



YOUR RIGHTS

A GUIDE TO HUMAN RIGHTS 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 strongly recommend that you seek specialist advice about your particular situation if you believe that your rights have been breached.

“My advice to other people living with HIV would be to educate yourself, and know your rights.”

Person living with HIV



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INTRODUCTION



There are lots of situations where knowing about human rights can be helpful, but if people are going to exercise their human rights, they first need to know what these are. This guide explains what your human rights are, how they are protected, and what you can do if things go wrong.

“The face of HIV has always been the face of our failure to protect human rights.”

Navi Pillay, former UN High Commissioner for Human Rights

“Rights are not the same as entitlements”

Person living with HIV

WHAT ARE HUMAN RIGHTS?

Human rights are the basic rights and freedoms that we are all entitled to, regardless of nationality and citizenship.

They belong to us all and cannot be taken away because every person is equal and deserving of dignity. Human rights are clearly defined and protected by British, European and International laws. They protect our freedom to control our day-to-day lives, and ensure that we can participate in all aspects of public life in a fair and equal way. All human rights are underpinned by the values of:

- ★ Fairness
- ★ Respect
- ★ Equality
- ★ Dignity
- ★ Autonomy

Although human rights cannot be taken away, there are some situations where rights might be restricted: for example, the right to liberty (freedom) can be limited if someone commits a crime and has to be imprisoned.

HOW ARE HUMAN RIGHTS PROTECTED IN THE UK?

In the UK, when we talk about human rights, we are often referring to the rights listed in the British Human Rights Act 1998. The Act lists rights which belong to all people in the UK, and outlines how these rights should be protected. These rights are taken from the European Convention on Human Rights, which the UK has signed up to.

The Human Rights Act means we all have:

- ★ The right to life
- ★ The right not to be tortured or treated in an inhuman or degrading way
- ★ The right to be free from slavery or forced labour
- ★ The right to liberty
- ★ The right to a fair trial
- ★ The right not to be punished without law
- ★ The right to respect for private and family life, home and correspondence
- ★ The right to freedom of thought, conscience and religion
- ★ The right to freedom of expression
- ★ The right to freedom of assembly and association
- ★ The right to marry and found a family
- ★ The right not to be discriminated against in relation to any of the rights contained in the European Convention on Human Rights
- ★ The right to peaceful enjoyment of possessions
- ★ The right to education
- ★ The right to free elections

The Human Rights Act has two aims:

1. To enable us to access our human rights here at home in the UK through UK courts or tribunals, instead of only being able to go to the European Court of Human Rights.
2. To promote a 'culture of human rights' by making sure that human rights underpin the workings of government and public services.

It does this by placing a legal duty on public authorities (e.g. hospitals, schools, local authorities and courts) to know, respect and protect our human rights in everything that they do. This duty is important in everyday situations because it allows us to challenge poor treatment and negotiate better solutions (some examples are given below). If you feel your human rights have been breached, there are a range of things you can do without ever having to take legal action (see page 17). The following examples describe some situations where you could use human rights to challenge unfair treatment.

CARE AND TREATMENT

We all have the right not to be treated in an inhuman or degrading way.

Public authorities have an obligation to prevent unfair treatment, and protect vulnerable people. This means medical staff must provide safe and effective care, and treat people appropriately at all times. If you encounter any of the following situations, you could use human rights to challenge them:

- Refusal of life saving treatment e.g. being refused access to your HIV medication while detained by the police.
- Not being given sufficient information to make informed choices about treatment or being given treatment without consent.
- Medical staff inappropriately sharing personal information e.g. your HIV status being disclosed without consent to staff who are not involved in your care.
- Use of excessive or unnecessary medication, or forced medication e.g. inappropriately being given sedatives by care home staff.
- Blood samples being taken without your permission.
- Poor conditions in health institutions e.g. buildings in disrepair or unsanitary surroundings.
- Assaults by staff and other patients, or other abusive behaviour e.g. being threatened because of your HIV status.

“It’s your right to get the best care and for your information to be kept confidential.”

Person living with HIV

DID YOU KNOW?

In Scotland, there is a Charter of Patient Rights and Responsibilities which sets out what you can expect when you receive NHS care in Scotland. It includes things like the right to be involved in decisions, the right for your personal information to be kept confidential, the right to safe and effective care, and the right to be treated with dignity and respect.

In England, there is an NHS constitution which has seven key principles. The first of these states that the NHS has "... a duty to each and every individual that it serves and must respect their human rights."

In Wales, the Health and Care Standards set out what Welsh people can expect when they access health services. Equality and human rights are embedded within the standards, and standard 6.2 specifically addresses protecting people's rights.

In Northern Ireland, the Quality Standards for Health and Social Care published in 2006 are underpinned by nine values. One of these is the 'Promotion of Rights' which states that "the individual and human rights of service users are promoted and safeguarded."

Challenging degrading treatment

CASE STUDY

After Robert had a stroke, he was moved to a care home from hospital. The care home staff were very concerned when they found out he had HIV, even though there's no risk of HIV transmission from everyday care activities. Care workers used excessive precautions when caring for him, for example wearing several pairs of gloves when washing and lifting him. He was always given the last bath of the day and other residents were told not to visit him in his room as he presented an 'infection risk'. Robert's social worker recognised that this sort of treatment was inhuman and degrading and may be in breach of his human rights. His social worker challenged this and Robert was quickly moved to a new care home where he received much better care.

RESPECTING PRIVATE AND FAMILY LIFE



We have the right to respect for our private and family life, home and correspondence.

Private life covers things like privacy, our individuality, relationships and participation in the community. People must respect our personal choices. In some circumstances, public authorities may need to take steps to support people to realise their right to a private life, including their ability to participate in society.

If you encounter any of the following situations, you could use human rights to challenge them.

- Not being allowed to see or communicate with your family while in hospital or another care facility e.g. family members being denied hospital visits.
- Staff in care homes, supported accommodation or hospital, etc. controlling mail, phone calls, etc. without authority e.g. being refused access to a telephone or email.
- Not being allowed to view your medical records e.g. not being allowed to read your GP record or blood test results.
- Your sexual relationship or right to marry being restricted e.g. a same sex couple being denied the same entitlements as a heterosexual couple within a care setting.

CASE STUDY

Failing to respect personal choices

Paul has been living well with HIV for many years but as he's got older he needs support with some activities. Sometimes a support worker will take him out for the day as he can't get to the places he used to go by himself anymore. As a gay man, Paul wanted to visit a gay pub where he used to meet old friends. However, his support worker is very uncomfortable with this and refuses to take him. Paul knows that the support worker has taken other people to pubs before and is very upset. He feels that his right to respect for his private life is being breached and he is unable to be himself. Paul decided to get help and advice on the matter because he was unsure if this was a human rights issue. He contacted Citizens Advice who have supported him to make a formal complaint.

CHALLENGING THE DECISIONS OF PUBLIC BODIES

The right to a fair trial does not just apply to criminal proceedings but to a broad range of areas where a person's civil rights are decided upon.

This could include the complaints procedures of public bodies, compensation claims, or appeal procedures in social security or mental health tribunals. It should cover most disputes concerning welfare benefits. The right to a fair hearing gives you the right to participate fully with access to all relevant information, for the hearing to be held within a reasonable period of time and to be allowed to be represented. If you encounter any of the following situations, you could use human rights to challenge them.

- Not being given the opportunity to present a case before a decision is made.
- Not being told the reasons why a particular decision has been made.
- A tribunal or hearing failing to act independently and impartially.



Challenging a housing decision

CASE STUDY

Asha lived in social housing with her six-year-old son. Without any warning, or consultation, her housing provider placed another family within her home. Asha was simply told that she would have to share. Asha was deeply concerned that her home was too small for two families and fearful of the implications should her HIV status become known. There were no locks on the doors and one day she came home to find her medication spilled across the floor. The house was overcrowded and her son's school work began to suffer. Asha felt her right to privacy and to her home had been breached, and she decided to challenge the decision of the housing provider. She first complained directly to the housing provider but they were dismissive and refused to reconsider their decision. Asha did not feel that the housing provider was handling her case fairly and impartially, so she contacted her MSP. Her MSP investigated the case and as a result the decision of the housing provider was overturned.

CHALLENGING DISCRIMINATION

Discrimination occurs when you are treated less favourably than another person in a similar situation and this treatment cannot be justified.

The Human Rights Act does not protect you from discrimination in all areas of your life, but protects you from discrimination in the enjoyment of the rights in the European Convention on Human Rights. This reflects the core idea that all of us, no matter who we are, enjoy the same human rights and should have equal access to them. There are other laws in the UK that protect you from discrimination more generally. If you encounter any of the following situations, you could use human rights to challenge them.

- Being denied access to medical treatment, based on race, disability, sex, sexuality, etc.
- Being treated unfairly within the criminal justice system e.g. HIV status being referenced in criminal court cases when it is not relevant to the crime and leads to harsher sentencing.



DID YOU KNOW?

The main anti-discrimination law in Great Britain is the Equality Act 2010.

This makes it unlawful to discriminate against someone on the grounds of age, disability, gender reassignment, race, religion and belief, sex, sexual orientation, marriage and civil partnership, and pregnancy and maternity. It prevents unlawful discrimination in a wide range of situations, such as access to employment, education, and private and public services. Under the Equality Act, HIV is considered to be a disability from the point of diagnosis.

In Northern Ireland, the N.Ireland Act 1999 Sect 75 covers all the equality and diversity issues, and the Disability Discrimination Act, amended in 2007, makes specific reference to HIV.

THE EUROPEAN CONVENTION ON HUMAN RIGHTS

CASE STUDY

The European Convention on Human Rights plays an important role in the development and awareness of human rights in Europe. This is a real-life example of how someone living with HIV used the European Convention on Human Rights to challenge a breach of confidentiality.

USING THE EUROPEAN CONVENTION - Z V. FINLAND

A woman was involved in criminal proceedings against her husband; both were HIV positive. During investigations and in the court judgment, the woman's HIV status was made known to the public via the press. The woman took a case to the European Court, arguing that there had been multiple violations of her right to respect for private and family life. The European Court held that two of her submissions did breach this right, making clear that only 'an over-riding requirement in the public interest can justify breaching medical confidentiality.'

The Court underlined the fundamental importance of keeping medical data confidential, stating that 'respecting the confidentiality of health data is a vital principle in the legal systems of all the contracting parties to the Convention. It is crucial not only to respect the sense of privacy of a patient, but also to preserve his or her confidence in the medical profession and in health services in general'. The applicant received financial compensation.

WHAT IF THINGS GO WRONG?

“The knowledge of where I can seek advice when my rights are violated is a comfort cushion for me to fall back on.”

Person living with HIV

If you feel that your human rights may have been breached, this section can help you to assess the situation and your possible options. It may be that you are able to resolve the problem without taking legal action, and there are a range of other steps to consider first.

The below has been adapted from information from the British Institute of Human Rights and the Equality and Human Rights Commission.

CLARIFY THE PROBLEM

The first thing to do if you believe your human rights may have been breached is to talk to someone else about the problem. It may sound obvious, but it is surprisingly common to feel scared to speak up about a situation. You could talk to a trusted friend, relative or colleague, or someone who may be part of a support group or advice line. This will help you to consider the issue as objectively as possible. Remember that, however distressing, your situation may not be covered by human rights law.

“There are a lot of people out there who don’t have the confidence to speak and some folk don’t have the language to communicate, so they need to understand and know that there is support out there; that there are people who will support them through whatever crisis they are facing.”

Person living with HIV



2 GET EXPERT HELP AND ADVICE

It’s a good idea to get some basic specialist advice about your problem as early as possible to help you decide on the best course of action. There are lots of organisations that can offer you free advice on finding a legal adviser who can help you. As a first step, you can contact the Equality and Advisory Support Service or Equality Commission for Northern Ireland (see page 24 for details).

You can also consider calling a reputable lawyer directly if you feel you have a potential claim. If you decide to hire a lawyer, it’s a good idea to shop around first. Many advice centres will recommend solicitors and this is often the best method, but you can also seek recommendations from friends and family, or look online for specialist firms in your area. Make sure you are clear on the details of how you will be charged before you hire anyone.

Local or national advice organisations, law centres or citizens’ advice bureaux may also be able to help with the problem themselves. Charitable organisations in your area may deal specifically with human rights problems, and this may include advice and help with making a claim. Your local Citizens Advice Bureau will be able to tell you if you are eligible for legal aid and signpost you to a suitable lawyer (see page 25 for details).



RESOLVE THE ISSUE INFORMALLY

Sometimes it's possible to resolve a problem quickly by talking to the people involved, without going through any formal procedures. It's always a good idea to seek advice before raising an issue directly with the people involved.

If you feel able to, raise the problem with the person, organisation or public authority that you feel has breached your human rights, either by speaking to them or writing a letter. You should explain the issue and say that you feel you have a complaint on human rights grounds, and ask for a response to your complaint. If you don't think you are able to speak to them yourself, you could find an advocate to support and help you get your views across.

Sometimes pointing out the human rights implications of a situation may not change things. The person or organisation concerned may disagree that there is a problem or refuse to listen to you. Or you may decide that the situation is best approached more formally.

COMPLAIN WITHIN AN ORGANISATION

If your complaint relates to an organisation such as your employer or a service provider and the organisation has a formal internal complaints system, you should use that as a first step. If not, you could make a complaint to the relevant person and/or that person's superior. It's a good idea to keep a written record of what has happened to you and when, as well as who you've spoken to, what action you've taken and any response you receive. If you need help in thinking about or making a complaint, you could contact a local or specialist advocacy organisation.

If your complaint relates to a public authority, it may be better to use the organisation's formal complaints procedure before taking legal action (but remember the time limit for legal action may run out before the complaints process has finished). All public authority service providers must have a complaints procedure setting out how people who use their services, or those acting on their behalf, can make a formal complaint.

COMPLAIN TO AN EXTERNAL PERSON OR ORGANISATION

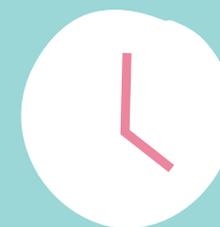
If you think your human rights have been breached and you have been unable to resolve the problem with the person or organisation involved, you may wish to consider complaining to an external person or organisation.

You can make a complaint to your local councillor or your MP/MSP/AM/MLA. Depending on the nature of your problem, there may be a person or organisation dedicated to providing help with particular issues, such as the Children's Commissioners. You may also be able to make a complaint to the relevant regulator for potential investigation.

Depending on the type of problem you have, you could take your story to the local, regional or national media – or engage in some other form of campaigning. Make sure you think very carefully before you do this as sometimes it can do more harm than good.

IMPORTANT NOTE

In all cases, there are time limits which mean that you may need to take legal action quite quickly so as not to lose your rights. Time limits can be complicated but in some cases you may have to bring a claim to court within three months.





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

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/

☎ 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.
www.equalityni.org

☎ 028 90 500 600
@ information@equalityni.org

Scottish Human Rights Commission

Promotes and protects human rights for everyone in Scotland. They are an independent public body, accountable to the people of Scotland through the Scottish Parliament.
www.scottishhumanrights.com

☎ 0131 244 3550
@ hello@scottishhumanrights.com

The Scottish Human Rights Commission have created a guide '*Help with Human Rights*' which you may find helpful:
www.scottishhumanrights.com/humanrights/helpandadvice

Citizens Advice

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

England call 03444 111 444
Wales call 03444 77 20 20

Citizens Advice Scotland

www.cas.org.uk/
☎ 0808 800 9060

Acas

Help and advice for employers and employees.
www.acas.org.uk
☎ 0300 123 1100

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The Equality and Human Rights Commission

The Scottish Human Rights Commission

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