Your Human Rights
A guide for disabled people
Please note that this guide is not legal advice. If you need advice please see the Useful contacts section for sources of information and advice. The information in this guide is correct at the time of printing in June 2006. The law may have changed since this was printed, so information in it may be incorrect or out of date.

Please also note that this guide focuses only on the rights contained in the European Convention on Human Rights and the UK Human Rights Act. There are a range of other human rights contained in various international agreements. Information about these can be found on our website or via its links.

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Your Human Rights –
a guide for disabled people

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Introduction

Many situations experienced by disabled people involve human rights. However, there is little information available about human rights and how they relate to disabled people. Too often a person may not realise that they are able to do something about their situation, or even that there is something wrong with the way they are being treated. It is therefore vital that disabled people are able to access information about their human rights and challenge bad treatment.

This guide provides practical information about human rights, and their relevance to disabled people. It is written directly for disabled people. The guide will also be useful for people working with disabled people or those wanting to learn more about the impact of human rights on disabled people.

Using this guide

This guide aims to give you an idea of situations that may involve your human rights. This will give you – or someone who can speak on your behalf – the knowledge to be able to recognise and challenge human rights abuses. Please note that this guide is not legal advice. If you think that someone is abusing your human rights, or you are unsure about anything in this guide, you should talk with an experienced adviser. Advice lines are listed in the Useful contacts section at the end of this guide.

The guide is designed so that you can either read it straight through, or pick areas that are most relevant for you. We have avoided using legal terms wherever possible, and have provided clear definitions where legal terms are used. We have used a number of examples to illustrate the information provided in the guide. Many of these are real life cases that have gone to court. These cases are important as they show how human rights arguments can make a real difference for individuals. However taking your case to court is a last resort. We hope that you will be able to use the information in this guide to resolve any human rights issues that you may face without having to go to court.
Section I

Introducing human rights
Why are human rights relevant for me?

Human rights belong to everyone, and they provide a very important means of protection for disabled people. Human rights place authorities in the UK – including the Government, hospitals and social services – under an obligation to treat you with fairness, equality, dignity and respect.

Many people think that human rights are only significant for overseas countries, or that they are a complex legal topic. But human rights are relevant to many of the decisions people make and the situations people experience on a daily basis. They are not just about the law and taking cases to court. Very often you can resolve a problem that involves human rights by talking it through and reaching a solution, without needing to go to court. To be able to understand how human rights can assist or protect you, it is important to have a basic knowledge of how human rights work in practice. This first section therefore gives a brief introduction to your human rights and how they are protected by law in the UK.

Things you need to know about human rights

- they belong to everyone
- they are based on principles of fairness, equality, dignity and respect
- they are about how public authorities – including the Government, local authorities and hospitals – must treat you
- they prevent authorities from doing certain things to you, like treating you in a degrading way
- they also sometimes force authorities to take certain actions, like taking steps to protect your life
- they were first legally defined by international agreement after the horrors of the Second World War
- since the Second World War there have been many different international human rights agreements
- one of the most important human rights agreements is the European Convention on Human Rights
How are my human rights protected in the UK?

In the UK, your human rights are protected by the European Convention on Human Rights and the UK Human Rights Act.

The European Convention on Human Rights (we shall call it the European Convention from now on) is a human rights agreement (or treaty) made after the Second World War by countries which belong to the Council of Europe, in order to protect the human rights and freedoms of everyone within their borders. The Council of Europe is not to be confused with the European Union. The Council of Europe represents ‘Greater Europe’ and includes countries such as Russia, Turkey and the Ukraine.

The European Convention sets out a number of fundamental human rights including the right to life, the right to liberty and the right to free expression. Each right is referred to as a separate ‘Article’ – for example Article 5 refers to the right to liberty. A list of rights included in the European Convention is given at the end of this guide.

The UK signed up to the European Convention in 1951. This means that since that time the UK is breaking international law if it does not respect the rights in the European Convention.

The European Convention provides a special level of protection compared with other human rights agreements. The European Convention established a European Court of Human Rights, based in Strasbourg, France. You can complain to this Court if you think your rights as set out in the European Convention have been breached. However, you must have taken your case through the UK court system first (please see the Practical advice and information section for information on taking cases to court).

The Human Rights Act became effective in the UK on 2 October 2000.

The purpose of the Human Rights Act is to bring most of the rights contained in the European Convention into UK law.

The Human Rights Act does this by placing a duty on all public authorities in the UK to act in a way that respects and fits with the rights in the European Convention.
What is a public authority?
‘Public authority’ is not fully defined in the Human Rights Act, but it should be interpreted broadly. It includes all central and local Government agencies, as well as courts and tribunals. The National Health Service (NHS), social services departments and prisons are included and, more generally, any person or organisation ‘whose functions are of a public nature’. The term also covers private organisations such as companies or charities, but only when carrying out a public function, for example a private hospital detaining someone under the Mental Health Act.

If public authorities fail to respect your rights, you can bring a case against them in the UK courts without having to go to the European Court of Human Rights. The Human Rights Act therefore provides you with an extra level of protection, and makes your rights more accessible. It is generally quicker, cheaper and more practical to bring your case before the UK courts. You do not have to be a British citizen to do this – the Human Rights Act protects everyone within the UK.

You can still take your complaint to the European Court of Human Rights if you do not agree with the outcome of your case in the UK courts.

Can my human rights ever be limited or restricted?
Some rights are so fundamental that they must never be limited or restricted in any way. These rights are known as absolute rights.

- For example, public authorities must never torture you or treat you in an inhuman or degrading way under any circumstances, not even during a war or national emergency.

However, it is important to know that the European Convention does allow for some rights to be limited or restricted in some circumstances.

For some rights – known as limited rights – the European Convention sets out specific circumstances in which the right can be limited.
For example, public authorities may limit your right to liberty if you are convicted of a criminal offence and you are sent to prison, or if you are legally detained because you have mental health issues.

Some, but not all, rights may be restricted under more general conditions in order to protect the rights of others or the interests of the wider community. These rights are known as **qualified rights**.

For example, the Government may restrict your right to freedom of expression if you are inciting racial hatred or if you are publishing lies about another person.

We will look at the different ways in which rights may be limited or restricted in more detail in the next section.

**Why is the Human Rights Act important for disabled people?**

Human rights are not just about the law. The Human Rights Act influences the way public services are delivered to disabled people. The Human Rights Act says that providers of public services, such as staff at residential homes, educational bodies or hospitals, or carers in your own home, must make sure that they do not breach your human rights.
Section 2

Human rights and disabled people
More than 10 per cent of the world’s population is disabled in some way. Over the past twenty years there has been a change from a charitable or medical approach towards services for disabled people, to one based on the rights of disabled people within society (called the social model of disability). This change has been slow, but it is happening.

**What is disability?**
The Disability Discrimination Act sets out the circumstances in which it considers a person to be ‘disabled’. It says you are disabled if:

- you have a mental or physical impairment;
- this has an adverse effect on your ability to carry out normal day-to-day activities; and
- the adverse effect is substantial and long-term (meaning it has lasted for 12 months, or is likely to last for more than 12 months or for the rest of your life).

Significant campaigning by disabled people and organisations of and for disabled people from the 1970s onwards led the Government to introduce the Disability Discrimination Act (DDA) in 1995. This has been brought into effect in stages since 1995, with the purpose of ensuring that disabled people are valued and treated as equal citizens. This Act was amended by the Disability Discrimination Act 2005 which, amongst other things, places a duty on public authorities to promote disability equality. The DDA covers both public and private bodies.

Disabled people are entitled to the effective enjoyment of all human rights, without discrimination. The Human Rights Act works alongside the DDA and other laws to make sure that disabled people are treated with respect for their human rights, particularly when receiving public services. The rights contained in the Human Rights Act belong to everyone – it does not contain any rights specifically for disabled people. However, the general principles in the Human Rights Act are relevant to several issues which many disabled people face. The Human Rights Act therefore provides an important tool for disabled people to use to challenge discrimination and unacceptable treatment.
Which human rights are relevant for disabled people?

All of the human rights protected by the European Convention belong to and may be relevant for disabled people. This guide will concentrate on the four human rights that are often the most relevant:

- the right not to be tortured or treated in an inhuman or degrading way;
- the right to respect for private and family life, home and correspondence;
- the right to life; and
- the right not to be discriminated against in relation to any of the rights in the European Convention.

These four rights raise a range of issues that can be relevant for disabled people, which are discussed below. However, the relevance of human rights for disabled people is not limited to these issues. The Human Rights Act is still a relatively new law and has great potential to empower disabled people in many areas of life.

Your right not to be treated in an inhuman or degrading way

Article 3 of the European Convention on Human Rights says that no one shall be tortured or treated in an inhuman or degrading way. This right is an absolute right (see page 8). This means that you should not be tortured or treated in an inhuman or degrading way in any circumstances, as this right may never be breached, restricted or limited.

Article 3 is not just about torture. The ban on inhuman or degrading treatment can be very relevant for disabled people.
inhuman treatment means treatment causing severe mental or physical harm

degrading treatment means treatment that is grossly humiliating and undignified

Situations in which disabled people may experience inhuman or degrading treatment are considered below. However, only the most serious kinds of ill treatment are covered by this right. Whether the treatment is serious enough to be inhuman or degrading will always depend on the particular circumstances of your case, taking into account factors such as your age, whether you are male or female, your state of health, and the length of time you were subjected to the treatment.

To illustrate this, compare the difference between a frail, older person being refused anything to eat or drink for 24 hours with a young healthy person being refused anything to eat or drink for 24 hours. Neither situation is acceptable, but the frail, older person is likely to be more severely affected.

The treatment does not need to be deliberate – it is the impact it has on you that matters. For example, if staff in a care home unintentionally leave residents in soiled bed sheets for long periods of time because they are understaffed, this may still amount to inhuman or degrading treatment.

At the core of this right is human dignity.

For disabled people, this right may be relevant in a number of situations:

**Abuse or neglect**
Abuse or neglect in residential or nursing homes, hospitals or during home care may in some circumstances breach the right not to be treated in an inhuman or degrading way.

**Unacceptable practices** such as leaving you for long periods in your own bodily waste, washing you in a way that leaves you inappropriately exposed in front of other people, or leaving trays of food without helping you to eat if you are unable to feed yourself may be serious enough to be inhuman or degrading treatment. On each occasion this will depend on the particular circumstances of your case, including how
severe the treatment is and the impact it has had on you. If you are unsure about whether you have been treated in an inhuman or degrading way you can speak with an experienced adviser – advice lines are given in the Useful contacts section at the end of this guide.

Situations that may involve inhuman or degrading treatment include:

- unchanged sheets
- neglect leading to bed sores
- excessive force used to restrain you
- your calls for help being routinely ignored
- washing or dressing you without regard to your dignity
- feeding you while you are strapped to a commode
- abusive treatment
- other forms of bad practice

Case example
A disabled woman, who was a wheelchair user, was sent to prison for seven days during debt recovery proceedings. She was kept in a cell which was dangerously cold. She could not reach her bed, and was unable to keep clean or use the toilet. A court found these conditions to be degrading treatment.

Inhuman or degrading treatment may also result from inadequate care. For example, you may need assistance to wash and go to the toilet. If the authorities fail to provide you with this care, this may lead to an uncomfortable or undignified situation such as being left in your own faeces or urine for several hours. Depending on the circumstances, this may be inhuman or degrading treatment.
In some instances, the use of restraint – physical or otherwise – may also amount to inhuman or degrading treatment. Examples may include tying you to a chair to prevent you from moving, or continually giving you medication to keep you sedated because there is a lack of staff. However, restraint is not necessarily in itself a breach of human rights. Again, whether the treatment is serious enough to be inhuman or degrading will always depend on your specific circumstances.

**Case example**
Two disabled sisters, who needed assistance in order to move around, lived with their parents in a specially adapted house. A local authority policy imposed a complete ban on all manual lifting of people. This ban was challenged in the courts. The courts concluded that a complete ban on manual lifting is unlikely to be lawful, because a complete ban will not consider a person’s individual circumstances. Inhuman or degrading treatment might occur if the women were left in their own bodily waste or stuck on the lavatory for hours. The judge emphasised that human dignity is the core value of our society.

**Conditions during care**
Extremely poor conditions in care homes, hospitals or other settings, such as overcrowding, lack of ventilation, lack of privacy or inadequate sanitary facilities, may also amount to inhuman or degrading treatment.

**Failure to act by public authorities**
Public authorities must sometimes take positive steps to protect you from inhuman or degrading treatment, even if the harm is caused by private individuals rather than directly by staff or carers at the public authority. For example, if a public authority is made aware that a relative or friend who is caring for you at home may be abusing you, they have a duty under the Human Rights Act to investigate or intervene. If you are subjected to inhuman and degrading treatment and the authorities are aware of it and fail to protect you, this failure to act may breach your right not to suffer this kind of treatment.
This also applies when there is evidence of abuse or neglect within a setting such as a hospital or residential home. Public authorities have a duty not to treat you in an inhuman or degrading way. But they also have a duty to take proactive steps to protect you from this kind of treatment even where it is not directly caused by their staff members, for example if it is caused by relatives visiting you in hospital. Public authorities must investigate where there is evidence that you have been treated in an inhuman or degrading way.

**Your right to respect for your private and family life, home and correspondence**

Article 8 of the European Convention protects the right to respect for private and family life, home and correspondence. It also sets out, in general terms, circumstances when an interference (also known as a restriction) with this right is acceptable – in other words when a restriction is justified.

This means that this right is not an absolute right, but a **qualified right** (see page 9). Your right to respect for your private and family life, home and correspondence may have to be interfered with in order to take account of the rights of other individuals and/or the wider community.

However, for any interference with this right to be justified, it must be lawful, necessary and **proportionate**. A proportionate response to a problem is one that is appropriate and not excessive in the circumstances.

A straightforward way of thinking about proportionality is that authorities **must not use a sledgehammer to crack a nut**.

If public authorities cannot show that they have acted in a proportionate way when interfering with a right, then the interference is not acceptable, and the right will have been breached.
In addition to public authorities not breaching your right to respect for your private and family life, home and correspondence by their own actions, they must also, in some situations, take proactive steps to make sure that your right is fulfilled. This might include providing extra resources, such as providing support to enable your family to stay together.

**What is meant by family life?**

Family life is defined broadly to include close and personal ties of a family kind. It does not just cover blood relatives. The right to respect for family life includes being able to live together and, where this is not possible, having regular contact.

Your right to respect for your family life will be relevant if you are in danger of being separated from your partner, children or other family members, or of having very limited contact with them. Public authorities will need to consider whether any actions they take that interfere with your family life are necessary, and whether there are less restrictive options to consider.
restrictive options which would allow you to remain living together or to have the maximum level of contact. In other words, public authorities will need to consider whether their actions are lawful, necessary and proportionate.

**Case example**
A disabled woman who required 24 hour care wanted to be cared for at home with her family, through an extensive care package. However, her local Primary Care Trust (PCT) wanted to place her in residential care due to the high cost of home care, and because of the higher quality of care in the residential care home in the event of a crisis. The Court found that the PCT had not properly considered the impact of this on her family life. They had not taken into account her improved quality of life at home, or her own wishes to be placed at home. The PCT was therefore told to remake their decision, taking her right to respect for her family life into account.

Sometimes public authorities must do something active to protect your family life. This might mean providing support to help your family live together. For example, this may include providing educational or financial resources for disabled parents who need this support in order to look after their children. It may also include providing adequate care that enables you to be cared for at home with your family, rather than in a residential home.

**Case example**
A couple in Germany, both with learning difficulties, had two children. The children were removed from their parents some years after their birth as a court decided the parents were incapable of bringing them up. However, there was no evidence of neglect or bad treatment. The children were separated and eventually fostered. They had very little contact with their parents after this. The European Court of Human Rights said the right to respect for family life was breached in this case. The separation of the family was not proportionate. The authorities could have provided educational or financial support to enable the family to stay together.
The example below shows that you should also be helped to lead as regular a family life as possible. Sometimes public authorities need to do more to protect your family life than just make it possible for a family to live together. If your circumstances living as a family are intolerable this may breach your right to respect for your family life.

**Case example**
A local authority in London provided a property to a family that was unsuitable for their needs. The father was looking after his six children and his wife, who was disabled. His wife was only able to access the lounge room, could not use the stairs and therefore had no access to the first floor where the bathroom and bedrooms were situated. This was a particular problem as she was incontinent. Although the social services department recommended that the family be provided with specially adapted accommodation, the family heard nothing for over a year. The Court held that the local authority had an obligation to enable the family to lead as normal a family life as possible. They had not met this obligation and had therefore breached the right to respect for family life.

**What is meant by private life?**
Private life is defined broadly. It means more than just ‘privacy’ and extends to include issues such as:

- being able to live your personal life as you choose;
- being able to establish relationships with others as you wish;
- being able to participate in the life of the community;
- your physical and mental well-being;
- having access to information about your own private life which might be in the possession of others; and
- having personal information which is part of your own private life kept confidential.
**Private life: personal choices and dignity**

Your right to respect for your private life includes a right to personal autonomy (making your own choices about your life) and human dignity. This is very **wide-ranging**, covering issues such as privacy, your relationships with other people, your life in the community, culture and language. It is relevant to the decisions you make about your life and the way you are treated. Issues that may be particularly relevant for disabled people include:

- **privacy concerning your body**: who sees or touches your body is an important part of your private life and may affect your dignity. Leaving you undressed in a busy ward, or a member of the opposite sex washing or dressing you when you have asked for this not to occur, may interfere with your right to respect for your private life.

- **personal and sexual relationships**: this could be significant where your ability to form or sustain relationships, including sexual relationships, might be restricted, for example in a residential care home. Blanket policies restricting sexual relationships may interfere with your right to respect for your private life.

- **participating in community life**: your private life may be involved if you are unable to participate in the life of the community or access essential economic, social, cultural and recreational activities. For example, if you attend a day care centre but are unable to go on their excursions because the centre does not attempt to accommodate your mobility or other support needs, this may interfere with your private life. Another example might be if a local authority fails to ensure that any school transport provided is accessible, meaning that a disabled child is unable to travel to school.

**Case example**

A local authority ran a social activity scheme where support workers accompanied physically disabled people to enable them to access a number of social events including pubs and clubs. A gay man asked for a support worker to accompany him to a gay pub. However, the manager of the scheme refused, stating that none of his staff were prepared to attend a gay venue. This situation could be challenged as a breach of the man’s right to respect for his private life.
• **abortion:** You have the right to make your own decisions about whether you would like to have a child, as part of your private life. If you are pregnant you have the right to make your own choices about whether to keep your baby. Medical staff can give you advice, but they cannot force you to have an abortion. Your right to respect for your family life may also be involved in these kinds of situations.

• **decisions about treatment:** as long as you have the capacity (see page 27) to make decisions for yourself, your right to make choices about your life includes choosing what treatment to accept or reject (although you may not be able to insist on a particular type of treatment). This does not apply to people who are compulsorily treated under the Mental Health Act. Please see BIHR’s Human Rights Guide for people living with mental health problems for more information about compulsory treatment.

Public authorities should make sure that your needs and wishes are central to all decisions about your private life. You should be supported as far as possible to make your own choices about how you live your life. If public authorities interfere with your private life in any way they need to have a legitimate reason for doing so. They cannot justify their decisions solely on the basis of a lack of resources, although they may take financial considerations into account. Any actions they take must be lawful, necessary and **proportionate** – they must not be excessive in the circumstances.

**Case example**
In the case of the two sisters detailed on page 16 the complete ban on manual lifting was found to breach their right to respect for their private life. The ban meant that the women could not take part in activities such as shopping or swimming. This participation in community life was recognised as an essential part of their private life.
Private life: independent living
As explained above, the broad nature of the right to respect for private life includes the right of disabled people to participate in the life of the community. The state also has a duty to actively assist disabled people in this regard. Therefore the right to respect for private life should be a helpful tool in the promotion of independent living for disabled people. Maintaining your independence is a very important part of your private life. If, for example, a local authority is considering placing you in a residential care home rather than providing you with support that enables you to stay in your home, they should take your wishes fully into account. The aim should be to preserve your independence as far as is possible. Any decisions to place you in residential care need to be lawful, necessary and proportionate.

Private life: access to your personal information
Information about you and your life is part of your private life. This includes your medical and financial records, and information about any care or treatment you are given. Whether sharing such private information with others without your permission amounts to a breach of your right to respect for your private life will depend on all the circumstances of your case. There must be a proper reason for disclosing the information, such as preventing a crime or protecting your own or someone else’s health. This reason must be lawful, necessary and proportionate.

You should have access to information about you that is held by public authorities. This includes information being provided to you in an accessible way. Public authorities should only withhold information if there is a legitimate reason for this – such as if giving you the information could cause significant harm to you or someone else. This reason must be lawful, necessary and proportionate.
Private life: treatment and resources

Not being able to access medical treatment and other services (including equipment such as a wheelchair) that you need may affect your physical and mental welfare, and may therefore have a strong impact on your private life. However, the courts have been very clear in saying that your right to respect for your private life does not automatically give you a specific right to treatment. Some treatment or services may require substantial resources and also may have little chance of success and/or may cause you considerable distress. The courts are careful not to place an unreasonable burden on public authorities. It is therefore generally up to public authorities such as the NHS to decide whether to give you treatment or services where they are not under a legal duty to provide it.

In some circumstances, however, public authorities will be under a legal duty to provide you with medical care or other services. If there is a duty to provide you with medical care or services, a delay in providing this could breach your right to respect for your private life, especially where too much delay has a serious impact on your health.

In addition, the courts have recognised that decisions to refuse treatment or services may have serious implications for the right to respect for private life. Therefore, public authorities cannot simply decide to withhold treatment without any justification. They need to consider each case carefully, and while they can take resources into account, they cannot justify their decisions solely on the basis of a lack of resources. The stronger
the impact a decision not to treat you has on your human rights, the greater the need for public authorities to be able to justify their decision.

In particular public authorities cannot refuse you medical treatment just because you are disabled. This would be discriminatory (see pages 31–32 for further details about discrimination) and would very likely be a breach of your human rights.

**What is meant by my right to respect for my home?**

Your right to respect for your home is not a right to housing, but a right to respect for the home you already have. Your home may be a setting such as a hospital or residential home if you have been living there for a significant period of time. If public authorities decide to move you from your home or to close a hospital or residential home that you have been living in without taking your needs into account, this may interfere with your right to respect for your home. Any attempt to move you from your home would have to be justified as being lawful, necessary and proportionate.

**Case example**

A health authority attempted to move a disabled woman from her specialist NHS Unit where she had lived for six years. The health authority had promised the woman that she could remain there for the rest of her life. The unit was being closed for budgetary reasons. No alternative accommodation had been provided which met her needs. In these circumstances the courts said that moving her from the unit breached her right to respect for her home.
Your right to life

Article 2 of the European Convention on Human Rights contains the right to life. This right has two aspects to it. Public authorities must:

- **not take away your life**, except in a few very limited circumstances. These circumstances are lawful action taken to defend someone from violence, to arrest someone, to prevent someone who is lawfully detained from escaping, or to suppress a riot. Any action taken must use no more force than is absolutely necessary.

- **take reasonable steps to protect your life**. For example there should be adequate laws in place to protect you from others who might try to take away your life.

The duty to protect life does not mean that public authorities such as the NHS must always do everything they can to save life whatever the circumstances. In some situations, a public authority may argue that a person should not face painful and intrusive treatment that will prolong their life, but not improve its quality in the opinion of the public authority. The courts have accepted that in some instances the suffering involved in the treatment should be balanced against respect for preserving life.

**Do Not Resuscitate orders (DNRs)**

Sometimes doctors may believe that keeping an already very ill person alive would only inflict more suffering, as recovery is impossible or very unlikely. In these circumstances, doctors may consider placing what is known as a ‘Do Not Resuscitate’ order (DNR) on a person’s file. In these circumstances, medical staff will not attempt to revive the person if, for example, their heart fails.

If a DNR is placed on your medical records without your consent, this may breach your right to life. You and your family should be consulted, and orders should only be made after very careful consideration of the facts of your individual case. Doctors should not make assumptions about your quality of life. Once a DNR has been placed on your file it should be regularly reviewed so that it can be lifted if your circumstances change.
On the other hand, if you are an adult with the capacity to make decisions for yourself and you ask for a DNR to be put on your medical records, this will not be a breach of your right to life.

**Refusal of treatment**

If you are an adult with the capacity to make decisions for yourself, your decisions about whether or not to accept treatment should be respected, even if not being treated will lead to your death. However, if you decide to accept treatment, you may not be able to insist on a particular type of treatment (see treatment and resources on pages 24–25 and 30).

Your right to respect for your private life gives you the right to make your own choices in this situation (see page 22). The only exception is if you are being compulsorily treated under the Mental Health Act (MHA). For more information about compulsory treatment under the MHA please see our Human Rights Guide for people living with mental health problems.
If you ask for your treatment to be withdrawn, and this leads to your death, this is known as **passive euthanasia**. Passive euthanasia is lawful in the UK and does not breach the right to life.

**Active euthanasia**

The practice of actively assisting a terminally ill person to die is known as **active euthanasia**. This is currently unlawful in the UK. However, active euthanasia is not in itself a breach of the right to life, and may in the future become lawful in the UK.

There is currently widespread debate in the UK regarding active euthanasia, particularly among disabled people. Some disabled people argue that they should have a right to be assisted to end their life at a moment and in a way of their own choosing. However, others argue that the low value that some in society place on disabled people’s lives creates a danger that disabled people’s lives may be ended prematurely.

A woman called Diane Pretty (see example below) argued before the courts that the right to life should extend to a right to die and that active euthanasia should therefore be allowed in her situation. However, the European Court of Human Rights disagreed and said that the right to life does not confer a right to die.

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**Case example**

Diane Pretty had motor neurone disease, with no chance of recovery. She wanted to be in control of when and how she died. However, she was paralysed from the neck down and therefore had lost the physical ability to commit suicide. She wanted her husband to help her commit suicide. However, under UK law he would be prosecuted for the offence of assisting a suicide. She argued that the right to life entitled her to choose whether or not to go on living. However, the European Court of Human Rights found that this was not the case. The right to life does not extend to the right to die.
What about those who cannot decide for themselves?
If you do not have the capacity (see page 27) to make decisions for yourself about your medical treatment, and you are facing painful and intrusive treatment to prolong your life, a balance needs to be made between the benefit and the harm of the treatment. A very high level of pain, discomfort or indignity must be reached before the duty to keep you alive is overridden.

It is essential that assumptions are not made about your quality of life in this situation. The circumstances of each individual case should be considered carefully.

Case example
A child, born with Down’s Syndrome, needed an operation in order to survive the first few days of her life. Her parents refused to consent to the operation as they felt it would be kinder to let her die. The courts ruled that the child should have the operation, overriding the wishes of her parents. The best interests of the child were very important. It was not for the courts, or the parents, to make assumptions about the child’s quality of life.

If you are in a ‘permanent vegetative state’ this means you are in a permanent and irreversible state of unconsciousness. If this is the case, your treatment may be withdrawn after very careful consideration, leading to your death. The courts have said this is not a breach of the right to life. There is no absolute obligation to continue to provide life saving treatment if the treatment would be futile.
**Advance directives**

An **advance directive** (sometimes called a living will) is a written statement that you do not wish to receive certain medical treatment in the event that you lose the **capacity** (see page 27) to consent to or make informed choices about your treatment in the future. Doctors must comply with these wishes in most circumstances. To be valid an advance directive must meet certain conditions – please consult an experienced adviser if you would like to make an advance directive. Advice lines are given in the Useful contacts section at the end of this guide.

**Treatment and resources**

The right to life does not include a right to life-sustaining treatment in all circumstances. However your right to life must be taken into account in decisions about whether to provide you with life-sustaining treatment.

Since the Human Rights Act came into effect, decisions about whether to provide or refuse treatment have been looked at more closely. Public authorities need to have rational policies making sure that their resources are distributed fairly. Decisions about providing treatment must be justifiable. Human rights arguments may become relevant when such decisions seem to be unfair. The stronger the impact a decision not to treat you has on your human rights, the greater the need for public authorities to be able to justify their decision.

Decisions about treatment are also relevant to your right to respect for your private life (see pages 24–25).
Your right not to be discriminated against


Disability is not specifically listed as a forbidden ground of discrimination in Article 14. There was no recognition of the concept of disability discrimination when the European Convention was drafted over 50 years ago. However, the European Convention prohibits discrimination on the ground of any ‘other status’, and this has been used to cover discrimination on the grounds of disability.

Discrimination under Article 14 takes place where you can show that you have been treated in a different way compared to someone else in a similar situation. For example, if you are refused life-saving medical treatment that would not be refused to a non-disabled person, this may be a breach of your right not to be discriminated against, as well as a potential breach of your right to life (see pages 26–30).

Such differential treatment will not be discrimination if it can be shown to be ‘objectively and reasonably’ justified and proportionate (see page 17–18). Special measures or positive action for the benefit of disabled people will not be discrimination if these can be objectively and reasonably justified.

The Disability Discrimination Act (DDA) also offers you protection against discrimination. Broadly speaking it protects disabled people in:

- employment and occupation;
- access to goods, facilities and services (including functions carried out by public authorities);
- the management, buying or renting of land or property;
- education; and
- private clubs (from December 2006).

The Human Rights Act works alongside the DDA as an additional tool for disabled people to challenge discrimination.
Section 3
Practical advice and information
This guide aims to help you understand what your rights are, and to recognise situations in which your rights, or those of someone you know, have been breached. This section gives practical advice about what you can do next if you think this has happened or is happening.

**Talking about it**

- talk to somebody you can trust
- there are many support groups or advice lines you can talk to
- remember not every problem will be a human rights issue

The first step in dealing with a human rights issue is to talk to someone about it. This might sound like an obvious step; however many people often feel isolated or unable to speak about their situation, feeling scared of the consequences, or that nothing will change if they do tell someone about it.

Talk to someone whom you feel able to confide in – a close friend or relative, a support group, or one of the organisations listed in the Useful contacts section below. It is generally a good idea to seek advice from an experienced adviser before taking action. This should help you understand more clearly what kinds of issues are involved. It could be that your situation, while distressing, does not involve human rights concerns. However, there may be a way of dealing with the problem using other routes.

**Taking action**

Sometimes situations can be resolved directly with the person or organisation involved. You (or someone who can speak on your behalf) may be able to do this in a less formal way by speaking directly with those involved and/or writing a letter (see *raising the issue initially*).

If you are unable to resolve your situation in this way, all providers of public services are required by law to have a formal procedure for you to complain through (see *complaints procedures*).
However it may be that the situation can only be resolved by a court. Taking a case to court can be a lengthy and expensive process, and therefore it is best to avoid court proceedings where possible. However, there are time limits for legal proceedings (see taking your case to court) and therefore if it seems unlikely that the situation will be resolved directly with the person or organisation involved you should seek legal advice as soon as possible.

1. Raising the issue initially

- sometimes human rights issues can be resolved quickly by communicating with those involved, without going through any formal procedures
- try to seek advice before raising the problem directly with the person(s) involved
- somebody you can trust may be able to speak up about your problem for you

If you feel you can, you or someone who can advocate for you should raise the problem directly with the person or public authority that you feel has breached your rights, either by speaking to them or writing them a letter explaining the issue and mentioning that you think you have a complaint on human rights grounds. An advocate will be able to provide you with support and help you get your views across.

What is an advocate?

An advocate is someone who can represent and defend your views, needs, wishes, worries and rights if you do not feel able to do this yourself. Advocates can also help you to participate in and make decisions. They are wholly independent – they will represent you without taking a view about your best interests. They are not to be confused with legal advocates who are people with specialist legal knowledge and training, such as lawyers. Legal advocates represent people in formal settings such as courts or tribunals.

You can find out more about advocates by calling any of the advice lines for disabled people listed in the Useful contacts section.
While raising the problem directly may be the simplest way to solve the problem, you should make sure you seek advice before doing this. Sometimes raising the issue directly may place you in a more vulnerable position, as the person(s) concerned may not react well to your complaint. If you have any worries that raising the issue may make things worse for you, you should consider approaching the problem more formally either through a complaints procedure, or – if the complaint fails or the matter is really urgent – by taking your case to court (see below for more details of these options).

If you do decide to raise the problem directly this will hopefully start a negotiation process towards resolving the issue. Public authorities (for a definition of public authorities see page 8) have a legal duty to respect your rights, so if they are failing to do so they have to listen and respond to you.

2. Using complaints procedures

- all registered providers of public services are required by law to have a procedure for you to complain about their service
- if your situation cannot be resolved in this way there are other organisations that you can make a complaint to without having to go to court
- it does not cost anything to make a complaint either through a complaints procedure or through a complaints organisation

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

Before attempting to take your case to court it is important to try to go through the formal complaints procedure of the public authority. All registered service providers are required by law to have a complaints procedure, setting out how people who use services or those acting on their behalf can complain about the service.
If your situation remains unresolved after having gone through the complaints procedure of the public authority, you can register your complaint with an organisation such as an Ombudsman, the Commission for Social Care Inspection or the Healthcare Commission. Details of how to contact these and other complaints organisations are given in the Useful contacts section below.

Another option is to write a letter to your MP or locally elected Councillor, who may be able to take the issue up for you. For details of how to contact your MP or Councillor, please see the Useful contacts section.

3. Taking your case to court
As mentioned previously, taking a case to court can be a lengthy process, and can be expensive if you do not qualify for legal aid (see below). It is therefore best to avoid court proceedings where possible. However, in some cases public authorities will not react appropriately to your complaint, and the only way to resolve the problem may be by taking legal action.

Seeking legal advice
- you may be able to receive free legal advice from a local law centre, Citizens Advice Bureau or an independent advice centre, or they can put you in touch with a suitable solicitor or charity that is able to provide advice
- the local authority’s information office at your nearest town hall will give you details of local legal agencies, or you can look on the internet
- you can find out the details of local solicitors and advice agencies through either the Community Legal Service or the Law Society
- details of these and other sources of legal advice are given in the Useful contacts section

If you think legal action may be the only solution then you should seek legal advice as soon as possible, as your claims have to be made quickly. While exceptions can sometimes be made, you usually have to bring a case within one year of the incident occurring.
You may be able to receive **free legal aid** from a solicitor if you qualify financially. The Community Legal Service website (listed in the Useful contacts section) has a ‘legal aid calculator’ which you can use to help establish whether you qualify for legal aid. When making an appointment with a solicitor, check with them to see whether you are eligible for free advice or, if not, how much they will charge for an initial interview. You should also check which areas the solicitor specialises in, as some solicitors may not have experience in disability or human rights law.

Your next action will depend on the legal advice you receive. Human rights cases are heard in ordinary UK courts, and your legal adviser will recommend the best procedure for your situation. If the case needs to be resolved by a court, you will need to be represented by a solicitor. The solicitor will advise you on whether you would qualify for a full legal aid certificate to cover the costs of representation. If your case is successful, depending on the procedure you go through, you may be awarded damages, and/or an order may be made to prevent the public authority breaching your human rights. If your case is unsuccessful it may be possible to appeal.

If your case goes all the way through the UK court system without success, your last option will be to take your case to the **European Court of Human Rights** in Strasbourg, France (see page 7). They will not hear your case unless it has gone through all possible UK courts, and you need to apply within 6 months of the final decision of the UK courts.

Proceedings before the European Court are free, but it does not grant legal aid to pay for a lawyer to draft your initial complaint. If the Court decides to accept your case you may be able to receive free legal help if you cannot afford to pay for a lawyer. If you are unsure about any of this you can seek advice from one of the organisations in the Useful contacts section below.
Section 4

Useful contacts
Seeking legal/human rights advice

Advice UK www.adviceuk.org.uk
A membership organisation of independent advice centres. They do not give out advice themselves but their website has a directory of advice centres.

**Telephone:** 020 7407 4070  
**Email:** general@adviceuk.org.uk

Citizens Advice www.citizensadvice.org.uk
Provides free, independent and confidential legal advice, and can help you find a solicitor. To receive advice, contact your local Citizens Advice Bureau, which you can find either by visiting the website or contacting your local authority’s information office at your nearest town hall. They also have a separate website giving advice on a range of topics including human rights.

**Telephone:** 020 7833 2181 (no advice is available on this line, but they will be able to give you details of your local Citizens Advice Bureau that can give you advice)  
**Advice website:** www.adviceguide.org.uk

Community Legal Service www.clsdirect.org.uk
Has an online directory providing details of solicitors, advice agencies and information providers across England and Wales, and a helpline giving free initial legal help and advice on some issues. Their website contains information on a range of issues.

**Helpline:** 0845 345 4 345

Law Centres Federation www.lawcentres.org.uk
The coordinating body for Law Centres. Law Centres provide a free and independent professional legal service to people who live or work in their catchment areas. The Federation does not itself provide legal advice, but can provide details of your nearest law centre.

**Telephone:** 020 7387 8570  
**Email:** info@lawcentres.org.uk
The Law Society www.lawsociety.org.uk
The regulatory and representative body for solicitors in England and Wales. Their website has an online directory of law firms and solicitors. You can also call their enquiry line for help in finding a solicitor. They do not provide legal advice.

**Enquiry line:** 0870 606 6575  
**Email:** info.services@lawsociety.org.uk

Liberty www.liberty-human-rights.org.uk
An independent human rights organisation, which runs an Advice Line for members of the public with human rights queries. They also have an advice website which gives comprehensive information on the UK Human Rights Act.

**Advice line:** 0845 123 2307  
(Monday and Thursday: 6.30–8.30pm; Wednesday: 12.30–2.30pm)  
**Advice website:** www.yourrights.org.uk  
(You can download a written advice request form from this website)

Rights of Women www.rightsofwomen.org.uk
A voluntary organisation committed to informing, educating and empowering women about their legal rights. They have an advice line providing free confidential legal advice to women.

**Advice line:** 020 7251 6577  
**Textphone:** 020 7490 2562  
(Tuesday, Wednesday and Thursday: 2–4pm and 7–9pm; Friday: 12–2pm)

In addition to calling any of the above organisations, if you feel you have a potential claim you could also directly call any other local advice centre or reputable lawyer.
Making a complaint
The complaints bodies listed here do not charge to investigate your complaint. However, they will only investigate your complaint if they believe that it may be valid.

Commission for Social Care Inspection (CSCI) www.csci.gov.uk
CSCI’s primary function is to promote improvements in social care. If you have a complaint about a registered care service provider you can contact your local CSCI office, and they will look at your complaint to determine the most appropriate way for the complaint to be investigated.

Customer Services Helpline: 0845 015 0120 (You can call this number to find out the details of your local CSCI office)
Email: enquiries@csci.gsi.gov.uk

Healthcare Commission www.healthcarecommission.org.uk
The Healthcare Commission is responsible for reviewing complaints about the NHS or private healthcare in England. They will only look at your complaint if it cannot be resolved through the formal complaints procedure of the NHS or healthcare body concerned.

Telephone: 0845 6013012
Email: complaints@healthcarecommission.org.uk

Parliamentary and Health Service Ombudsman www.ombudsman.org.uk
Looks into complaints that Government departments, their agencies and some other public bodies in the UK – and the NHS in England – have not acted properly or fairly or have provided a poor service. Their website contains detailed information about how to make a complaint.

Complaints helpline: 0845 015 4033
Email: phso.enquiries@ombudsman.org.uk
The Local Government Ombudsman www.lgo.org.uk
Investigates complaints of injustice against local authorities and certain other bodies. They investigate complaints about most council matters including social services. You must give the council concerned an opportunity to deal with the complaint against it first. Details of how to make a complaint can be found on the website, or you can call their advice line.

Advice Line: 0845 602 1983
(Weekdays 9am – 4.30pm)

Contacting your MP or Councillor
You can find out how to contact your MP through the House of Commons Information Office:

Telephone: 020 7219 4272
Email: hcinfo@parliament.uk

Or on the web at: www.locata.co.uk/commons
You can find contact details for your local Councillor through your local authority, or on the web at: www.councillor.gov.uk

Advice lines and websites for disabled people
In addition to the national advice lines listed below, there may be a range of local advice and support services near to you. A national advice line may be able to direct you towards these.

Action for Blind People www.afbp.org
Offers legal advice to visually impaired people and people with other disabilities on a range of issues through their Legal Helpline.

Helpline: 0800 915 4666
Email: info@afbp.org
DIAL UK www.dialuk.org.uk
A national organisation for a network of 139 local Disability Information and Advice Line services (DIALs) run by and for disabled people. DIALs are based throughout the UK and provide information and advice on all aspects of living with a disability.

Telephone: 01302 310 123
Textphone: 01302 310 123 (please use voice announcer)
Address: St Catherine’s, Tickhill Road, Doncaster, South Yorkshire DN4 8QN
Email: informationenquiries@dialuk.org.uk

Disability, Pregnancy and Parenthood International (DPPI) www.dppi.org.uk
A charity run by disabled parents that promotes better awareness and support and provides information regarding pregnancy and parenthood for disabled people.

Telephone: 0800 018 4730
Textphone: 0800 018 9949
Email: info@dppi.org.uk

Disability Law Service www.dls.org.uk
A charity run by disabled people providing confidential and free legal advice on a range of issues for disabled adults, their families and carers.

Advice line: 020 7791 9800
Minicom: 020 7791 9801
(Weekdays 10am – 1pm, 2 – 5pm)
Address: 39–45 Cavell St, London E1 2BP
Email: advice@dls.org.uk
Disability Rights Commission www.drc-gb.org
An independent body established to stop discrimination and promote equality of opportunity for disabled people. Their helpline gives advice about the Disability Discrimination Act. They are unable to advise on individual human rights issues, but there is a section on their website dedicated to human rights. A useful report by Rowena Daw entitled ‘Human Rights and Disability: The impact of the Human Rights Act on Disabled People’ can be downloaded from their website.

**Helpline:** 08457 622 633
**Textphone:** 08457 622 644
(Weekdays 8am – 8pm)
**Address:** DRC Helpline, FREEPOST MIDO2164, Stratford upon Avon CV37 9BR

Disabled Living Foundation www.dlf.org.uk
Helps older and disabled people in finding equipment solutions that enable them to have independent lives. They run a helpline giving free and impartial advice on equipment.

**Helpline:** 0845 130 9177
**Textphone:** 020 7432 8009
(Weekdays 10am – 4pm)
**Email:** advice@dlf.org.uk

Disabled Parents Network www.disabledparentsnetwork.org.uk
A national organisation of and for disabled people who are parents or who hope to become parents, and their families, friends and supporters. They run a helpline operated by disabled parents.

**Helpline:** 08702 410 450
(Monday, Tuesday, Thursday and Friday: 12–2pm, Thursday: 7–9pm)
**Email:** e-help@disabledparentsnetwork.org.uk
**Mencap www.mencap.org.uk**
A learning disability charity working with people with a learning disability and their families and carers. They provide advice and support to meet people’s needs throughout their lives.

**England:**
**Helpline:** 0808 808 1111
**Minicom:** 0808 808 8181
(You can call 24 hours a day; if there is no adviser available you can leave a message and they will get back to you)
**Email:** help@mencap.org.uk

**Wales:**
**Helpline:** 0808 8000 300
**Email:** helpline.wales@mencap.org.uk

**Northern Ireland:**
**Information Service:** 08457 636 227
**Email:** mencapni@mencap.org.uk

**Scope www.scope.org.uk**
A disability organisation in England and Wales with a focus on Cerebral Palsy. They run an advice line staffed by qualified counsellors who can provide information and advice, emotional support and initial counselling.

**Helpline:** 0808 800 33 33
(Weekdays 9am – 9pm, Weekends 2 – 6pm)
**Email:** cphelpline@scope.org.uk
The Royal National Institute for Deaf People (RNID) www.rnid.org.uk
Provides a wide range of services and training for deaf and hard of hearing people, including an information line which offers free confidential and impartial information on a range of subjects.

Information line: 0808 808 0123
TextPhone: 0808 808 9000
Email: information@rnid.org.uk
Address: 19–23 Featherstone Street, London EC1Y 8SL

The Royal National Institute of the Blind (RNIB) www.rnib.org.uk
Provides a range of services including a helpline which offers information, support and advice to people with sight problems.

Helpline: 0845 766 9999
Email: helpline@rnib.org.uk

The British Council of Disabled People (BCODP): www.bcodp.org.uk
A national umbrella organisation set up by disabled people to represent their interests at the national level.

Disability Alliance www.disabilityalliance.org
Provides various services to disabled people, their families, carers and professional advisers including advice, information, campaign work, research and training, with a focus on social security benefits.

Disability Awareness in Action www.daa.org.uk
An international organisation providing information and support, run by and for disabled people.

Disability Information Services (DISS): www.diss.org.uk
Provides a comprehensive database of information and service providers for disabled people.
Disability Wales: www.disabilitywales.org
Their website provides a range of information for disabled people.

Disabilityworld.com: www.disabilityworld.com
A comprehensive directory of information and websites for disabled people both within the UK and Internationally.

Enable www.enable.org.uk
A charity based in Scotland for people with learning disabilities that provides a range of services.

National Centre for Independent Living (NCIL): www.ncil.org.uk
An organisation run by disabled people, providing information, training, expertise and policy development on all aspects of direct payments and independent living.

Useful websites on human rights/legal issues
Advice Now www.advicenow.org.uk
Website providing accurate, up-to-date information on rights and legal issues.

The Aire Centre – Advice on Individual Rights in Europe
www.airecentre.org
Provides information and advice on international human rights law.

The Council of Europe www.coe.int
International organisation which has the defence of human rights as one of its central aims. The home page of the European Court of Human Rights can also be found here.

Human Rights Division, Department for Constitutional Affairs
www.dca.gov.uk/hract/hramenu.htm
The Human Rights Division ensures the successful implementation of the Human Rights Act. It promotes human rights inside and outside Government, organising events and publishing information and study guides on human rights.
Justice www.justice.org.uk
An independent legal human rights organisation that aims to promote human rights, influence law and practice and improve the system of justice.
The British Institute of Human Rights

The British Institute of Human Rights (BIHR) is an independent charity based in London which raises awareness and understanding about the importance of human rights in the UK. A major part of our work is providing training on human rights to voluntary and public sector organisations working in a range of areas including disability. This gives us an insight into the kinds of human rights issues experienced by disabled people.

Many of the organisations we train have requested practical and accessible information on human rights written directly for disabled people. This guide is our attempt to fulfil this need.

Thank you

This guide was written by Sarah Cooke in conjunction with Lucy Matthews and project managed by BIHR staff Lucy Matthews and Carolina Gottardo. We would like to thank Kevin Caulfield of the National Centre for Independent Living, Natasha Jentle of Disability Action in Islington, and the Disability Rights Commission, particularly Catherine Casserley, Chris Benson, Myra White and Martin Crick, for their extensive help in preparing this guide. We would also like to thank Comic Relief for funding this project.
The rights contained in the European Convention on Human Rights include:

- 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 to no punishment 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
- the right to peaceful enjoyment of possessions
- the right to education

Remember that not all of these rights are absolute. Some of these rights may be limited or restricted under certain conditions (see pages 8–9).
Guides available in this series are:

- Your Human Rights – a guide for people living with mental health problems
- Your Human Rights – a guide for disabled people
- Your Human Rights – a guide for older people
- Your Human Rights – a guide for refugees and asylum seekers

The guides are available in single copies for individuals free of charge. They are also available in larger quantities for organisations. Please contact the British Institute of Human Rights for printed copies. You can also download them from www.bihr.org.

**The British Institute of Human Rights**

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Email: admin@bihr.org

Registered charity number 1101575

Please note that the British Institute of Human Rights is a small charity and cannot give advice on individual cases. If individuals feel they need advice they should contact a reputable lawyer or one of the organisations listed in the Useful contacts section of this guide.

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