



End of Life Care and Human Rights: A practitioner's guide

About this Guide

This Guide is written by the **British Institute of Human Rights** in partnership with **Sue Ryder**, and in consultation with **palliative care specialists** who have acted as ‘experts by experience’ throughout the drafting process.

BIHR and Sue Ryder would like to thank the practitioners who gave up their time to be part of this process, helping to ensure the Guide is accessible, relevant and useful for end of life care practitioners working in a range of settings.

Sue Ryder

The British Institute of **Human Rights**

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Who this Guide is for

This Guide is for **practitioners caring for people at the end of their lives**. This may be in a hospice, a care home, a hospital or in the community (including in people's own homes). It may also be useful for people accessing end of life care services, and their friends, families and carers. When we say '**you**', we mean **the practitioner**.







How to use this Guide

The aim of this Guide is to support you to deliver care services that respect human rights by providing accessible information about human rights and how they are relevant in an end of life care context. It offers **practical assistance when navigating difficult decisions** which may impact on the human rights of the people you work with and for. The Guide includes **decision-making flowcharts to pull out and keep with you for everyday use**.

No knowledge of human rights or the Human Rights Act (HRA) is assumed. Those with some human rights knowledge may also **find it useful, particularly sections 4 to 6**. The guide is designed to allow you to '**dip in and out**', rather than having to read it cover-to-cover.

The human rights information in this Guide covers the UK; references to health law, policy, practice and institutions refer to England.

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I. Introduction

Our **human rights** are the basic rights and freedoms we have because we are human. They provide a set of **minimum standards**, outlined in law, for how the government should treat us. Our human rights are protected through the Human Rights Act (HRA), which makes 16 of the rights written in the European Convention on Human Rights part of UK law.

The HRA guarantees these minimum standards in two key ways:

- 1** Firstly, it places a legal duty on public officials (including health services) to uphold these standards by respecting our human rights in everything they do (section 6 HRA).
- 2** Secondly, all legislation, including health and social care law, should be compatible with human rights or 'human rights compliant' (section 3 HRA). In practice this means the laws that are relevant to your sector should be designed and applied in a way that respects, protects and fulfils our human rights.

Human rights are not 'new' or 'extra' in the field of end of life care. Human rights are at the heart of much of the law, policy and practice that you will be familiar with, and have supported practitioners to provide person-centred care. Here are a few examples:

The now abolished Liverpool Care Pathway

The Liverpool Care Pathway, which had been designed to help doctors and nurses provide end of life care, was reviewed following concerns about its use. The recommendations in **More Care, Less Pathway 2013** and the subsequent guidance **One Chance to get it Right 2014** are in line with human rights principles. A central theme of the recommendations

is the need to **involve patients in decisions about their care**. Patients must be supported to be involved in the development of their end of life care plan, and in key decisions about care and treatment. Being involved in these important decisions is a key part of our right to respect for private and family life protected by Article 8 of the Human Rights Act.

Five Priorities for Care

Following **More Care, Less Pathway** and **One Chance to get it Right**, the Liverpool Care Pathway was abolished, and the Five Priorities for Care were developed by the Leadership Alliance for the Care of Dying People.

These are:

- The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly
- Sensitive communication takes place between staff and the person who is dying and those important to them
- The dying person, and those identified as important to them, are involved in decisions about treatment and care
- The people important to the dying person are listened to and their needs are respected
- Care is tailored to the individual and delivered with compassion – with an individual care plan in place

Being treated with dignity and respect in the last days and hours of someone's life is central to the Five Priorities, and protected by the right to respect for private and family life (Article 8 in the Human Rights Act).



NICE and End of Life Care

NICE has published new Quality Standards on care of dying adults in the last days of life (QS, Dec 2015) in addition to the quality standard on end of life care adults (QS, 13 Nov 2011). This new guidance aims to put people at the heart of decisions about their care and to support them in their final days in accordance with their wishes.

Key elements of the Quality Standard include:

- Ensuring good communication and shared decision-making (with the person, families and named healthcare professionals)
- Supporting people at the end of life to drink if they want to
- An individualised rather than a 'blanket' approach to care

The Quality Standard has a clear link to ensuring respect for people's right to private life, including their well-being and having a say over what happens to them, as protected by Article 8 in the Human Rights Act.

Human rights will underpin many of the situations you come across in your day-to-day work. The HRA can be a practical tool, providing a framework to help practitioners make (often difficult) decisions.

Being able to identify the human rights involved and the impact a particular decision or action will have on a person's human rights will help you to deliver good quality care that is person centred, accountable, and balances the needs of individuals against the needs of others and the wider community.



Human rights in regulation of services: The new Care Quality Commission approach

The health and social care regulator, the Care Quality Commission (CQC), launched a new policy, **‘Human Rights Approach to the regulation of services’** in September 2014. The CQC will be applying their new approach to all the health and social care services they register or inspect. It will therefore be important for your service and staff to be familiar with human rights and the CQC approach.

Using this resource and being aware of human rights and putting them at the heart of healthcare can help staff contribute to service performance and outcomes, and can provide evidence of compliance with CQC regulation standards. BIHR, lead author of this guide, has developed and delivered the CQC’s staff education programme to support their new human rights approach. This Guide reflects similar learning and information on human rights in healthcare.



2. How the Human Rights Act works

The **Human Rights Act (HRA)** is the main law protecting human rights in the UK. It contains a list of 16 rights (called Articles) taken from the European Convention on Human Rights. These rights belong to all people in the UK, and the HRA specifies several ways in which these rights should be protected.

The HRA provides a useful and practical tool which can be used by non-lawyers and non-specialists. As a practitioner in health services you will usually have legal duties under the HRA (see below). **The HRA is designed as a framework to help negotiate better outcomes before a situation gets to court** (unless it has to):



You can use this framework to help **inform your practice**, including challenging decisions internally with colleagues and in your interaction with other services. This guide provides information, tools and tips on how you can do this.



People may also rely on the HRA to **hold health services to account** without necessarily having to go to court, if services act in ways that don't respect rights.

In everyday situations

Section 6 of the HRA places a duty on public authorities to comply with human rights in everything that they do. This means that public authorities have legal responsibilities for respecting, protecting and fulfilling human rights. In everyday situations this duty enables people using services and you as a practitioner to challenge poor treatment

and to negotiate better solutions, using a language of rights and duties. Rather than waiting to be challenged, public authorities can also use the HRA proactively to develop and deliver better services, policies and practices. For practitioners, this means you can use the HRA to help inform your decisions and practice.

Who has duties under the Human Rights Act?

Only public authorities or bodies exercising public functions have legal duties under the HRA.

This includes:

- NHS organisations and staff, including commissioners
- Outsourced NHS services provided by the private sector or charities
- Local authorities and their employees e.g. social services staff etc.
- Charities (including hospices) providing care arranged and/or paid for by a local authority or the NHS
- Private nursing and domiciliary care arranged and/or paid for by a local authority or funded by the NHS

The duty applies across services, whether it is about frontline practitioners, senior managers, at board level etc.

When the HRA was being made law it was intended to apply to a range of organisations, recognising that lots of public services are now provided by private organisations and charities. The Care Act 2014 says **all local authority-funded and/or arranged care and support services regulated by the CQC have a legal duty under the HRA**. This includes commissioned services that are provided under contract to a local authority, and services obtained through local authority direct payments, if delivered by a regulated service provider (Care Act 2014).

Individuals do not have legal duties under the HRA. This means you cannot bring a human rights claim against other individuals like family members or neighbours.



However, because of the HRA, public authorities have **positive obligations** which means they sometimes have to **step in and protect someone from harm** (often referred to as **safeguarding**). This is explained next.

How human rights duties work: You can think of the legal duties under the HRA as requiring three types of actions. These are:

Respect

(known as a ‘negative’ duty): this means ensuring you respect people’s rights. This can help you to **avoid interfering with someone’s rights unless absolutely necessary**. For example, the right to respect for family life (Article 8) means not interfering with someone’s family life unless it is necessary and proportionate to do so, such as to protect the rights of others.

Protect

(known as a ‘positive’ duty): this means public authorities must **take action to protect people’s human rights**. This can sometimes include protecting a person from harm by another (non-official) person (such as their spouse or neighbour). For example, under the right to life, **officials should take action if they** become aware that a person is in real and immediate danger, e.g. to protect someone from an abusive family member who has threatened to kill them. This is often referred to as **safeguarding** which has its legal foundations in this positive duty to take action to protect human rights.

Fulfil

(known as a ‘procedural’ duty): this means public authorities should take steps to strengthen access to and realisation of human rights. It includes having **systems in place to prevent or investigate human rights abuses**. For example, the right to life (Article 2) requires that the death of a person in hospital should be investigated where the hospital may be implicated (this is usually through an inquest).

3. Key human rights in end of life care

There are 16 rights protected by the Human Rights Act (HRA). You can find a full list of these human rights below. This section provides information about the key rights which are most likely to be relevant to your practice.



Right to life
(Article 2)



Right not to be tortured or treated in an inhuman or degrading way
(Article 3)



Right to be free from slavery or forced labour
(Article 4)



Right to liberty
(Article 5)



Right to a fair trial
(Article 6)



Right not to be punished for something which wasn't against the law when you did it
(Article 7)



Right to respect for private and family life, home and correspondence
(Article 8)



Right to freedom of thought, conscience and religion
(Article 9)



Right to freedom of expression
(Article 10)



Right to freedom of assembly and association
(Article 11)



Right to marry and found a family
(Article 12)



Right not to be discriminated against in relation to any of the human rights listed here
(Article 14)



Right to peaceful enjoyment of possessions
(Article 1, Protocol 1)



Right to education
(Article 2, Protocol 1)



Right to free elections
(Article 3, Protocol 1)



Abolition of the death penalty
(Article 1, Protocol 13)

Right to life (Article 2)



Q1. How might I encounter this in my work?

Examples could include:

- situations where a person's life may be at risk;
- decisions being made to withdraw life sustaining treatment or not to resuscitate a person; and
- when someone requests life-prolonging treatment against medical opinion.

Q2. What do the legal duties mean for me?



Respect: As a healthcare practitioner you cannot deliberately take away someone's life (for information on withdrawing care see [page 15](#)).



Protect: If you know that someone's life is at risk, you must take reasonable steps to protect it. This does not mean providing treatment at all costs (for more information see [page 14](#)).



Fulfil: There needs to be an independent investigation into a death where your organisation may be implicated or involved.

Q3. Can I restrict the right to life?

No, as a healthcare professional it is unlawful to deliberately take away someone's right to life. For information on withdrawing care see [page 15](#).

Note: there are very limited circumstances where it may be possible for public officials to justify a use of force which results in someone losing their life, e.g. when defending someone from violence. However, such a use of force must be a last resort and be absolutely necessary. This will usually only apply to law enforcement and armed forces personnel.

Real life: Right to life and protecting patients' lives



There is a **positive obligation on health services to protect life in certain circumstances**. Where there is a **real and immediate risk** to a patient's life that you know about, or should know about (because it has been reported to you for example), you have a legal obligation to take reasonable steps to try and protect that life. For example, if you know that someone in your care is at risk of suicide, there may be a positive obligation for you to act to protect life.

Legal cases: *Osman v UK* (1998) and *Savage v South Essex Partnership NHS Foundation Trust* (2009)



Remember! When making decisions about this right...

- This right is absolute and healthcare practitioners cannot deliberately end life. For information on withdrawing care see page 15.
- There is a positive obligation to protect this right. This means that if you are aware that a person is at risk of losing their life (for example by a family member) you must take steps to protect them.
- Wherever possible people – i.e. the patient and those who are family or with legal responsibility – should be consulted about decisions about care and treatment that may impact on the right to life. The right to be involved in these important decisions is a key part of our right to respect for private and family life see pages 21 - 24.

Withdrawing and administering care

Decisions about withdrawal of care will be dependent on the particular circumstances of the patients involved. The following principles can be used to guide decisions:

Withdrawing care

NOTE: Some decisions involving withdrawal of life-sustaining treatment must be referred to a court (Court of Protection or Family Court for under 18s).

- Healthcare professionals have a medical duty not to withdraw treatment where it is still of some benefit to the patient. (Legal case: Bland v Airedale NHS Trust (1993))
- Where a patient is conscious and has capacity to make decisions about their care, withdrawing care serving a therapeutic purpose against their wishes would be a breach of the medical duty of care. It is also likely to breach the HRA e.g. the right to respect for private life under Article 8 (including decision-making) and potentially the right to life (Article 2). (Legal case: Burke v GMC (2005))
- Where a patient is unconscious and unable to make decisions about their care, healthcare professionals could make a clinical decision to withdraw treatment where it is in the patient's best interest, provided there is no therapeutic or other benefit to a patient. For this to not breach the right to life (Article 2), it would have to be a responsible clinical decision which accords with respectable medical opinion. This can involve withdrawing artificial nutrition and hydration where a patient is in a persistent vegetative state but the decision would need to be referred to the Court of Protection.
- The right to life does not entitle anyone to compel healthcare professionals to continue with life-prolonging treatment where this would expose the patient to inhuman or degrading treatment breaching Article 3. (Legal case: Burke v GMC (2005))

Administering care

- It would be unlawful to administer medical treatment to someone who is conscious and has capacity to make decisions about their care without their consent. (Legal case: In re F case (1990))
- Healthcare professionals cannot actively seek to end life (Legal case: Bland v Airedale NHS Trust (1993)). Administering medicine which deliberately ends life, with no other therapeutic or pain relief benefit, would likely be a breach of Article 2 in the HRA and likely be a criminal offence.
- The right to life (Article 2) does not include a right to die. Assisting someone to commit suicide is a criminal offence. The positive obligation to prevent inhuman and degrading treatment (Article 3) does not stretch to requiring a practitioner to assist a terminally ill person to die. (Legal case: Pretty v UK (2002))
- Administering pain relief which has the result of hastening death could be justified as protecting people from inhuman or degrading treatment (Article 3) where the purpose is to ease pain, depending on the circumstances. The purpose cannot be to end life. This is known as the doctrine of double effect.

Right to be free from inhuman or degrading treatment (Article 3)



Q1. How might I encounter this in my work?

Examples could include:

- where a patient is neglected, or not cared for, in a way that is likely to cause serious harm or suffering;
- where decisions are being made to withdraw treatment such as **artificial feeding**, dialysis, turning off a pacemaker or withholding hydration – none of which may cause an immediate death;
- continuing with treatment that may be causing serious harm or suffering; and
- assessing and responding to the need for appropriate pain relief.

This human right essentially covers serious harm, abuse or neglect.

Q2. What do the legal duties mean for me?



Respect: You cannot treat someone in an inhuman or degrading way (whether or not this is your intention, the impact is what counts).



Protect: If you know that somebody may be being subjected to such treatment, you must take reasonable steps to protect them.



Fulfil: There needs to be an independent investigation where inhuman or degrading treatment has occurred and where your organisation may be implicated or involved.

Q3. Can I restrict the right to be free from inhuman or degrading treatment?

No, This right is absolute so there are no circumstances when it is acceptable to restrict or interfere with it.

Treatment must have a **very serious impact** on a person to be considered inhuman or degrading. Inhuman treatment causes severe **mental or physical suffering**. Degrading treatment is less severe than inhuman treatment but still grossly **humiliates** or causes the victim to **feel fear, anguish and inferiority**.

Individual circumstances are important. Practitioners will need to look at a patient's situation and the **impact** on them to determine whether the harm amounts to inhuman or degrading treatment. Important factors to consider include **age, health, disability and gender**.

Real life: Right to be free from inhuman or degrading treatment, Mid Staffordshire and severe neglect in hospital



Family members of patients who lost their lives at Stafford Hospital started legal proceedings under the HRA. Over 100 cases were taken and were settled out of court. One case was taken by “Jean’s” family. Jean went into hospital following a fall at home (she had cancer but was not expected to die at that time). Whilst on the ward she was often not given fluid and food was left out of reach, and Jean’s family repeatedly found her in soiled bedding. Jean developed **pressure sores, became dehydrated and malnourished**, and **contracted Clostridium difficile, MRSA and E-Coli**. Jean was often left **without pain medication**.

After three months as an in-patient Jean died. The funeral home could not embalm her as her body was too full of infection and contagions and she had to be buried in a body bag. The family started legal proceedings arguing that Jean’s treatment amounted to inhuman and degrading treatment (under Article 3) and that the rights of family members to respect for their privacy, including well-being (under Article 8), had been breached due to the anxiety and stress of watching Jean suffer. The case was settled out of court.

Information provided by the family’s legal team. Names have been changed.

Remember! When making decisions about this right...

- This right is an absolute right. This means there are no circumstances where inhuman or degrading treatment is acceptable, no matter the reason or cause.
- There is a positive obligation to protect this right. This means that if you are aware that a person is at risk of being treated in this way (for example by a family member) you must take steps to protect them.
- The treatment, decision or policy must have had a very serious impact on a person to be considered a breach of this right. Individual circumstances are important.
- Because this right cannot be restricted in any circumstances, limited resources are not a defence for treating someone this way.

Right to liberty (Article 5)



Q1. How might I encounter this in my work?

Examples could include:

- where a person has restrictions placed on their movement as part of their care arrangements;
- when you need to prevent somebody from leaving the place they are being cared for because of concerns about their welfare; and
- when you are caring for somebody who requires constant supervision or monitoring for their own safety.



Q2. What do the legal duties mean for me?



Respect: You cannot deprive someone of their liberty apart from in the specific circumstances set out in the right.



Protect: If a person in your care has been detained because they have mental health problems or lack capacity to make certain decisions, you have a legal obligation to apply the following **procedural safeguards**:

- Has the detained person been informed of the reason for detaining them?
- Are they able to challenge or appeal the decision?
- Are they being given the opportunity to tell their side of the story?
- Can they see and comment on all the relevant documents?

Q3. Can I restrict the right to liberty?

Yes, This is a limited right which means that it can be restricted, but **only in the specific circumstances** set out in the right itself. This reflects the need to balance the right to liberty against others and the needs of society.

This includes situations where a person has a mental health problem and is detained for the purposes of treatment or protection under the Mental Health Act or Mental Capacity Act. Lawful restrictions to a person's liberty may also happen in other settings, for example within the criminal justice system.

Even if a restriction of liberty is for a lawful reason, the **procedural safeguards must also be in place**. Without these the right to liberty may still be breached.

Real life: Right to liberty for disabled people



The UK's highest court has clarified whether a deprivation of liberty occurs in social care settings for adults who lack capacity to make decisions about their care. It involved three people with learning disabilities. One was living in a permanent home, one in a residential school and one with a foster mother. All care arrangements were recognised as positive but the providers confirmed that should the people attempt to leave the care they would be stopped.

The court ruled that all three were deprived of their liberty. The intention behind stopping the people leaving (or the positive nature of the care) is not the test for whether liberty has been deprived. The test is whether a person is '**under continuous supervision and control** and **not free to leave**'. As the DOLS scheme only applies to hospitals and care homes, for each of these placements the Court of Protection had to authorise the deprivation of liberty, ensuring that people's Article 5 rights were protected.

Legal case: P v Cheshire West and Chester Council and P & Q v Surrey County Council (2014)



Deprivation of liberty and end of life care

In response to the Cheshire West case the Department of Health has written to local authorities clarifying when it may be necessary for deprivation of liberty to be authorised. Where a person who lacks the capacity to consent to their placement or care is deprived of their liberty in a hospital or care home, a DOLS authorisation by the local authority will be needed. For anyone deprived of their liberty in a domestic setting, including supported living arrangements, a Court of Protection order will be required.

Deprivation of liberty safeguards may be needed for care arrangements for people in the **last few weeks of life**. If, during this time, a person has the capacity to consent to their care arrangements, this **consent lasts until the end of life** and they will not be deprived of their liberty. However, such consent **is not likely to cover significant changes to care arrangements**, which are more restrictive or likely to be against the person's wishes. Where an individual **lacks capacity and there is no valid consent**, the 'acid test' from the Cheshire West judgment applies:

- **Is the person under continuous supervision and control?** A person in a private room who is checked on every few hours will not necessarily be under continuous supervision and control.
- **Is the person free to leave?** A person will be free to leave (even if they are physically unable to) if they are able to leave with, for example, the assistance of their family.

If the answer is yes to the first question and no to the second, and if there is no valid consent, a DOLS application is likely to be necessary.

Source: Letter from the Department of Health to MCA-DOLS leads in local authorities and the NHS (Jan 2015)

Remember! When making decisions about this right...

- **The right to liberty is not a right to do whatever a person wants**; it protects against extreme restrictions being placed on movement.
- **This right can only be restricted in very specific circumstances as set out in the right**, for example when someone has a mental health or capacity problem, to keep someone safe, or to protect the rights of others.
- Restricting the liberty of someone who lacks mental capacity to make specific decisions about their care or who has serious mental health problems may be lawful – but the **appropriate legal safeguards must be followed**.

Right to respect for private and family life, home and correspondence (article 8)



Q1. How might I encounter this in my work?

Examples could include:

- when balancing the need to control pain with a person's wish to be physically able to communicate with their loved one immediately prior to death;
- where resuscitation decisions are made without consulting with a patient and/or family members or carers;
- if somebody in your care is requesting assistance to take their own life or euthanasia;
- managing family contact in environments with restricted visiting hours; and
- using family members as translators when making important decisions about care and treatment.

The four parts of this human right

Private life covers more than just traditional ideas of privacy. It includes the protection of **physical and mental well-being**, having **choice and control** over what happens to you (including being involved in **care and treatment decisions**), **participation in the community** and access to **personal information**.

Family life includes developing and maintaining 'ordinary' family relationships and **on-going contact** if your family is split up (including when accessing care).

Home includes enjoying the home you already have (not a right to be given a home), which could include long-stay wards or residential homes.

Correspondence covers **all forms of communication** including the right to receive, send and retain phone calls, letters, emails, etc.

Q2. What do the legal duties mean for me?

Respect: You cannot restrict a person's right to respect for family life, private life, home and correspondence unless there is a need for you to do this and you follow the rules for doing so.

Protect: If a person in your care is at risk of having this right breached, you must take reasonable steps to protect this right.

Fulfil: Your organisation must set out procedures to ensure fair decision making when decisions are being made which could impact on this right.

Q3. Can I restrict the right to respect for private and family life?

Sometimes, yes, The right to respect for private and family life etc. is not an absolute right. It is a qualified right and there are specific circumstances where it might be necessary to restrict it, for example to protect the rights of others or the needs of society.

When making decisions that may restrict this right, three tests must be met:

Lawful: is there a law which allows this restriction?

Legitimate aim: have you got a legitimate reason for restricting this right? These reasons are written out in the right itself and include the need to protect the rights of others or the wider community.

Necessary: are you taking the least restrictive action necessary to achieve the aim? The key principle to remember here is proportionality.

Proportionality in everyday situations

A blanket policy: A care home has a policy of placing CCTV in the bedrooms of all residents for safety reasons.

Outcome: This restricts the right to respect for private life of all residents.

A proportionate policy: Only residents who pose a risk to themselves and/or others will have CCTV placed in their rooms. This decision will be made on a case-by-case basis.

Outcome: Some residents have their right to respect for private life restricted for their own safety or the safety of others; other residents do not have their right to respect for private life interfered with.

Real life: Right to respect for private life and decisions about end of life



The right to respect for private life does **not include a right to be assisted in taking your life** (assisting suicide is currently a criminal offence). Diane Pretty, who was in the late stages of motor neurone disease, applied to the courts on human rights grounds to clarify whether her husband would be prosecuted if he helped her to take her life.

The court ruled that the positive obligation to prevent inhuman or degrading treatment (Article 3) **did not stretch** as far as allowing a terminally ill person to **be assisted to take their life**. They also said the **interference with her right to respect for private life**, including exercising choice (Article 8), was **justified** because the ban on assisting people was to protect the wider interests of society. This includes preventing people being pressured into assisted suicide.

Legal case: Pretty v UK (2002)



Real life: Right to respect for private life and Do Not Resuscitate orders



Janet Tracey, who had been diagnosed with cancer ended up in hospital following an accident. A **Do Not Resuscitate Order** (DNR) was placed on her records, without consulting Mrs Tracey or her family. When they found out about the DNR, they asked for it to be removed, which the staff did. Following discussions with the family, a second DNR was made and Mrs Tracey died a little while later in hospital. However, the family challenged the making of the first order without considering their views as they thought this did not respect the right to respect for private life (Article 8).

The court agreed with the family. It said decisions about how a person spends the **last days of their life** are about **autonomy, integrity, dignity and quality of life**, which are **protected by the right to respect for private life** under Article 8. Hospitals **must consider a patient's rights before making a DNR** and **wherever possible involve** them in **and inform** them of the decision. The patient should only not be involved if involving them is likely to cause them to suffer serious physical or psychological harm.

Legal case: Tracey v Cambridge University Hospitals NHS Trust (2014)

Remember! When making decisions about this right...

- This right is a qualified right. This means it can be restricted or interfered with in certain circumstances, for example to protect the rights of others or to keep a person safe.
- Any restriction on this right must be lawful, for a legitimate reason and necessary.
- Proportionality is key! Don't use a sledgehammer to crack a nut – make sure any action that might restrict this right is proportionate to the problem or issue.

Right to freedom of thought, conscience and religion (Article 9)



Q1. How might I encounter this in my work?

Examples could include:

- when people nearing the end of their life wish to observe practices or make special arrangements in accordance with their own beliefs;
- where religious convictions lead people to decline life-sustaining intervention or pain controlling medication; and
- when family members make special arrangements in accordance with religious or other beliefs that are not shared by an individual receiving end of life care.

Q2. What do the legal duties mean for me?



Respect: You cannot interfere with a person's right to think or believe what they want. You can only restrict a person's freedom to manifest their beliefs in certain circumstances (see below).



Protect: In some situations you may have a positive duty to secure people's enjoyment of these rights.

Q3. Can I restrict the right to be free from inhuman or degrading treatment?

This right has **two components**; the freedom to think or believe what you want, and the freedom to manifest or act on those beliefs.

The first part, **believing what you want, is an absolute right** and cannot be restricted. The second part, the **freedom to manifest your religion or beliefs, is a right that it can be restricted** and balanced against the rights of others and needs of society.



When making a **decision that may restrict a person's right** to act on their beliefs, you must meet the same **three tests** set out on [page 22](#):

- **Lawful:** is there a law which allows this restriction?
- **Legitimate aim:** have you got a legitimate reason for restricting this right? These reasons are written out in the right itself and include the need to protect the rights or freedoms of others.
- **Necessary:** are you taking the least restrictive action necessary to achieve the aim? The key principle to remember here is proportionality.

Remember! When making decisions about this right...

- The right to manifest a religion or belief is a qualified right. This means it can be limited or restricted in certain circumstances, for example to protect the rights of others or to keep a person safe.
- Any restriction on this right must be lawful, for a legitimate reason, and necessary.
- Proportionality is key! Don't use a sledgehammer to crack a nut – make sure any action that might restrict this right is proportionate to the problem or issue.



Right to enjoy these human rights without discrimination (Article 14)



This is a special right, because it is about **not being discriminated against in relation to any of the other rights listed in the Human Rights Act (HRA)**. You can think of it like a “piggy-back” right, because it must connect to or piggy-back onto another right. For example, if a doctor does not administer life-saving treatment based on a discriminatory attitude about a person’s age or disability, this would engage Article 14 alongside Article 2, the right to life.

Under Article 14, discrimination can be based on a wide range of grounds such as sex, race, language, religion, political opinion, birth or **‘any other status’**.

Discrimination may involve:

- Treating someone less favourably than other people in the same situation on the basis of a characteristic or status.
- Failing to treat someone differently when they are in a significantly different situation to others, for example when they are pregnant.
- Applying blanket policies that have a disproportionately adverse effect on a person and other people who share a particular status.

If there are objective and reasonable grounds for treating someone differently, this will not breach Article 14. For example, officials may be trying to take positive steps to compensate for inequality, or there is indirect discrimination and the authority is taking proportionate steps towards achieving a legitimate aim.

Article 14 has an important relationship with the Equality Act 2010. The Equality Act provides specific protection against discrimination on the basis of 9 protected characteristics, including race, gender, and disability. However, Article 14 protects against discrimination on a wide range of areas because it includes “any other status”. For example, a woman may be able to show that health services are discriminating against her because she is a disabled woman who is an asylum seeker (rather than only on the basis of disability or gender or nationality which is how the Equality Act works).

4. How to identify a human rights issue

This section provides you with a flowchart for identifying human rights issues. We use the word ‘decision’ to refer to a decision, action or policy that may raise human rights concerns.



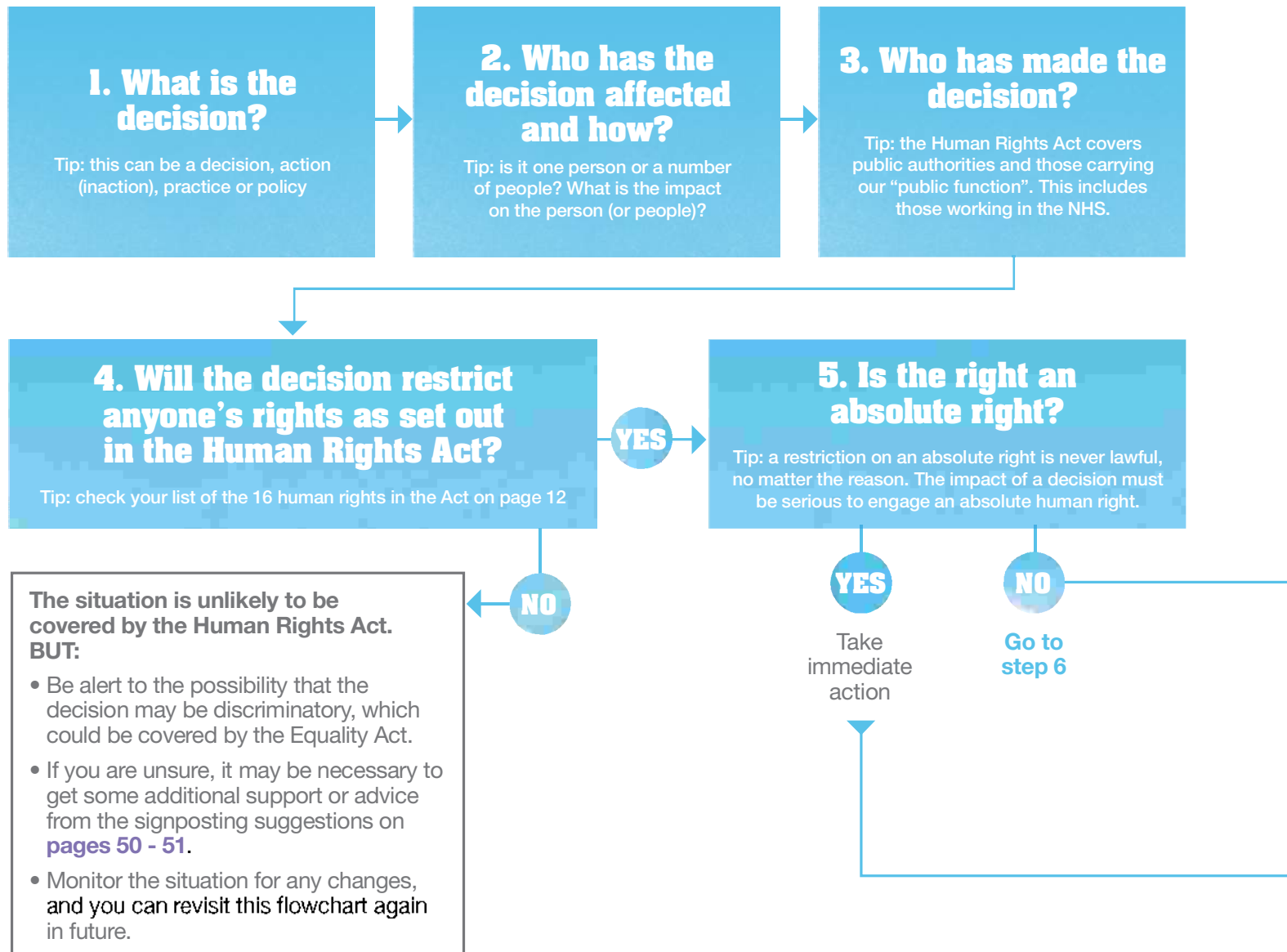
How do I know when something is a human rights issue?

Many situations in end of life care are likely to engage human rights in some form. As a practitioner you will be making decisions that are likely to impact on the rights of the **people you are caring for**, and their **families** and **carers**. You may also be making decisions that impact on the rights of your colleagues, and your own rights.

It's important to remember that a situation has to have had a serious impact on someone to be a breach of human rights. The flowchart below can help you decide this. It's also important to remember the **Human Rights Act (HRA) underpins all other law, policy and procedure**. So it's **not a case of either/or**. For example, the situation you are faced with might be **both a human rights issue and a safeguarding issue**, and human rights underpin the processes and procedures you will undertake. This could include making a safeguarding referral to protect someone's right to be free from inhuman or degrading treatment. You can use human rights arguments to make the case for why the safeguarding referral is necessary, or why you believe a particular course of action is necessary.



Using human rights: is my issue about human rights?





6. Is your right to liberty involved?

YES

NO

Go to step 7

Can you:

Challenge or appeal the decision? AND

Tell your side of the story? AND

See all relevant documents about you? AND

Has the decision taken place within a reasonable period of time?

NO

YES

Go to step 7

7. Does the decision involve any human rights I can restrict?

Tip: these are the rights in Articles 8, 9, 10, 11 (listed on page 12).

YES

NO

Restrictions are only allowed if they are :

Lawful? AND

For a legitimate reason? AND

Necessary (i.e. proportionate)?

Has this test been met?

NO

YES

Decision is not likely to be human rights compliant

Proceed to how to raise a human rights issue flowchart on page 34-35.

Decision is likely to be human rights compliant

Top tips for working through the flowchart

Step 1. What is the decision?

Be clear about the details, consider:

- What happened, when and where?
- What is it you want to challenge? Is it the way a person has been treated or something that has affected you, your colleagues, families or carers?
- Is it a specific decision or action or a policy affecting a number of people?

Step 2. Who has it affected and how?

Consider:

- Does the decision affect one person or a number of people?
- How has it affected the person involved? Think about the impact, and include any relevant information about relevant personal circumstances or characteristics, e.g. age, health, gender.

Step 3. Who has made the decision?

Remember:

- When care is provided by public authorities (e.g. NHS) or those carrying out a public function this is covered by the duties in the HRA. For more information see [pages 10 - 11](#).
- If a person's rights are at risk because of someone who is not part of a public authority (e.g. a family member) the positive obligations under the HRA mean you may need to step in and protect them. For more information see [page 11](#).

Step 4. Will the decision restrict anyone's rights as set out in the Human Rights Act?

Consider:

- Which human rights are affected? Remember it may be more than one. Be as specific as possible. All the rights in the HRA are on [page 12](#).
- You need to be able to show the decision in question has restricted the human right(s) in some way.



Step 5. Is the right an absolute right?

Consider:

- If you are dealing with an **absolute** right, remember the impact of the decision must be very serious to breach this type of right
- There is **no justification** for breaching an absolute human right, no matter the reason (including resources)
- Two key rights here will be the right to life (check back on [pages 13 - 15](#) for information) and the right to be free from inhuman and degrading treatment (check back on [pages 16 - 17](#) for information).
- Remember most human rights in the HRA are non-absolute and can be restricted in certain circumstances.

Step 6. Is the right to liberty involved?

Remember this right has two parts:

1. Is liberty being restricted for a permissible reason? **AND**
2. Are the safeguards in place, meaning can the person:
 - Challenge or appeal the decision?
 - Tell their side of the story?
 - See and comment on all relevant documents?
 - And has the decision taken place within a reasonable period of time?

Both 1 and 2 must be met for the deprivation of liberty to be lawful.

Step 7. Does the decision involve any human rights I can restrict? (Articles 8, 9, 10, 11, all listed on [page 12](#)):

Remember:

- A careful balancing act must be applied to make sure any restriction of a qualified right is **lawful**, for a **legitimate reason** and **necessary** (i.e. proportionate).
- In practice this means there should be a good reason for restricting this right and any restriction should be the **least restrictive option available** and proportionate in the circumstances. Consider whether there are other less restrictive alternatives that could be explored?
- Check back on [pages 21 - 24](#) for information about the right to respect for private and family life and on [page 25 - 26](#) for information about the right to religion and belief.

5. How to raise a human rights issue

This section provides you with a flowchart for taking action to raise human rights concerns.

Raising human rights concerns is an important part of the legal duty to respect and protect human rights set out in the Human Rights Act (HRA). Most human rights include positive and procedural obligations. These can mean taking steps to protect people who are being cared for at the end of their lives. Raising human rights concerns is a key way of ensuring your organisation is meeting its human rights obligations.



If you are worried about an issue affecting patients, their family/carer, other staff members or the wider organisation, you may be able to raise this as a human rights issue. This flowchart is designed to help you do that. We use the word ‘decision’ to refer to a decision, action or policy that may raise human rights concerns.

This flowchart **does not** cover making a complaint about how you personally have been treated at work. In this case you may need to make a complaint to your employer. Human rights may be relevant to the situation you face, and could form part of your arguments about why what has happened to you is not appropriate. It is likely you will need to follow your employer’s complaints or grievance procedure and seek further advice, e.g. legal advice and/or support from your union or professional body.

1. Raise the issue informally

Tip: often issues can be resolved informally with the person who made the decision.



2. Raise the issue with your manager

Tip: be clear about why you think there is a human rights issue to resolve.



3. Raise the issue at a higher level in your organisation

Tip: find out who is responsible for hearing staff concerns.



4. Contact the regulator

Tip: The CQC has a contact line for staff, and remember they have a new human rights approach to regulation.



5. Raise your concerns externally

Tip: think carefully about your options.

Top tips for working through the flowchart

Step 1. Raise the issue informally

It is often worth raising the problem directly with the person who made the decision that you are concerned about, e.g. can you arrange a meeting to discuss your concerns. Be clear about why you think the decision raises human rights concerns.

Remember:

- Tell them about the impact of the decision for the individual/s concerned and link this impact to their rights protected by the HRA and your organisation's legal duties to respect and protect these rights.
- Think about what you are trying to achieve. A change in policy, or a specific decision about a person you are caring for?
- Raising a human rights issue doesn't need to be confrontational. Can you think of less restrictive alternatives to suggest?

Step 2. Raise the issue with your manager

If you are unable to raise your issues directly with the person concerned, or you do this and you are unable to resolve the issue, the next step is to discuss your concerns with your manager.

Remember:

- Set out your concerns clearly in human rights terms, explaining which rights you believe have been affected and why.
- Make explicit reference to the HRA legal duty to protect rights.
- You can do this verbally or in writing but keep a record.

Step 3. Raise the issue with at a higher level in your organisation

If you are unable to talk to your line manager or if concerns are not addressed, escalate to the next level of management or director of nursing or equivalent.

If your concerns are still not addressed satisfactorily then escalate the issues again to the chief executive or equivalent. You should always ensure that you have support from your trade union or other appropriate body to do this.

Most NHS organisations and care providers have a designated person who deals with concerns raised by staff (this person should be named in your whistleblowing or raising concerns policy). Consider raising your concerns with this person, making explicit reference to human rights law and the duty to respect rights under the HRA.

Remember:

- For advice about whistleblowing procedures contact the Public Concern at Work (PCaW) whistleblowing helpline ([see page 51](#)).
- If you are unable to raise your concerns with the designated person, you can discuss concerns with your department manager, head of service or chief executive.

Step 4. Contact a Regulator

If you are unable to resolve your concern internally, you may want to consider contacting a regulator. Practitioners working in England can contact the Care Quality Commission (CQC), using their helpline for staff wishing to raise concerns about the health or social care provider they work for ([see page 50](#)).

Remember:

- Raise your concerns in human rights terms, making explicit reference to the rights in the HRA.
- As a public authority, the Care Quality Commission has duties under the HRA, so they should take action if they believe an organisation is failing to protect rights.

Step 5. Raising your concern externally

If previous steps fail, you have the option to raise concerns externally. A list of bodies to which you can make a disclosure can be found at www.gov.uk; enter 'Blowing the whistle: list of prescribed people and bodies'. Other options you may want to consider include contacting your MP or the media. **You should consider this step carefully** and should be sure that you can demonstrate that you have used and exhausted all routes to resolve the issue internally.

Remember:

- You must also be able to clearly demonstrate you are 'acting in the public interest'; otherwise you may lack legal protection.
- If you are considering this option please seek advice from your union, Public Concern at Work ([see page 51](#)) or seek legal advice.



6. Identifying and raising a human rights issue



Example case study: #1. Tom

One of your patients, Tom, is an 88 year old man diagnosed with metastatic lung cancer. He has lived at home alone for many years and was previously in hospital after struggling to cope with his increasing symptoms and care needs. Tom was not happy in hospital and repeatedly told ward staff that he wanted to return home as he did not want to die in hospital. Hospital staff had concerns about how he would cope alone, particularly as he has restricted mobility and would need a lot of support with eating and drinking, but they were reassured when his sister Abby said she would provide all his care for him at home.

Following his discharge from hospital, you have visited Tom at home three times. In three weeks, **he has lost a significant amount of weight, appears more drowsy and disorientated and his mouth appeared swollen on the last two occasions.** You are becoming increasingly concerned about the quality of care Abby is providing. Tom is also less communicative than usual but when asked, he **insists that he is fine, is getting all the care he needs and does not need to go into hospital.**

You have observed Abby feeding Tom in your presence but you suspect that she is not visiting him every day and that he is missing meals and possibly not drinking for long periods. You decide to speak to her about the deterioration in Tom's physical health and ask her sensitively, if she

is having difficulties caring for him. After some encouragement, Abby eventually tells you that she is struggling to balance her role as Tom's carer with her other responsibilities at home and at work. Whilst Abby admits to you that she is really worried about Tom being at home alone for long periods, she is strongly against the idea of adult social care services getting involved as she fears that Tom will be forced to move into a care home. She insists that the situation will improve and that she will somehow manage to visit Tom every day from now on.

A week later, you notice that Tom's condition has further deteriorated and he has lost further weight. You ask Tom again about his care and whether or not he has the support he needs. Tom is adamant **that he is doing fine and that his sister is providing him with all the care he needs.**

You speak to your manager and tell him you think it may be necessary to make a safeguarding referral. Your manager is reluctant to intervene on the basis that Tom's choice of care arrangement should be respected, that deterioration in his health including weight loss is normal in these circumstances and that Abby had agreed to increase the levels of care that she currently provides. He advises you to continue monitoring the situation.

Identifying a human rights issue

Step 1. What is the decision?

Your manager has made the decision to allow Tom's current care arrangements to continue with no change. You respect Tom's right to make choices about his care but you are concerned that he is not receiving adequate care and support at home.

Step 2. Who has it affected and how?

As it seems he is not being supported to eat and drink regularly, Tom's health is suffering and he is likely to be experiencing significant levels of pain and distress. Tom is already frail due to his age and illness so the impact on his health is likely to be more severe.

Abby is also visibly distressed by the impact of caring for Tom alongside her work and family responsibilities. You are concerned about her physical and psychological wellbeing.

Step 3. Who has made the decision?

The decision to take no action to change the situation was taken by your manager. As employees of the NHS Trust, you and your manager have legal duties under the HRA to respect and protect Tom's human rights.

Step 4. Will the decision restrict anyone's rights as set out in the Human Rights Act?

Not supporting Tom to eat or drink may have an impact on his well-being; this is part of his right to respect for private life under Article 8, which is protected by the HRA. You are also concerned that his dehydration may become severe enough to be inhuman or degrading treatment under Article 3, also protected by the HRA. If Tom's condition continues to deteriorate then his right to life could be at risk, protected by Article 2.

Tom also has the right to make decisions about his care; this is also protected by the right to respect for private life under Article 8.

Abby has the right to have her views taken into account; this is protected by the right to respect for private and family life under Article 8. Abby's right to have her physical and psychological wellbeing protected also falls under the private life, part of Article 8.

Step 5. Is the right an absolute right?

The right not to be treated in an inhuman or degrading way under Article 3 is an absolute right. The treatment must be very serious to be considered inhuman or degrading. If you believe this treatment is so serious it reaches this threshold, your organisation should take action immediately. The hospital may also have to take reasonable steps to protect Tom's right to life if it gets to the stage where his life is at risk.

Step 6. Is the right to liberty involved?

No.

Step 7. Does the decision involve any human rights I can restrict?

Tom's right to make decisions about his care, protected by Article 8, is a qualified right. You know that any decision to restrict Tom's Article 8 rights must be lawful, for a legitimate reason and necessary. Making a safeguarding referral may result in a change in Tom's care arrangements and this may impact on his right to respect for private life. However you believe it is lawful, for a legitimate reason and necessary in the circumstances. You believe it is a proportionate response to the problem and the least restrictive option, given the risks to Tom's Article 3 and Article 2 rights.

Making a safeguarding referral may also impact on Abby's Article 8 rights to have her views taken into account, as you are taking action Abby does not agree with, but you believe the restriction of her rights is proportionate in the circumstances. In addition the action you are taking is designed to offer Abby more support in caring for Tom, which will help protect her psychological and physical wellbeing, an important aspect of Article 8.



What do I do now?

Tom's condition appears to be deteriorating rapidly and if nothing changes, you believe that his right not to be treated in an inhuman or degrading way and his right to life may be at risk. You think you need to take action promptly.

Raising a human rights issue

Step 1. Raise the issue informally

You start by raising the issue urgently but informally. You have a conversation with your manager but this time making reference to the HRA. You highlight your service's obligation under the HRA, particularly positive obligations to protect Tom's right to life and his right to be free from inhuman or degrading treatment. You also mention Tom's preference to die at home and his fear that he will be readmitted to hospital if his home care arrangement breaks down. Based on your account, your manager agrees that action is needed to protect Tom's human rights. Your manager asks you to make a referral to the local safeguarding team.



Step 2. Raise the issue with the relevant manager

It has been ten days since you made a safeguarding referral for Tom and there has been no further action taken as far as you are aware. You contact the Adult Safeguarding Team and are informed that the referral has been closed. A social worker has spoken to Tom and Abby over the phone and they are satisfied that Tom's care arrangements are adequate to meet his needs. On your next home visit to Tom, you observe that he continues to lose weight and he asks you for water as soon as you arrive.

You decide to write to the manager of the adult safeguarding team to suggest that the referral be reopened.



From: nurse@nhstrust.net
To: Deborah@nhstrust.net
Subject: Tom Matthews dob: 15.08.1926

Dear Deborah,

I recently made a safeguarding referral for Mr Tom Matthews due to my concern that the care being provided by his sister is inadequate and that his basic needs are being seriously neglected. I have since been informed that the referral is now closed with no further action. I visited Tom this morning and observed him to be dehydrated and underweight. In my assessment, he is suffering from neglect and his health is likely to get significantly worse if his current care arrangement is allowed to continue.

As an NHS and local authority service, we have duties under the Human Rights Act to people in our care. I am very concerned that in allowing this situation to continue, we may be putting Tom's rights at risk, particularly given his advanced age, frailty and his dependency on carers to help him to eat and drink.

If we allow Tom to become dehydrated and malnourished, we risk leaving him in conditions which may be inhuman or degrading. The right not to be treated in an inhuman or degrading way is an absolute right under Article 3, protected by the Human Rights Act, so there are no circumstances where this treatment is acceptable. If this situation is allowed to escalate we may also be risking his right to life under Article 2, also an absolute right protected by the Human Rights Act.

In my opinion, any assessment of Tom's circumstances would have to take into account the fact that he wishes to die at home and he may be reluctant to disclose problems with his care as he believes that, if the current arrangement breaks down, he will be readmitted to hospital.

I hope you agree that this is a serious problem that needs to be addressed urgently. I appreciate that the adult safeguarding team has limited resources and that difficult decisions need to be made but not at the expense of patient safety – something which our human rights duties can help us with.

The adult safeguarding team manager agrees to reopen the referral. A social worker from the safeguarding team arranges a joint visit with you to see Tom and Abby at Tom's home. Tom eventually agrees to allow other carers to care for him at home after he is reassured that this change in his care plan will not interfere with his wish to die at home.

Example case study: #2. Camille

You are a ward nurse specialising in end of life care, attending a ward meeting with Camille, an 88 year old patient in your care being treated for pneumonia and congestive heart failure. Camille has been a patient on the ward for almost a month. She has made a slow recovery from pneumonia and is physically weak. Camille is considered by doctors to be nearing the end of her life. Whilst she **has difficulty breathing and has difficulty walking unaided**, Camille has been assessed as having capacity to make decisions about her care and treatment and is able to make her wishes known to others. She has told doctors and family several times that she plans to leave hospital as soon as possible to return home.

Prior to her hospital admission, Camille lived alone in her family house, where she had been since childhood. Camille has two daughters and a son, who had recently shared helping out with daily tasks like getting out of bed, dressing, shopping and cleaning.

All the children are at the ward meeting, as are the ward Consultant and the ward manager. The meeting is to decide where Camille will receive her end of life care. Having spoken to Camille, the Consultant knows her wish to die in her family home, cared for by her family. She is of the opinion, however, that Camille is too unwell and requires hospital care to meet all her physical health needs.

Camille's family agree with the doctor. Although they sympathise with their mother's wishes, they are more concerned about the consequences for her of returning home and not getting the care she needs.

Camille's son, Daniel, says that his worst case scenario is his mother dying alone or having no access to pain relief when she needs it. Camille assures him she understands the risks but still wishes to die at home. The ward manager who has spent time with Camille during her stay in hospital says she believes Camille should be able to die at home with help from the NHS. However she questions whether the care she is likely to have access to in the community will be enough to guarantee her a basic level of comfort and a 'good death'. Finally, you share your own concerns that by prolonging Camille's stay in hospital, when she is nearing the end of her life, health professionals would not be respecting her wishes about how and where she wants to die.

At the end of the meeting, the decision reached is for Camille to remain on the ward to give her **time to recover sufficiently from pneumonia** before making plans about where she will receive her end of life care.

Identifying a human rights issue

Step 1. What is the decision?

The decision is to keep Camille in hospital as an inpatient when to do so may go against her own wishes for how and where she wants to die. You accept there may be risks involved in discharging her from hospital both for herself and her family. However, you are satisfied that Camille understands the risks and still wants to go ahead with the move.

Step 2. Who has it affected and how?

Camille will be directly affected by the decision because it means she will have less control in this final stage of her life. At a time when she is coming to terms with dying, Camille may also now be faced with the prospect of her life ending in a way she has neither chosen nor consented to. This makes it less likely she will experience a 'good death'.

It's possible that Camille may feel more secure in the knowledge that she will have access to 24 hour care and treatment in hospital. However she has shown she can take factors like this into account when making her decision to accept the risks involved in being discharged.

Camille's family will be affected by the decision for her to remain on the ward. They are likely to be relieved as they believe it is in her best interests to stay in hospital. They may also be feeling emotionally conflicted as they are having to act against their mother's expressed wishes to secure an outcome she does not agree with.

Step 3. Who has made the decision?

The final decision was made by the Consultant who is responsible for Camille's care whilst she is in hospital. The Consultant and many others involved in the decision (e.g. you), as NHS staff, have legal duties under the HRA to respect and protect Camille's human rights.



Step 4. Will the decision restrict anyone's rights as set out in the Human Rights Act?

The decision about how and where a person wishes to receive end of life care and ultimately how they choose to die engages the right to respect for private and family life (Article 8, protected by the HRA). Not respecting Camille's wish to die at home may restrict her right to make an important decision about her own life.

Whilst public services are not legally required to ensure that specialist end of life care is available for everybody who chooses to die at home, they do have a legal duty to provide a basic level of care to prevent inhuman or degrading treatment under Article 3, also protected by the HRA.

Camille has capacity to make decisions about her care and has said she wants to return home, so the decision not to discharge Camille could potentially interfere with her right to liberty protected by Article 5. Camille is able to physically leave

the ward, in line with Department of Health guidance this is not likely to be an interference with Article 5. However, as she is weak, leaving her to return home without support would likely risk to her physical health, potentially raising a safeguarding issue under Article 3 (see step 5).

Step 5. Is the right an absolute right?

The right to be free from inhuman or degrading treatment in Article 3 is absolute, so there can be no justification for allowing Camille to suffer inhuman or degrading treatment in the process of dying.

The Consultant and family are concerned that if Camille returns home she risks experiencing inhuman or degrading treatment due to lack of appropriate community care services. There is a positive obligation on staff to prevent this by taking reasonable action. Simply requiring Camille to remain in hospital is not likely to be reasonable, when other alternatives can be explored, e.g.:

- assessing the risks to Camille of dying at home, identifying where gaps in care may result in inhuman or degrading treatment (e.g. lack of nutrition and hydration, bladder and bowel care, skin integrity), and putting solutions in place to meet these
- closely monitoring and regularly reviewing end of life care arrangements to ensure that basic standards are still being protected at every stage of dying and that Camille's treatment does not fall below Article 3 standards

Step 6. Is the right to liberty involved?

Camille's right to liberty could be involved; however, as she is able to physically leave the ward, this is not likely to be an interference with Article 5. Nevertheless, as Camille is weak, leaving her to return home without support would likely risk to her physical health, potentially leading to a safeguarding issue under Article 3 (see step 5).

Step 7. Does the decision involve any human rights I can restrict?

The right to respect for private and family life (Article 8), including being involved in decisions about what happens to us, is clearly relevant here. Any restrictions to a qualified right must be:

- **Lawful:** is there a law which allows this restriction?
- **Legitimate aim:** have you got a legitimate reason for restricting this right? These reasons are written out in the right itself and include the need to protect the rights of others or the wider community.
- **Necessary:** are you taking the least restrictive action necessary to achieve the aim? The key principle to remember here is **proportionality**.

When considering applying restrictions to Camille's Article 8 rights by deciding she should receive treatment on the ward for the time-being, against her wishes, decision-makers would need to take into account that:

- Camille has capacity to make decisions about care and returning home, so she can leave at any time. If the ward staff attempted to stop her from doing this, then their actions would not be **lawful**. If Camille's capacity changes, there should be a reassessment, and it may be necessary to get authorisation to deprive her of her liberty under the Mental Capacity Act or Mental Health Act.
- The **legitimate aim** would be to make sure Camille's health needs are met and try to ensure she doesn't die in pain.
- There are less restrictive, more **proportionate** ways to provide end of life care for Camille, such as providing care for her within her own home.

In light of the above, supporting Camille to return home safely with a care package in place would be the course of action that best respects her rights.

If you are uncertain about the extent to which a proposed care package is able to meet all of Camille's palliative care

needs at home, then you will be concerned about her safety on being discharged. For example, if Camille becomes immobile, suffering severe pain and is without a carer or access to pain relief, this could amount to inhuman or degrading treatment, prohibited by Article 3.

What do I do now?

You speak to Camille after the ward meeting and she is visibly upset by the prospect of remaining in hospital. She is angry with her family for going against her wishes and depressed by the thought that she may never see her family home or close friends again. No date has been agreed for another meeting to discuss discharge plans. Camille has told you she has arranged a lift from a friend and will be leaving the ward at the end of the week. You decide to raise the issue again, this time in terms of Camille's human rights.

Raising a human rights issue

Step 1. Raise the issue informally

You start by raising the issue informally. You have a conversation with the consultant. In the previous meeting Camille's human rights weren't raised so this time you speak to the consultant about Camille's right to respect for private and family life under Article 8, protected by the HRA, and the hospital's human rights duties. You point out that Article 8 protects Camille's right to have a say over her care and treatment. The consultant repeats her concerns that Camille is too unwell to return home and that she can only get the care she needs at the hospital. The Consultant is worried that if Camille returns home and dies in pain they might be held responsible for her suffering by the family.



Step 2. Raise the issue with the relevant manager

You decide to discuss it again with the ward manager. She is in agreement with you about Camille being able to die at home with help from the NHS but is concerned about the community care available. You talk to her about Camille's right to respect for private and family life and also her right to be free from inhuman or degrading treatment under Article 3, which is protected by the HRA. As the hospital has a positive obligation to protect Camille's rights, you point out that you could use this in your discussions with the community care team to try and ensure Camille gets a basic level of care at home. The ward manager agrees this is a good way forward and you organise a multi-disciplinary team meeting to discuss the options, with the Discharge Co-ordinator, the consultant, Community Care Services, Camille and the family.

At the meeting you make sure Camille has a chance to talk about the impact of the decision to keep her in hospital, how it has upset her and made her feel depressed. You raise Camille's right to respect for private and family life and that this is a **qualified right which can be restricted** but that the hospital should look into the options open to them and pick the one which is most respectful of Camille's rights. You raise your concerns that the

decision taken is not the most respectful, given Camille's views and the impact on her. You also raise Camille's right to be free from inhuman or degrading treatment and the concerns that she might be returned home to a situation where she doesn't have the care she needs and be in pain which could be severe enough to breach this right. You say there is a positive duty under Article 3 to take reasonable steps to protect someone at risk of inhuman or degrading treatment. You point out that the hospital would need to make sure Camille is able to receive a basic care package at home, to try and ensure her treatment does not become inhuman or degrading.

The Community Care Services team, the Discharge Co-ordinator, the consultant, Camille and the family discuss what basic care package Camille would need to live at home. It is agreed that a Community Nurse will visit Camille once a day to administer any treatment or pain relief and Camille will be provided with an emergency call alarm to contact the nurse if necessary in between these visits. A social worker will also visit Camille once a day to keep this care package under review and check that Camille is still happy with this arrangement. Camille's GP is also contacted and informed about this care package. The family and Camille are happy with this arrangement and Camille is discharged from the hospital and supported to return home.



7. Where can I get more information and support?

If you need some advice or support about your human rights, here are some organisations who can help:

Care Quality Commission

The CQC has a disclosure line for reporting concerns in all the services they inspect, which includes End of Life Care:

cqc.org.uk

03000 616161

Compassion in Dying

Compassion in Dying has a free information line supporting people to use their rights to make choices about their end of life care:

03000 616161

Equality Advisory Support Service

Free helpline and website providing information and advice for people with equality and human rights questions:

equalityadvisoryservice.com

Freephone 0808 800 0082

Text phone 0808 800 0084

Equality and Human Rights Commission

The EHRC provides a range of information on human rights for health and social care providers and commissioners:

equalityhumanrights.com

General Medical Council

The GMC has a helpline for doctors who are concerned about patient safety:

0161 923 6399

Health and Care Professions Council

You can raise a concern about a registered member of HCPC using their website:

hcpc-uk.org.uk

Health Ombudsman

The Health Ombudsman has a complaints procedure when you have exhausted all internal processes. For more information on how to make a complaint you can call their helpline on:

0345 015 4033

Healthwatch England

Your local Healthwatch can help you raise a complaint. You can locate them here:

healthwatch.co.uk

Leadership Alliance for the Care of Dying People

“One Chance to get it Right”
Improving people’s experience of care in the last few days and hours of life:

gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

Liberty

Human rights and civil liberties organisation Liberty run a public helpline three afternoons a week. Contact them by phone or online:

yourrights.org.uk

0845 123 2307
020 3145 0461

Monday and Thursday 6.30 p.m.
to 8.30 p.m., Wednesday 12.30 p.m.
to 2.30 p.m.

MND Connect

MND connect is an advice line for those with Motor Neurone Disease, family, friends and support staff:

mndassociation.org

NHS and Social Care Whistleblowing Helpline

For advice on the whistleblowing process within the NHS and to raise concerns:

08000 724 725

Nursing and Midwifery Council

You can also make a 'prescribed disclosure' (bodies authorised by the Government to receive complaints) to the NMC using the fitness to practice referral route:

020 7637 7181

or their email address for other concerns:

whistleblowing@nmc-uk.org

Public Concern at Work

Public Concern at Work runs a whistleblowing helpline providing independent advice for workers who are unsure whether to raise a public interest concern. You can call:

020 7404 6609

or email:

whistle@pcaw.org.uk

This Guide has been produced for staff delivering health and care services. If it has helped you to deliver rights-respecting care BIHR would love to hear your examples. You can email your real life examples of positive changes to your practice on info@bihr.org.uk

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The British Institute of Human Rights (BIHR) is an independent charity working to bring human rights to life here at home.

We empower people to:

- **know** what human rights are (and often what they are not),
- **use** them in practice to achieve positive change in everyday life without resorting to the courts, and
- to make sure those in power **respect** and progress our human rights laws and systems.

At the heart of everything we do is a commitment to making sure the international promise of the Universal Declaration of Human Rights, developed after the horrors of World War II, is made real here at home.

Our innovative work seeks to achieve a society where human rights are respected as the cornerstone of our democracy and enable each of us to live well in communities that value the equal dignity of each person.

BIHR has been working on human rights in healthcare for over 15 years, making the links between human rights and health and helping organisations in the public and voluntary sectors to use the Human Rights Act to promote better health and social care. We have trained thousands of individuals from NHS trusts, social services, and voluntary organisations; raising awareness and building the capacity of individuals and organisations to use human rights to make a difference.