't even believe that there is a way you can manage your life and live longer. Once they hear that someone is HIV positive, the thing that comes into their head is death. I wouldn't want her to know about it - she might die thinking about it."

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 following questions, and check that it still seems a good idea.

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.

Deciding whether to tell people that you have HIV

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 – and is not – transmitted at hand to provide reassurance.

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

What are your options if they react badly?

In some situations, while it would be very disappointing if a person reacted badly, it wouldn't have serious consequences. For example, you might want to stop seeing the person, but this may be okay if there are other people you can turn to.

But in other cases, you might be considering telling someone that you are financially or emotionally dependent on, or who is important to you in some other way. The consequences of the person reacting badly would be more serious.

For example, if you are thinking about telling someone you live with, what would your options be if they reacted badly and you couldn't go on living with them?

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

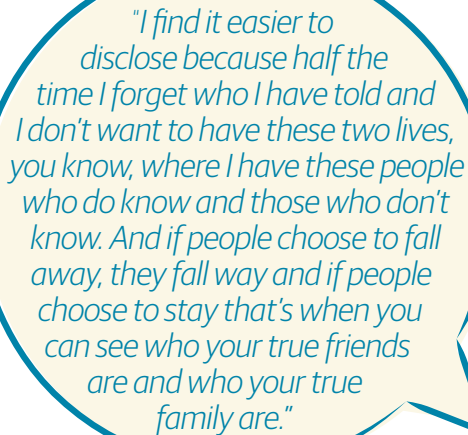
Deciding whether to tell people that you have HIV

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 meant to talk about it with anyone at all, this will be hard for them.

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.



"I find it easier to disclose because half the time I forget who I have told and I don't want to have these two lives, you know, where I have these people who do know and those who don't know. And if people choose to fall away, they fall way and if people choose to stay that's when you can see who your true friends are and who your true family are."

Sexual partners

The decision to tell (or not to tell) a sexual partner can be particularly complex. There can be several reasons for this. There may be strong feelings and emotions between you, while at the same time there may be concerns about the risks of HIV being passed on. Many people with HIV have faced rejection from sexual partners, so don't find disclosing their status easy.

There is no legal obligation to tell your sexual partners that you have HIV. But it's important to know that there can be legal implications to not telling, if the sex you have puts the other person at risk of HIV infection.

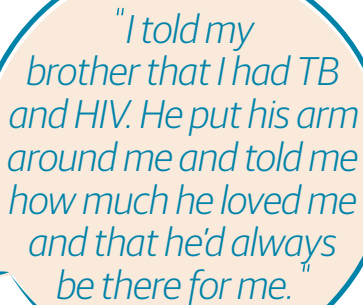
In England, Wales and Northern Ireland, a person can be sent to prison if they do not tell a partner that they are HIV-positive before having sex without a condom – and the sex results in HIV transmission.

In Scotland, the law is different. A person with HIV may be sent to prison if they do not tell a sexual partner that they are HIV-positive before having sex without a condom. They may be convicted even if there is no HIV transmission.

In order to get more detailed information about the law or to talk through the issue of telling a sexual partner, it may be helpful to contact a confidential telephone helpline such as THT Direct (0808 802 1221). You can also

Telling people you are close to

get information on these topics at www.aidsmap.com, in the NAM booklet *HIV & sex* or in the Terrence Higgins Trust booklet *Your decision*. Talking to other people with HIV about how they deal with these things might also be helpful.



"I told my brother that I had TB and HIV. He put his arm around me and told me how much he loved me and that he'd always be there for me."

Telling people you are close to

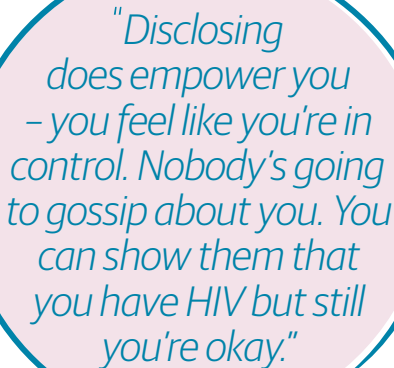
The thought of facing HIV alone is daunting. People often look first to their partner, family members or friends for support.

In a 2010 survey, over two-thirds of people in the UK said that if a family member said that they were HIV-positive, it wouldn't damage their relationship with them.

And a great many people with HIV have found that those who were closest to them before they got HIV have continued to provide loving support. The knowledge that people you are close to are still supportive can provide the confidence and strength to

Telling people you are close to

overcome any prejudice or discrimination you face in wider society.



"Disclosing does empower you – you feel like you're in control. Nobody's going to gossip about you. You can show them that you have HIV but still you're okay."

Even if somebody close to you reacts badly when they first find out that you have HIV, it could be that their attitude will change over time. It may just be that they are shocked, upset, or worried about your health. They may be worried about their own health.

But sometimes relationships do get worse, either for a short period or for a longer period.

If you don't feel that you can trust or rely on family or friends for support – or if someone reacts badly when you tell them you have HIV – remember that there are specialist HIV organisations that can help. Even if you feel that you're alone, you don't have to be.

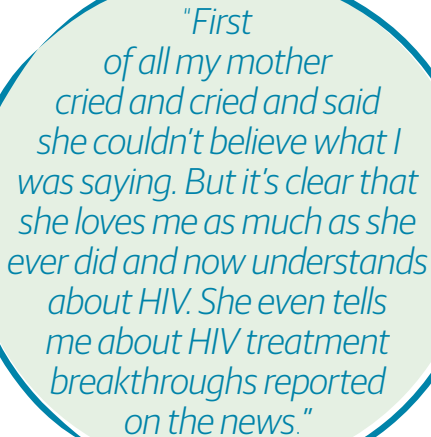
Telling people you are close to

HIV support organisations can help with practical problems you might be facing, such as housing or financial problems. Talking with people from these organisations can also help you identify who might be the best people in your life that you can rely on to be supportive.

You can find contact details for HIV support organisations towards the end of this booklet.

Telling children

Giving a child information about HIV is usually an ongoing process. You may need to tell the child about their own health, or about that of a family member. What you say at any one time will depend on the child's age, their level of understanding, and their readiness to know. For more on this, see NAM's booklet *HIV & children*.



"First of all my mother cried and cried and said she couldn't believe what I was saying. But it's clear that she loves me as much as she ever did and now understands about HIV. She even tells me about HIV treatment breakthroughs reported on the news."

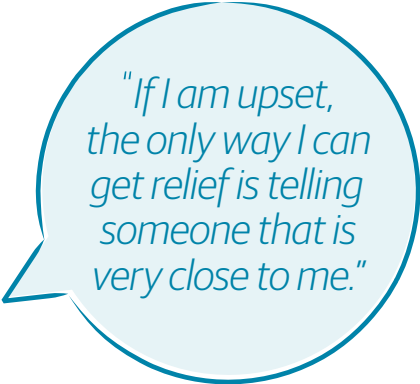
Dealing with stigma and discrimination

Experiencing stigma and discrimination can be very painful. Try not to bottle up your feelings about these experiences.

First of all, don't blame yourself. Remind yourself that stigma and discrimination are wrong.

If you can, talk to somebody close to you that you trust, or make contact with an HIV support organisation so that you can safely talk through your experiences and feelings. (You can find contact details for HIV support organisations towards the end of this booklet.)

If it feels safe, and you have the confidence to do so, it may be worth speaking to the person who has said or done something that you think is stigmatising or discriminatory.



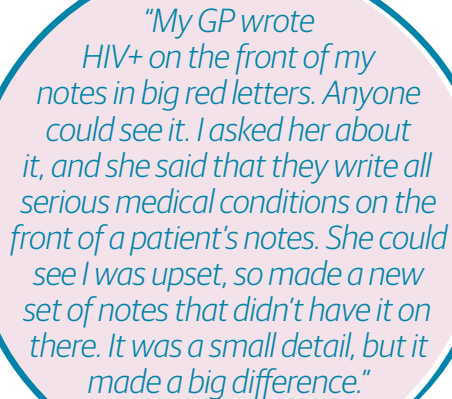
"If I am upset, the only way I can get relief is telling someone that is very close to me."

Dealing with stigma and discrimination

It's best to stay calm and open-minded when doing this. It's possible that the person did not mean any offence or that you've misinterpreted their words or actions. If you fear stigma or discrimination, it's sometimes possible to misinterpret quite innocent episodes.

You could ask the person why they said or did the thing that has upset you. You could then calmly explain your point of view. This gives the person an opportunity to put things right.

But if the person's response isn't satisfactory, you may want to take things further. For example, if he or she works for a business or an organisation, you could speak to someone more senior.



"My GP wrote HIV+ on the front of my notes in big red letters. Anyone could see it. I asked her about it, and she said that they write all serious medical conditions on the front of a patient's notes. She could see I was upset, so made a new set of notes that didn't have it on there. It was a small detail, but it made a big difference."

Dealing with stigma and discrimination

There are often more formal ways of challenging discrimination. This may involve using complaints procedures or the law. Going through these processes can be emotionally draining and time-consuming, with no guarantee of a satisfactory result. But there are a number of organisations which can help you with them, some of which are listed towards the end of this booklet.

Discrimination against people with HIV is taken seriously by the government, its agencies and organisations that work for people with HIV. The *Equality Act* makes it illegal to discriminate against people with HIV in employment, education, housing and the provision of goods and services.

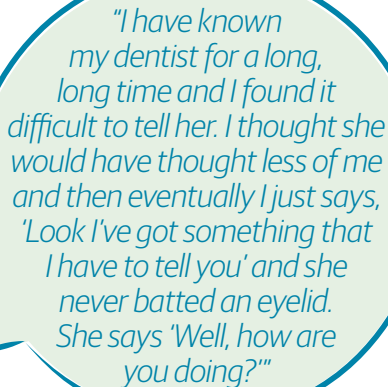
It may be reassuring just to know what the law or a policy says. That way you can know for sure that you shouldn't have been treated in a certain way.

Your rights in health care

Everybody with HIV needs to go to a specialist HIV clinic to get the best possible treatment and care. It's also important to have a GP and from time to time you'll probably have to see other health specialists.

Sometimes people with HIV experience difficulties with healthcare workers. But there are similar rules and codes of ethics in all healthcare services and in all parts of the NHS, so you ought to be treated with respect whether you are at the HIV clinic, other hospital service, GP or dentist.

Under the *Equality Act*, it is illegal to discriminate against people with HIV in health care – this means that you should not be refused a service or receive a less favourable service because you have HIV. Also, healthcare



"I have known my dentist for a long, long time and I found it difficult to tell her. I thought she would have thought less of me and then eventually I just says, 'Look I've got something that I have to tell you' and she never batted an eyelid. She says 'Well, how are you doing?'"

Your rights in health care

professionals work to codes of ethics to make sure that their personal prejudices don't interfere in the kind of treatment they offer to patients.

There are strict rules about the confidentiality of medical information and medical records. Although it's normal for healthcare workers who are treating you to have access to your medical records (which may mention your HIV status), this information should not be shared with others. For example, you must give permission before your doctor can provide medical information about you to an insurance company or an employer.

To find out more about confidentiality, visit our website, www.aidsmap.com, or read the

NAT booklet *Personal information and the NHS: a guide for people living with HIV*. It is available at www.nat.org.uk or by calling 020 7814 6767.

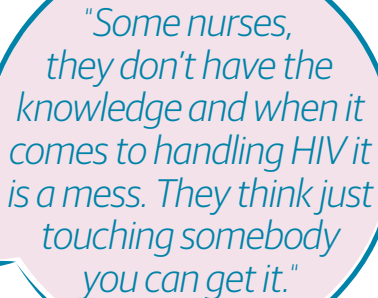
If you have moved to the UK from another country, you may have questions over your entitlement to free NHS care. The rules covering this are complex, so it's important to get specialist advice. Good places to start would be THT Direct (0808 802 1221) or I Do It Right (0800 0967 500).

Some medical procedures involve contact with blood and other body fluids. To avoid infection or onward transmission, healthcare workers should follow 'universal' infection control procedures. No extra precautions are

Your rights in health care

required when the healthcare workers know that their patient has HIV.

Unfortunately there are occasions when healthcare workers don't live up to the



"Some nurses, they don't have the knowledge and when it comes to handling HIV it is a mess. They think just touching somebody you can get it."

standards that we expect. Sometimes it's a simple mistake or oversight, or ignorance, but sadly it can be because a healthcare worker is prejudiced.

If you have tried discussing the problem with the healthcare worker concerned or with a manager and haven't had a satisfactory response, then you may want to deal with the matter in a more formal way.

In most areas, the NHS has a Patient Advice and Liaison Service (PALS) which should help you to sort out the problem or, if necessary, make a complaint. You could also tell an HIV organisation about what you've experienced – they may be able to help you make a complaint and offer practical and emotional support.

There are well-established complaint procedures in the NHS. The standard of care you receive should not be affected because you are making a complaint. There's information on how to make a complaint on page 46.

Your rights at work

Most people with HIV will never experience any problems at work because they have HIV.

But stigma and discrimination can occur in the forms of breaches of confidentiality, gossip, being left out of activities, or even losing your job after your employer finds out you have HIV.

It's therefore good to know that the *Equality Act* provides very important protections at work to people with HIV. The protection covers recruitment, terms and conditions of employment, the way you are treated at work, and opportunities for job development and promotion.

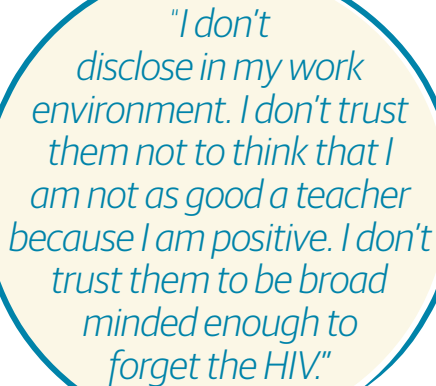
Your rights at work

For the purposes of the law, people with diagnosed HIV are considered to have a disability and cannot be discriminated against because of their health status.

But there are two important exceptions. Healthcare workers with HIV can be excluded from jobs such as surgery and dentistry. Also, people with HIV can be excluded from the armed forces.

When applying for a job, you may be asked to complete an equal opportunities monitoring form which asks if you have a disability. The form should be handled separately from your job application and treated in confidence. Nonetheless, you are not obliged to complete this form or answer this question.

In most cases, the employer is not permitted to ask more detailed questions about your health *before* making a job offer. However, once a job



"I don't disclose in my work environment. I don't trust them not to think that I am not as good a teacher because I am positive. I don't trust them to be broad minded enough to forget the HIV."

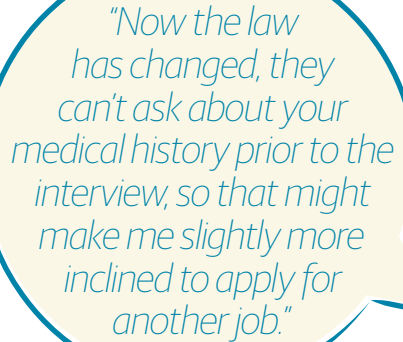
Your rights at work

offer is made, the employer may ask you to complete a more detailed medical questionnaire.

While many people choose not to mention their HIV status, dishonesty at this stage could be considered grounds for termination of employment. On the other hand, if the employer withdrew an initial job offer after learning that you have HIV, you may be able to show that this was illegal discrimination.

If an employer asks your doctor for a medical report, you need to give permission before a report is sent.

Your employer is also legally obliged to protect the confidentiality of private information that it holds about you.



"Now the law has changed, they can't ask about your medical history prior to the interview, so that might make me slightly more inclined to apply for another job."

Most people find that having HIV doesn't make any difference to their ability to do their job at all. But if having HIV does make doing the job more difficult, then you can ask for what's called a 'reasonable adjustment'. For example,

some people have asked for time off to go to their medical appointments. And others have asked for flexible working hours when they've had trouble with treatment side-effects.

HIV organisations have helped people with HIV secure fair treatment at work. Two leaflets explaining the rights of people with HIV at work have been produced by the National AIDS Trust (NAT), called *HIV+ Recruitment* and *HIV @ Work*. They are available at **www.nat.org.uk** or by calling 020 7814 6767.

Your rights with insurance companies

Unfortunately, some personal finance products are not available to people who know they have HIV. This includes most life insurance policies, private medical insurance, critical illness cover and income protection. Insurance application forms should be filled in honestly and accurately – if they are not, the policy will not be valid and the company may refuse to pay out if a claim is made.

On the other hand, if you took out a policy *before* you found out that you have HIV, it may continue to be valid. You need to check the small print of the policy, in particular the list of 'exclusions'.

If an insurance company asks your doctor for a medical report, you need to give permission before a report is sent.

In terms of travel insurance, policies often exclude cover for pre-existing medical conditions, including HIV. Nonetheless, it may be worth taking out cover just in case you have an illness that is unrelated to HIV, have an accident, lose your luggage or have something stolen. In addition, some specialist companies do provide cover for people with pre-existing medical conditions, including HIV.

Having HIV shouldn't prevent you from getting a mortgage or a pension.

Your rights in housing, shops and services

The *Equality Act* also makes it illegal to discriminate against people with HIV in the provision of goods and services, such as when finding housing or when using shops, restaurants and hotels. This means, for example, that a business can't refuse your custom or treat you less favourably because you have HIV. Similarly, a landlord cannot refuse to let a property to you because you have HIV.

A few people with HIV have suffered threatening or abusive behaviour from neighbours or other people in the community. This sort of harassment is illegal, whatever its motive.

Your rights in housing, shops and services

In addition, if you are harassed or attacked because you have HIV (or because of your race or sexuality), this is classed as a 'hate crime'. The police give a high priority to investigating hate crimes and the perpetrator may be given a tougher sentence by a court.



"Our windows were smashed and our car vandalised when our neighbours found out we had HIV. We reported it to the police. They were understanding and helpful and took action. But it was still a horrible experience and we ended up moving."

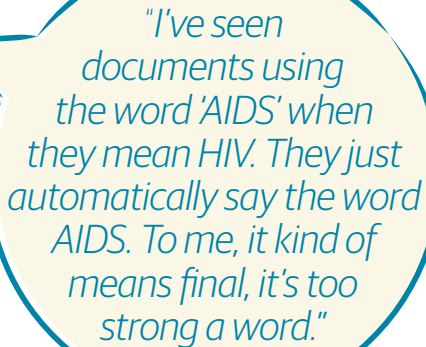
Your rights with the media

HIV sometimes gets good coverage in the media. At other times the media uses clichés, is inaccurate and expresses prejudice. It can be annoying to find HIV described as a 'death sentence' or to see people with HIV being represented as irresponsible.

One way of coping with stigma in the media is to ignore it. If you know that an article in a newspaper or a programme on the TV or radio is going to upset you or make you angry, then you don't need to read, watch or listen to it.

Try and develop a strategy for dealing with inaccurate or stigmatising media items. For

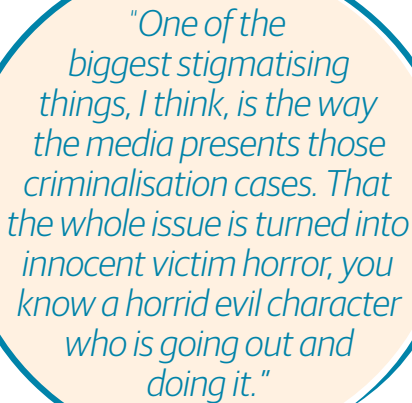
example, tell yourself how poor it is that a journalist is so bad at their job that they can't get basic facts right. Or try reminding yourself that the stigma or prejudice that an item reflects is simply wrong.



"I've seen documents using the word 'AIDS' when they mean HIV. They just automatically say the word AIDS. To me, it kind of means final, it's too strong a word."

Your rights with the media

You might want to write a letter of comment or complaint, pointing out the item's faults and inaccuracies.



"One of the biggest stigmatising things, I think, is the way the media presents those criminalisation cases. That the whole issue is turned into innocent victim horror, you know a horrid evil character who is going out and doing it."

News-based websites usually have a response page where you can point out errors and inaccuracies. Any reputable TV or radio station will have a department to respond to viewers' and listeners' comments and complaints, and newspapers and magazines have letters pages.

The National AIDS Trust (NAT) has a specialist press department which actively challenges bad coverage of HIV. So if you don't feel confident complaining to the media yourself, try contacting NAT's press office on 020 7812 6767. NAT has made successful complaints to the Press Complaints Commission (0845 600 2757) about the way HIV is reported.

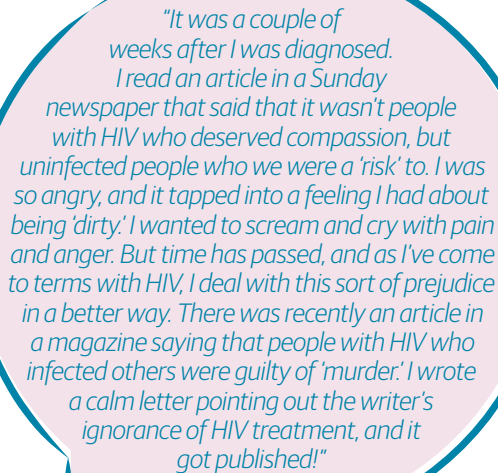
NAT also has a team of people with HIV called the 'Press Gang.' They are interested

Your rights with the media

in engaging with the media to try and make sure that HIV is accurately reported and that inaccuracies are challenged. For more information, contact NAT on the number listed above.

Similarly, the African Health Policy Network (AHPN) has a group called Ffena. They also aim to influence the way the media talks about HIV and can be contacted on 020 7017 8910.

Should you become the focus of media attention, think very carefully before speaking to a journalist and consider asking an HIV agency with experience of media work for support.



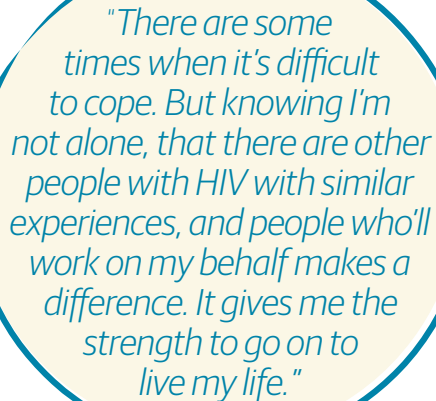
"It was a couple of weeks after I was diagnosed. I read an article in a Sunday newspaper that said that it wasn't people with HIV who deserved compassion, but uninfected people who we were a 'risk' to. I was so angry, and it tapped into a feeling I had about being 'dirty.' I wanted to scream and cry with pain and anger. But time has passed, and as I've come to terms with HIV, I deal with this sort of prejudice in a better way. There was recently an article in a magazine saying that people with HIV who infected others were guilty of 'murder.' I wrote a calm letter pointing out the writer's ignorance of HIV treatment, and it got published!"

Getting support and championing your rights

There are a lot of organisations to turn to if you feel stigmatised or have experienced discrimination. There are also organisations which can help you make your voice heard or who lead campaigns against the unfair treatment of people living with HIV.

Here are the details of just some of the organisations which support people with HIV.

To get details of organisations in your local area, telephone THT Direct (0808 802 1221), ask at your HIV clinic or visit www.aidsmap.com/e-atlas.



"There are some times when it's difficult to cope. But knowing I'm not alone, that there are other people with HIV with similar experiences, and people who'll work on my behalf makes a difference. It gives me the strength to go on to live my life."

Getting support and championing your rights

African Health Policy Network (AHPN)

The African Health Policy Network (AHPN) is an umbrella organisation that represents African community groups addressing HIV/AIDS and sexual health throughout the UK.

A number of its projects tackle HIV-related stigma and it has worked to improve faith leaders' understanding of HIV. AHPN organises a network called Ffena which helps make the voices of African people with HIV heard.

New City Cloisters
196 Old Street
London EC1V 9PF

Tel: 020 7017 8910

Email: info@ahpn.org

Web: www.ahpn.org

I Do It Right helpline

Advice and referrals on sexual health and HIV for African people in the UK. Support and advice is provided in English, French, Luganda, Shona and Swahili. Advisers have experience of talking to people about stigma in everyday settings.

Tel: 0800 0967 500 (Mon - Fri, 10am - 6pm)

Web: www.idoitright.co.uk

Equality and Human Rights Commission (EHRC)

The EHRC helpline gives information and guidance on the Equality Act, discrimination and human rights.

England: 0845 604 6610

Wales: 0845 604 8810

Getting support and championing your rights

Scotland: 0845 604 5510

(Mon - Fri, 8am - 6pm)

Web: www.equalityhumanrights.com

GMFA

GMFA is a gay men's health charity doing HIV prevention work as well as projects aiming to improve the health of HIV-positive gay men.

11 Angel Wharf

58 Eagle Wharf Road

London N1 7ER

Telephone: 020 7738 6872

Email: gmfa@gmfa.org.uk

Web: www.gmfa.org.uk

The Haemophilia Society

The Haemophilia Society provides information and support to all those living with haemophilia and other blood clotting disorders and represents their interests to the NHS and government.

Petersham House

57a Hatton Garden

London EC1N 8JG

Telephone: 0800 018 6068

Email: info@haemophilia.org.uk

Web: www.haemophilia.org.uk

HIV Scotland

HIV Scotland is an HIV voluntary sector policy and support organisation, providing co-ordination and responding to issues such as stigma and health inequalities in Scotland.

Getting support and championing your rights

Suite 2
Beaverhall House
27 Beaverhall Road
Edinburgh EH7 4JE

Telephone: 0131 558 3713

Email: info@hivscotland.com

Web: www.hivscotland.com

NAM

NAM produces a range of HIV treatment and other related information, both in print and online. Our website includes lots of information on HIV and an e-atlas of HIV services, so you can find what's available near you.

77a Tradescant Road
London SW8 1XJ

Telephone: 020 3242 0820

Email: info@nam.org.uk

Web: www.aidsmap.com

National AIDS Trust (NAT)

A campaigning and policy organisation that has taken a lead in fighting HIV-related stigma. Its campaigning work and information resources have dealt with employment, benefits, housing, confidentiality, the immigration system, criminal prosecutions and other issues. NAT takes an active role in challenging inaccurate and stigmatising media coverage of HIV.

New City Cloisters

196 Old Street

London EC1V 9FR

Telephone: 020 7814 6767

Getting support and championing your rights

Email: info@nat.org.uk

Web: www.nat.org.uk

Naz Project London

Naz Project London provides sexual health and HIV prevention and support services to South Asian, Muslim, Horn of African, Portuguese-speaking and Spanish-speaking communities. Naz aims to educate and empower communities to face up to the challenges of sexual health and the AIDS pandemic, and to mobilise the support networks that exist for people living with HIV/AIDS.

30 Blacks Road
London W6 9DT

Telephone: 020 8741 1879

Email: npl@naz.org.uk

Web: www.naz.org.uk

The People Living with HIV Stigma Index

This is a participatory research project, led by people with HIV, aiming to better understand how stigma and discrimination are experienced by people with HIV. The project is being rolled out across the world, including in the UK.

Some of the quotes used in this booklet came from Stigma Index participants in the UK. More details are available at www.stigmaindex.org/50/analysis/uk.html

Web: www.stigmaindex.org

Positively UK

A national charity working for people affected by HIV, Positively UK offers one-to-one and peer support as well as information, advice

Getting support and championing your rights

and advocacy for HIV-positive women, men and families.

345 City Road
London EC1V 1LR

Telephone: 020 7713 0222
(Mon - Fri, 10am - 4pm)

Email: info@positivelyuk.org

Web: www.positivelyuk.org

Shout Loud

A joint project from several sexual health, contraception and HIV organisations, campaigning for better services.

Web: www.shoutloud.org.uk

Terrence Higgins Trust

Terrence Higgins Trust (THT) is the largest HIV charity in the UK. THT provides extensive published information and a wide range of support and advocacy services in towns and cities throughout England, Wales and Scotland.

THT Direct is a phone line providing a gateway to HIV information, services and support. Details of services provided by THT and by other HIV organisations can be obtained from THT Direct.

THT has also taken a leading role in campaigning for equality for people with HIV and for better sexual health services for everybody. Its campaigning website provides details of current campaigns and tips on how to influence health services.

Making a complaint

THT Direct: 0808 802 1221

10am to 10pm Monday to Friday

12 noon to 6pm at weekends

Email: info@tth.org.uk

Web: www.myhiv.org.uk

Web: www.campaigning.tth.org.uk

Your Work Health

Information about your rights at work.

Web: www.yourworkhealth.com

Making a complaint

Most of the organisations listed in these pages can help you complain if you encounter stigma and discrimination.

Before you make a complaint, it's worth thinking about what you'd like to happen as a result of your complaint. Perhaps you want an apology, an explanation or a decision to be changed. On the other hand you might want to be sure that the same thing won't happen to anyone else again.

It's helpful to keep detailed notes about the incident you wish to complain about. Don't be abusive or threatening – try to remain calm. Official complaint procedures can be lengthy and can be emotionally demanding.

Religious and faith groups

When making a complaint, it's important to contact the right organisation. For detailed information about who to complain to – whether your problem is with a public body, the NHS or a business – see the information on the website **www.direct.gov.uk**. Type “making complaints” into the website’s search box to find the relevant pages.

Religious and faith groups

Some faith groups have responded excellently to HIV and provide an important source of comfort, friendship and practical support. However, some faith leaders and faith groups can themselves be a source of stigma.

A number of organisations work to raise awareness of HIV in faith groups and to provide support to people with HIV who have a faith. Just a few of these organisations are listed below.

LEAT (London Ecumenical AIDS Trust)

Telephone: 020 7701 2200

Web: www.lead.org.uk

Religious and faith groups

Cara Trust

Telephone: 020 7243 6147

Web: www.caralife.com

Positive Catholics

Telephone: 07505 608655

Web: <http://positivecatholics.googlepages.com>

This booklet is part of NAM's information series for HIV-positive people. The whole series is freely available on our website, **www.aidsmap.com**, as well as our other resources, news, FAQs, and information on HIV services.

The screenshot shows the AIDSmap website interface. At the top, the browser address bar displays "http://www.aidsmap.com". The website logo "nam aidsmap" is prominent, with the tagline "HIV & AIDS - sharing knowledge, changing lives" below it. A search bar is located in the top right corner. A navigation menu includes links for Home, News, HIV Basics, Topics, Resources, Translations, E-atlas, and About us, along with a "Donate" button featuring a ribbon icon. A main banner states: "NAM works to change lives by sharing information about HIV and AIDS. We believe independent, clear and accurate information is vital in the fight against HIV and AIDS. More about us >".

The main content area features a large article titled "International AIDS Society Conference". The article text reads: "Delegates making their way back from Rome are leaving with a sense of optimism, as scientific breakthroughs demonstrate the efficacy of a range of prevention approaches. But there are challenges ahead for the global HIV community in applying the lessons learned from the conference." Below the text are three bullet points: "> Read NAM's daily conference bulletins", "> Revolutionary and luminary: meet Eric Fleutolet", and "> Get all of our news from the conference". To the right of the article are four buttons: "Sign up for our emails" (with an envelope icon), "Recently diagnosed" (with question mark icons), "Find an HIV service" (with a world map icon), and "Our resources" (with a folder icon). At the bottom, there is a "Connect with NAM" button with social media icons for Twitter and Facebook.

Below the main article, there is a grid of smaller articles with the following titles: "International AIDS Society Conference", "Paying people to be healthy", "Task shifting of care", "No one forced into treatment", and "Preventing HIV".

Keep yourself up to date – get more from NAM

HIV Treatment Update

NAM's quarterly newsletter keeps you up to date with the latest news and developments about HIV, to help you talk to your doctor, and make decisions about your health and treatment.



HIV Weekly

NAM's weekly email round-up of the latest HIV news. Sign up today at www.aidsmap.com/bulletins for straightforward news reporting and easy-to-read summaries of the latest HIV research.



To subscribe to either of these publications, please use the form on the reverse

To read previous copies of HTU visit www.aidsmap.com/htu
or for general HIV news www.aidsmap.com/news

Order form **Please set up my free subscription to the following publications**

HIV Treatment Update – NAM's quarterly newsletter

Please tick which format you require Paper Email (PDF)

HIV Weekly – NAM's weekly HIV news round-up by email

Name.....

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.....

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Signature.....

Please do not send me information about NAM's full range of publications on HIV

Please tick this box if you would not like to receive information about NAM's fundraising campaigns

NAM is unable to provide free subscriptions to *HTU* to professionals or organisations – please contact us for prices

Please complete this form and send to NAM, FREEPOST LON17995 London, SW9 6BR

Under the terms of the Data Protection Act you may advise us at any time if you do not wish to receive further mailings from NAM

What did you think of this booklet?

We need your help – please, please help support NAM's work by returning this form.

At NAM, we really value feedback – it is used to help us keep our resources useful to you and others.

How useful was this booklet to you?

Very useful

Useful

Not very useful

Not at all useful



Has this booklet helped you make decisions about your health and treatment?

Yes, very much

Yes

A little bit

No



Has this booklet made you feel more informed about key issues?

Yes, very much

Yes

A little bit

No



Has this booklet made you feel more confident when talking to your healthcare team/doctor/GP?

Yes, very much

Yes

A little bit

No



Please turn over 



In your own words tell us how this booklet has helped you



Are there other topics that booklets like this should cover?
Please give details.



This questionnaire is anonymous and confidential.

NAM is a charity, returning this form is a simple and easy way for you to support our work so in turn we can continue to support you and others with free, useful, independent information. Thank you for taking the time to help us.

Please tear off this page and post it for free to: **NAM, FREEPOST, LON17995 London, SW9 6BR**



HIV helplines

THT Direct

From the Terrence Higgins Trust

Telephone 0808 802 1221

Opening hours Monday-Friday, 10am-10pm

Saturday & Sunday, 12pm-6pm

I Do It Right

Telephone 0800 0967 500

Opening hours Monday-Friday, 10am-6pm

HIV i-Base Treatment Phonenumber

Telephone 0808 800 6013

Opening hours Monday-Wednesday, 12pm-4pm

NAM information series for HIV-positive people - visit www.aidsmap.com/booklets

The booklet series includes:

- Adherence & resistance
- Anti-HIV drugs
- CD4, viral load & other tests
- HIV & children
- HIV & hepatitis
- HIV, mental health & emotional wellbeing
- HIV & sex
- HIV & TB
- HIV & women
- HIV therapy
- Nutrition
- Side-effects

More from NAM

aidsmap.com

NAM's website aidsmap.com hosts a huge range of useful resources on key HIV topics. With booklets, factsheets, frequently asked questions about HIV, news and listings of local services, you can keep up to date and find information to support the decisions you make about your treatment and health. It is a reliable source of independent information that you can trust.

HIV Health Support Service

NAM supports THT in providing one-to-one and group skills sessions on health and treatments to people living with HIV. Call THT Direct for details.

NAM

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UK

Tel: +44 (0) 20 3242 0820
Website: www.aidsmap.com
Email: info@nam.org.uk
Registered charity no. 1011220

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This booklet can be
viewed in large print
as a PDF file using
Acrobat Reader.

Call NAM on
020 3242 0820.

About NAM

NAM is a charity that works to change lives by sharing information about HIV & AIDS. We believe that independent, clear, accurate information is vital to those living with HIV.

Please help us

If you would like to support our work and help us to continue to provide resources like this one, please donate today at www.aidsmap.com/donate or call us on 020 3242 0820.

