

Your Human Rights

A guide for older people



The British Institute of
HUMAN RIGHTS

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 The law may have changed since this was printed, so information in it may be incorrect or out of date.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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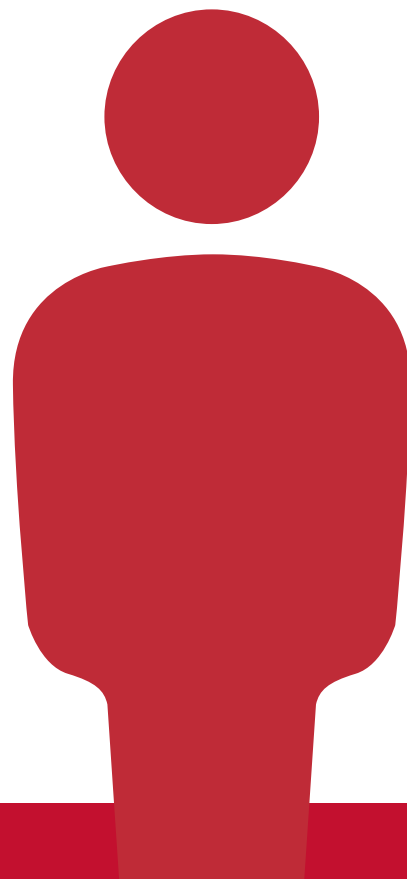
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Introduction

Many situations experienced by older people involve human rights. However, there is little information available about human rights and how they relate to older 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 older 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 older people. It is written directly for older people. The guide will also be useful for people working with older people or those wanting to learn more about the impact of human rights on older 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 older 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, hospitals and social services – 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. Currently, not all care homes run by private companies or voluntary organisations are treated as ‘public authorities’. However, the Government has promised to take action to make sure that all older people have the protection of the Human Rights Act, whatever type of care home they may be in.

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 older people?

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

Section 2

Human rights and older people



You may have heard stories about abuse of older people in residential care homes or by their carers in their own homes, doctors refusing to give older people medical treatment solely because of their age, or residential care homes for the elderly being closed at short notice without regard to the needs of the residents. You may even have direct experience of these kinds of situations.

However, you may not realise that these circumstances all involve human rights issues. The Human Rights Act is an important mechanism for protecting older people against various forms of ill treatment. This section gives practical information about the kinds of human rights issues which older people may be facing.

Which human rights are relevant for older people?

All of the human rights protected by the European Convention belong to and may be relevant for older people. However, this guide will concentrate on the three 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; and
- the right to life.

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

- inhuman treatment means treatment causing severe mental or physical harm
- degrading treatment means treatment that is grossly humiliating and undignified

Situations in which older 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 older people, this right may be relevant in a number of situations:

Abuse or neglect

Older people may suffer abuse or neglect in settings such as hospitals or residential care homes, or during home care. In some circumstances this may be challenged on the basis that it is inhuman or degrading treatment.

Situations that may involve inhuman or degrading treatment include:

- unchanged sheets
- neglect leading to bed sores
- leaving trays of food without helping you to eat if you are too frail to feed yourself
- excessive force used to restrain you
- your calls for help being routinely ignored
- washing or dressing you without regard to your dignity
- other forms of bad practice

Unacceptable practices such as routinely refusing to take you to the toilet, undressing you in view of others, or physical or verbal abuse, 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.

Inhuman or degrading treatment may also result from inadequate care. For example you may be assessed as needing assistance to wash and/or 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 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 depend on the specific circumstances.

Case example

Staff in a residential care home routinely feed elderly residents breakfast whilst they are strapped to a commode. They refuse to take residents to the toilet in the middle of the night, and most are too frail to take themselves. This means that they are often left lying in soiled bed sheets all night. Many residents also suffer from bedsores, caused by staff neglect. This kind of treatment is unacceptable and may amount to inhuman or degrading treatment.

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, could also amount to inhuman or degrading treatment.

Failure to act by public authorities

Public authorities must sometimes take proactive steps to protect you from inhuman or degrading treatment, even if the harm is caused by private individuals rather than staff or carers of a public authority. For example, if a public authority is 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 public 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.

Case example

An older man is cared for at home by his daughter. Friends of the man have reported to the local authority that the daughter acts in an abusive way towards her father. She is often heard yelling abuse at him, and frequently refuses him food or drink. However, the authority has failed to take any steps to investigate this situation. This failure to act may breach the man's right not to be treated in an inhuman or degrading way.

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 positive 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 an interference 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.

Explaining proportionality

Certain questions can be asked to help decide if an action is proportionate, such as whether alternative approaches to the problem were considered that were less drastic.

For example, suppose an older woman who is cared for at home by her daughter is forced to move into residential care because her daughter is no longer able to care for her alone. Depending on the circumstances this may not be proportionate if, for example, the authorities have not considered other less restrictive options, such as a care package which enables the woman to continue living at home.

Sometimes however public authorities will act in a proportionate way and an interference with your right will be justified. For example, suppose the authorities have clear evidence that the woman in the above case is being abused by her daughter. Placing the woman in residential care may be an appropriate response in the circumstances in order to protect her.

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 restriction 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 positive steps to make sure that your right is fulfilled. This may include providing extra resources, such as providing adequate support to enable you to remain living at home rather than move to a residential care home.

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. Your right to respect for your family life includes being able to live together with your family and, where this is not possible, having regular contact.

Your right to respect for your family life will be relevant if you are separated from your partner and/or other family members, or if you are placed in a care home which is far from your family and this makes it very difficult for them to visit you. For example, if you need care while continuing to live at home with your partner, but the local authority says that they do not have the necessary resources to enable you to stay at home, this may interfere with your family life.

Case example

A local council refused to place a married couple in the same nursing home in Oxfordshire, which was a potential breach of their right to respect for family life. The decision attracted national publicity, and the council eventually accepted that the couple should be placed together.

If public authorities do separate you from your partner, or place any other restrictions on your family life, they will need to be able to justify their decision. They will need to consider whether their actions are lawful, necessary and **proportionate**. If they are not, this will be a breach of your right to respect for your family life.

What is meant by private life?

Private life is also 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;

- your physical and mental well-being;
- being able to access medical treatment;
- 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 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 older people include:

- **personal and sexual relationships:** this could be significant in a residential care setting where your ability to form or maintain relationships may be restricted. Policies which restrict your ability to decide who you want to spend time with and how you spend your time may interfere with your private life.
- **cultural and other needs:** if you are in a hospital or a residential care home, those caring for you should respect your cultural needs such as religious practices or dietary requirements, or any other needs which may be part of your private life.
- **your physical and mental well-being:** decisions which affect your physical and/or mental well-being are likely to have a strong impact on your private life. This may arise if, for example, you need care and wish to stay living in your own home, but your local authority decides to place you in residential care. You may feel very distressed at the thought of leaving your home, and this may affect your mental well-being. This may therefore interfere with your private life.

- **participating in community life:** your private life may be involved if you are unable to participate in community life or to 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.
- **decisions about treatment:** as long as you have the capacity (see page 26) 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 including your care. 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

An older woman living in a residential care home had a fall and was admitted to hospital. While she was in hospital, the local authority decided that she needed full time nursing care and should therefore be moved to a nursing home, rather than returning to the residential care home. The Court found that the local authority had not properly considered the impact this would have on her private life. Moving a frail, older person to a strange environment could have serious if not fatal consequences. The authority was therefore asked to reconsider its decision, taking her right to respect for private life into account.

Private life: privacy concerning your body

Another very important aspect of your private life which can have a strong impact on your dignity is who sees or touches your body. Your privacy and dignity should be properly considered when you are being washed, dressed or cared for generally. Situations that may interfere with your right to respect for your private life include:

- changing you or leaving you without clothes in front of others;
- a member of the opposite sex washing or undressing you if you have requested that this does not occur;
- making you go to the toilet in front of others; and
- forcing you to stay in a mixed sex environment if you are particularly distressed by this.

Any action taken by public authorities that interferes with your private life in any way must be lawful, necessary and **proportionate**. It must not be excessive in the circumstances.

Case example

An older woman is a long-term patient in a hospital ward. She has asked to be washed only by female nurses, as she feels humiliated by male nurses seeing her undressed. However, she is still frequently washed by male nurses. If the hospital is unable to justify this as being lawful, necessary and proportionate, this may breach the woman's right to respect for her private life.

You may have noticed that some of these situations could be seen as **inhuman or degrading treatment**. If a situation that has an impact on your private life is particularly serious – for example if you are severely distressed by being undressed by a member of the opposite sex because you have been sexually abused in the past, or for religious reasons – this may also amount to inhuman or degrading treatment, depending on the particular circumstances.

Where this is the case, public authorities will not be able to justify their actions by pointing to, for example, short staffing or a lack of resources, because your right not to be treated in an inhuman or degrading way is **absolute** (see page 8).

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 treatment you are given. Whether sharing such private information with others without your permission amounts to a breach of your right to respect for private life will depend on 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. 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 your or someone else's health or safety. Again, this reason must be lawful, necessary and **proportionate**.

Case example

A man wanted access to his personal file held by the local authority. He had been in care since a young age and wanted to find out about his past. The local authority refused. The European Court of Human Rights found that this breached his right to respect for his private life. The Court stated that people should have access to information about themselves unless there is a specific justification for withholding the information.

Private life: treatment and resources

Not being able to access medical treatment and other services that you need may affect your physical and/or 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 them.

In some circumstances, however, public authorities will be under a legal duty to provide you with medical care or other services. Where 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 of your age. This would be discriminatory 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. Home closures may also affect your right to respect for your private life, since moving you is likely to have a serious impact on your way of life, and may mean you lose the company of friends among staff and residents.

Case example

A local authority in Plymouth was considering closing a residential care home for the elderly, for financial reasons. The residents brought a case against the authority claiming that the closure of the home would be a breach of their human rights including their right to respect for private life, family life and home. They argued that they had a reasonable expectation that the home would be their home for life. The panel deciding their case agreed and the home was not closed. The panel said that people's age should not be used as a justification for restricting their rights.

Your right to respect for your home may also apply if you would prefer to be cared for in your own home rather than be forced to move into residential care (as well as involving your right to respect for your family life if this means you are going to be separated from your family – see page 18).

Any decisions to close a residential home or hospital, or to move you from your home, will need to be justified as being lawful, necessary and **proportionate**.

In some cases it may be found that the decision to close a care home is proportionate. However, at the very least, your own needs and views, and those of each individual resident, must be taken into account in the decision-making process. Suitable alternative accommodation should be identified for you.



Your right to life

Article 2 of the European Convention on Human Rights protects 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 want 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.

However, a DNR should not be placed on your medical records without your consent or knowledge, nor should an institution have a policy saying that DNR orders can be placed on the files of anyone over a certain age.

These kinds of situations have serious implications for the right to life and can be challenged. You and your family should be consulted, and DNR 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.

Case example

An older woman is admitted to hospital with a chest infection. Medical staff place a 'Do Not Resuscitate' order on her file, because they consider that as an older person, she has a low quality of life which should not be prolonged. They have not consulted with her or any of her family members. This kind of situation could be challenged as a breach of the right to life.

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.

What does capacity mean?

If you are unable to make decisions for yourself about a particular issue, for example about whether or not you want a certain treatment, this means that you lack capacity in relation to this decision. The law uses a test to decide whether or not you have capacity. This will look at whether you are able to understand, remember and believe information about your options, weigh up the pros and cons of your available choices, and make a decision based on these factors.

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 do decide to accept treatment, you may not be able to insist on a particular type of treatment (see treatment and resources on pages ages 22–23 and 28–29).

Your right to respect for your private life gives you the right to make your own **choices** in this situation (see page 20). The only exception is if you are being compulsorily treated under the Mental Health Act. For more information about compulsory treatment 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 patient to die is known as **active euthanasia**. This is currently unlawful in the UK.

Case example

Diane Pretty had motor neurone disease, with no hope 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 in court 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.

A woman called Diane Pretty (see example on this page) 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 did not confer a right to die.

There is currently widespread debate in the UK regarding active euthanasia. Active euthanasia is not in itself a breach of the right to life, and may in the future become lawful in the UK.

What about those who cannot decide for themselves?

If you do not have the **capacity** (see page 26) 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.

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 that 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 26) 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 are looked at more closely. Public authorities should 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 page 22–23.

Inquests

The right to life may place public authorities under a positive duty to carry out **inquests** into deaths in suspicious circumstances. Examples may include where life saving treatment has been withheld, or if there have been suspicious deaths at a residential home and there is strong evidence to suggest there may have been abuse or neglect. Public authorities are under an obligation to protect your life, and if they fail to properly investigate these deaths, this could be a breach of the right to life.

The right to life also places public authorities under a duty to make sure that **families are involved** in the inquest process. They should have access to information they need in order to find out what happened to their family members.

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.

I. 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 older people listed in the Useful contacts section.

While this 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.

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.

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

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 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 by visiting the Citizens Advice 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. They also have a helpline giving free initial legal help and advice on benefits, tax credits, debt, education, housing and employment problems.

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

A regulatory and representative body for solicitors. 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 service 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 dedicated to women's 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 601 3012

Email: complaints@healthcarecommission.org.uk

The Local Government Ombudsman www.lgo.org.uk

Investigates complaints 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)

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: phto.enquiries@ombudsman.org.uk

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 older people

Action on Elder Abuse www.elderabuse.org.uk

An organisation that aims to prevent the abuse of older people. Runs a confidential helpline for anyone concerned in any way about the abuse of older people.

Helpline: 0808 808 8141

Address: Astral House, 1268 London Road, London SW16 4ER

Email: enquiries@elderabuse.org.uk

Age Concern www.ageconcern.org.uk

The UK's largest organisation working with and for older people. Their website and Information line provide information materials on a wide range of issues affecting older people. There are a number of local Age Concerns that offer a range of services, which may include advocacy – for contact details please see their website.

Information line: 0800 00 99 66

(7 days a week, 8am – 7pm)

Address: Astral House, 1268 London Road, London SW16 4ER

The Alzheimer's Society www.alzheimers.org.uk

A care and research charity for people with dementia, their families and carers. They have a helpline for carers and a comprehensive website.

Helpline: 0845 300 0336

(Weekdays 8.30am – 6.30pm)

Address: Gordon House, 10 Greencoat Place, London SW1P 1PH

Email: enquiries@alzheimers.org.uk

Counsel and Care www.counselandcare.org.uk

A charity giving advice and information to older people, employers and service providers on care homes, community care and housing with care.

Helpline: 0845 300 7585

(Weekdays 10am – 12noon and 2 – 4pm except Wednesday afternoons)

Address: Twyman House, 16 Bonny Street, London NW1 9PG

Email: advice@counselandcare.org.uk

Help the Aged www.helptheaged.org.uk

Works to free disadvantaged older people in the UK and overseas from poverty, isolation and neglect. They have comprehensive advice and information sheets on their website, together with an advice line – Seniorline – which offers advice and information on a wide range of welfare rights issues.

Seniorline: 0808 800 6565

(Weekdays 9am – 4pm)

Address: 207 – 221 Pentonville Rd, London N1 9UZ

Email: info@helptheaged.org.uk

Polari www.casweb.org/polari

Works for better services for older lesbians, gay men and bisexuals. They run an information service for lesbian, gay and bisexual older people and those who support them. They do not give advice themselves but they can help you find the service or advice you need.

Telephone: 020 7255 4480

Address: 5th Floor, Central House, 14 Upper Woburn Place, London WC1H 0AE

Email: info-polari@madasafish.com

The Relatives and Residents Association www.relres.org

An organisation with the aim of improving quality of life for older people in care. Their helpline offers information and support to all those involved with long term care.

Helpline: 020 7359 8136 (Weekdays 9.30am – 4.30pm)

Address: 24 The Ivories, 6–18 Northampton Street, London N1 2HY

Email: advice@relres.org

Witness www.witnessagainstabuse.org.uk

Helps people who have been abused by health or social care workers and works to prevent abuse. They provide professional support and advocacy services and a helpline for anyone concerned with professional abuse issues.

Helpline: 08454 500 300

Email: info@witnessagainstabuse.org.uk

Are you over 50? www.over50.gov.uk

A practical guide to advice, support and services across government for those over 50.

The Association of Retired and Persons over 50 www.arp050.org.uk

A social and campaigning membership organisation for the over 50s, dedicated to changing attitudes to age. Their website has a help section containing useful information for older people.

Care Directions www.caredirections.co.uk

A website providing a guide to the care and rights of the elderly in the UK, aiming to empower people with the information they need to make informed choices.

Housingcare.org www.housingcare.org

A website which aims to help older people make decisions about where to live, and any support or care that they need.

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 older people. This gives us an insight into the kinds of human rights issues experienced by older people.

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

Thank you

This guide was written by Lucy Matthews and project managed by BIHR staff Lucy Matthews and Carolina Gottardo. We would like to thank Nony Ardill of Age Concern England, Sheena Dunbar of Age Concern Waltham Forest and Beryl Harwood 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.bihhr.org.

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Email: admin@bihhr.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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