



# **Draft Guidance on a Human Rights-Based Approach to Care and Support in Health and Social Care Settings**

For public consultation 2019

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## About this guidance

The purpose of this guidance is to promote a human rights-based approach to care and support in adult health and social care settings. A human rights-based approach ensures that the human rights of people using services are protected, promoted and supported by staff and services. It makes sure that the delivery of services is focused on the human rights of each individual. The attitudes of staff and the language they use when working with people who use their service are crucial to implementing this kind of approach. By using a human rights-based approach, service providers will improve the quality of care, quality of life, and safety of people who use health and social care services. This kind of approach can also help staff recognise and uphold their own rights.

This guidance has been informed by a thorough review of evidence and extensive engagement with stakeholders. It is written primarily for all staff working in health and social care settings, but will also be useful for people using services, their families, carers, friends and advocates.

## An overview of human rights

### 1. What are human rights?

Human rights are the basic rights and freedoms that all people should enjoy. Human rights are about people being treated with fairness, respect, equality and dignity, having a say over their lives and participating as fully as possible in decisions about their care and support.

### 2. Who has human rights?

We are all born with human rights regardless of who we are, where we are from or any other status or characteristics. Although our ability to exercise our rights can sometimes be limited or restricted, our rights cannot be taken away from us.

### 3. Why are human rights relevant to you?

In recent years there has been a shift in health and social care policy and practice to focus on human rights, autonomous decision-making, empowerment and choice. This has highlighted the importance of embedding human rights in service provision. Set out below are some of the main reasons why human rights are relevant to your work in a health and or social care setting.

## It is the law

A human rights-based approach to care and support is underpinned by a legal framework and human rights treaties which states have agreed to uphold. Irish legislation that sets out human rights includes:

- the Constitution
- the European Convention on Human Rights Act 2003
- the Equal Status Acts 2000-2015.

**Resource 1 at the back of this guidance provides a description of key human rights set out in the European Convention on Human Rights Act 2003 that are relevant to health and social care settings.**

Importantly, there have also been recent changes to Irish law which relate to a human rights-based approach to care and support, including:

- the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD)
- the introduction of the Assisted Decision-Making (Capacity) Act 2015.

## It supports your day-to-day service delivery

Implementing a human rights-based approach can help to support you in your delivery of person-centred care. Human rights are not 'new' or extra to your work in health and social care services. They already underpin many of the situations you come across in your service. Using a human rights-based approach can be of help when you are making decisions in relation to areas of care and support such as staffing levels, provision of treatment, physical restraint, personal care, end-of-life decisions and privacy of personal information. Human rights should not be viewed in any way as a risk, threat or burden to the provision of care and support.

## It is your professional obligation

Respect for human rights is implicit in the codes and guides of conduct and ethics of different health and social care staff including doctors, social workers and nurses, and within national standards. A human rights-based approach ensures your ability to protect the human rights of people using your services. It also promotes professional accountability within your service.

## The FREDA principles – Human rights in practice

Although human rights exist in law, it can be useful to think of them in your day-to-day work in the context of principles. For the purpose of this guidance, we have used the FREDA principles. These are: Fairness, Respect, Equality, Dignity and Autonomy. A human rights-based approach involves all five principles. While it is useful to understand and consider each principle individually (as demonstrated in this guidance), it is important to recognise that the five principles are interdependent and often overlap.

Under each FREDA principle you will find:

- a brief explanation of the principle
- the article(s) from the European Convention on Human Rights (ECHR) Act 2003 most relevant to that principle
- examples of how you can support and promote the principle in your work
- short, real-life case studies of the principle.

The examples of supporting and promoting the principles in your work can also help you reflect on whether or not you are upholding a person's human rights in your day-to-day work.

In addition to the short case studies in each section, there are three extended case studies at the end of the section describing the FREDA principles that illustrate situations where all five principles are applied.

The resources at the end of this booklet are provided as tools to help you understand human rights and how a human rights-based approach can support you to make decisions in your work.

## 1. Fairness

Fairness means ensuring that when a decision is made with a person using a service about their care and support, the person's views are sought, listened to and weighed alongside other factors relevant to the decision. It is important that decisions are made in a way that is clear and fair to allow others to know how they might be treated in similar circumstances. If a decision interferes with a person's human rights, this must be legally justified, proportionate and only taken when all other alternatives have been considered.

In a health or social care setting, fairness can relate to decisions being made about a person's care and treatment. It can also relate to the process of raising and resolving concerns or complaints, or conducting a risk assessment. Fairness is linked with the core values of equality and autonomy, in ensuring that the decision-making process is free from discrimination and that the person is involved in the decision-making process.

The principle of fairness relates to the following articles of the European Convention on Human Rights: Article 6 – the right to a fair trial, and Article 14 – prohibition of discrimination.

### 1.1 How I uphold fairness in my day-to-day work\*

#### Providing relevant information

- I recognise that people who use my service have the right to receive information about their own needs, condition, treatment and care provider in a format they can understand. They also have the right to decide how much information they wish to receive.
- I provide people with accessible and tailored information on their human rights, treatment options, care providers and health status so that they can make independent and informed choices.

#### Seeking consent

- When seeking consent<sup>†</sup> I ensure that both I and the person I am seeking consent from are actively involved. I fully explain the risks and benefits of proposed and

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\* This is not an exhaustive list but provides an indication of how fairness can be supported and promoted.

<sup>†</sup> In all cases, 'seeking consent' refers to the granting of permission or agreement for an intervention, receipt or use of a service, or participation in research following a process of communication in which

alternative options in a format they can understand. I encourage the person to ask questions and I check their understanding throughout this process.

- I ensure that the person knows they have a choice and they can give or withhold their consent freely and without pressure.
- Where communication with a person is no longer possible, I consult with the person's Designated Healthcare Representative<sup>‡</sup>. If there is no Designated Healthcare Representative, I consult the person's family, friends or independent advocate and consider any written documentation (for example, an advance healthcare directive) to discover the person's past and present will and preferences.

### Protecting personal information

- I recognise that all medical records and other information recorded about a person are confidential, and any disclosure of this information must respect their right to a private life.
- I facilitate people to access their own personal information.
- I facilitate people to access information about their care and support.

### Ensuring participation during risk assessment<sup>§</sup>

- I ensure that there are clear and consistent processes in place for undertaking a risk assessment and that this assessment is carried out in consultation with the person, taking their views into account.

### Supporting a person to make a complaint

- I facilitate a supportive, open and transparent environment for making a complaint.
- I fully explain to people how they can make a complaint and work to lessen the fear of negative consequences from making a complaint.
- Where possible, I ensure that a complaint made by a person is responded to promptly and appropriately.

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the person using the service has received sufficient information to enable them to understand the nature, potential risks and benefits of the proposed intervention or service.

<sup>‡</sup> A Designated Healthcare Representative is the named individual designated by the directive maker in their Advance Healthcare Directive, to exercise the relevant powers.

<sup>§</sup> Risk assessment is defined by the HSE as the overall process of risk identification, risk analysis and risk evaluation. For more information, see *Guidance for Designated Centres Risk Management* at [www.hiqa.ie](http://www.hiqa.ie).

## Supporting a person to make an Advance Healthcare Directive

- I adhere to the Codes of Practice on Advance Healthcare Directives<sup>\*\*</sup> in order to ensure the person's will and preferences guide their treatment when they no longer have the capacity<sup>††</sup> to make decisions for themselves.

## Preventing restrictive practices

- I promote a restraint-free environment at all times in my service.<sup>‡‡</sup>
- I understand that a restrictive practice should only be approved when the risk to the person of not using it is greater than the risk of using it.
- I only restrict a person's movement when absolutely necessary and legally justifiable. I regularly review these practices.
- I understand that a person's right to liberty is violated if they are prevented from leaving a residential care home or hospital, with the exception of units where procedural safeguards can be applied according to relevant legislation.

## Participating in decisions

- When decisions need to be made with a person, this is done in a way that is fair, open, timely and impartial.<sup>§§</sup> I ensure that the person is supported to make the decision in question as far as is practicable and is given adequate time and facilities to do so. The person is given the opportunity to be heard and to participate in decision-making.

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<sup>\*\*</sup> The Codes of Practice are in draft form at the time of publication of this guidance.

<sup>††</sup> A person's decision-making capacity is assessed on the basis of their ability to understand, at the time that a decision is made, the nature and consequences of the decision, in the context of the available choices at that time.

<sup>‡‡</sup> See *Guidance on Promoting a Care Environment that is Free from Restrictive Practice* available online at [www.hiqa.ie](http://www.hiqa.ie).

<sup>§§</sup> See Resource 2 for a decision-making aid that uses a human rights-based approach.

## 1.2 Fairness in real life

The following examples illustrate real-life situations where the principle of fairness has been upheld and not upheld.

### Fairness is upheld

- In a mental health setting, staff fulfil their duty by ensuring people using their services are not unlawfully detained. When Marie is detained under the Mental Health Act 2001, she is provided with full information on her rights, including her right to legal representation, a second independent medical review and an independent review of her detention by a mental health tribunal. Staff facilitate Marie's access to these options. Providing this information and support enables Marie to challenge any issue in relation to her detention.
- Liz has an intellectual disability and lived at home with her father until his death. As there were concerns that Liz might not be able to live independently, she was placed in a residential centre. Liz was unhappy in the residential centre and expressed her wish to live independently in the community. Her care team worked with her to put a support plan in place. Liz took part in all discussions about her options and managing risks. She was provided with all the relevant information and training she needed to ensure she understood the choices available to her and could actively participate in the decision-making process regarding her care. Liz was supported to move back into the community. She now lives independently and receives six hours of support per week.

### Fairness is not upheld

- Jack has an intellectual disability and lives at home with his parents. Jack's parents control his finances as they believe he is not capable of managing his own money. Jack attends a day centre during the week and has told staff that he would like to manage his own money. Staff are aware that Jack has never been supported to learn the skills of managing his own money. They feel he has the right to choose how he spends his own money and is capable of doing so with training and support. However, they also feel that Jack's parents know best and do not interfere with their wishes. Both the staff and Jack's parents have prevented Jack from managing his own money without legal justification.
- In an acute healthcare setting, Eamon was recently given a terminal diagnosis. During the appointment, he was informed of his future care pathway but did not receive any additional information on his diagnosis, care plan or alternative care pathways to consider. It took Eamon a number of days to process his diagnosis. Eamon now has many questions about his future care and alternative treatments but does not know where to go to find this information. Eamon was not provided with all of the relevant information relating to his diagnosis and treatment options and was not supported in making his own informed and independent choice regarding his care pathway.

## 2. Respect

Respect is the objective, unbiased consideration and regard for the rights, values, beliefs and property of other people. Respect applies to the person as well as their value systems.

In health and social care settings, respect is shown in the actions towards a person by others and can be demonstrated by communicating in a courteous manner. This helps people feel valued through taking time to get to know them as a person and not as a number or a 'condition'.

Respect is central to providing person-centred care and support. People who use services must be listened to, and what is important to them must be viewed as important to the service. The principle of respect must be upheld regardless of a person's impairment or loss of capacity. Upholding the principle of respect also means that another person nominated by the person themselves, such as a family member or friend, is valued and listened to.

The principle of respect relates to the following articles of the European Convention on Human Rights: Article 8 – the right to respect for family and private life; Article 9 – the right to freedom of thought, conscience and religion; and Article 1, Protocol 1 – the right to protection of property.

### 2.1 How I uphold respect in my day-to-day work<sup>\*\*\*</sup>

#### Day-to-day communication

- When meeting a person using my service for the first time, I take the time to introduce myself properly in order to connect with the person from the start.
- I ensure that the person has all the available information necessary to make a decision about their care and support, in a way they understand, and has had their questions answered in a way they can understand.
- When providing information to a person, I consider their preferences and their background, for example previous life experience, educational attainment, literacy, culture and religious beliefs.

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<sup>\*\*\*</sup> This is not an exhaustive list but provides an indication of how respect can be supported and promoted.

- I take the time to listen to a person, and to understand them as an individual without judgement.
- I avoid using technical language to describe the person's condition or care. Instead, I use the person's own words and terms they can understand.

### Person-centred planning

- I respect the person as the expert on their own life and support them to lead the development of their person-centred plan as much as possible.
- I ensure the person-centred plan reflects the goals that are unique to the person and that are meaningful to them. A person's goals should not be dependent on available resources.
- I ensure that a person's plan focuses on what is important to them, how they want to live and what support they want to achieve their goals.

### Supporting relationships

- I take time to get to know the person and their preferred lifestyle.
- I support the person and respect their wishes concerning maintaining and developing personal relationships with family and others, but with due regard for their safety and with the agreement of those concerned.

### Supporting the achievement of human rights

- I promote the person's right to access appropriate services.
- Where applicable, I support a person to realise all their rights including the right to have intimate relationships, to marry and to have a family.

### Respecting property and personal information

- I respect the property and possessions of the people using my service and ensure that they are able to access their possessions and property as required or requested.
- I respect the privacy of a person's personal information and medical records in line with data protection legislation. I seek consent to share their information where necessary, and explain the reason the information needs to be shared.

### Participating in developing and evaluating services

- I encourage people to participate in the development and evaluation of the service when the opportunity arises.

## 2.2 Respect in real life

The following examples illustrate real-life situations where the principle of respect has been upheld and not upheld.

### Respect is upheld

- Liam is a new resident in a residential centre for older people, where he has chosen to live. When he meets a new member of staff, they introduce themselves to him. The staff learn about Liam's background, including his love of painting. When staff speak to Liam, they always address him by his name as he has requested. They ask Liam if there is anything else that would help him settle into the centre. Liam asks for photos of his family and for his paintings to be displayed around his room. The staff support Liam in picking out and displaying the photos and paintings he would like to keep in his room. Staff have taken the time to get to know Liam and his preferences and have respected his request for access to his possessions.
- Claire has an intellectual disability and lives in the community. She is attending a vocational education centre. She wishes to travel on her own by bus to her education centre each day. Claire's circle of support, which includes her parents and support worker, recognise that this is important to her. They listen to her and do not judge her because of her disability. They respect her personal preference and look at how they can best facilitate her choice.

### Respect is not upheld

- Eleanor has a physical disability and is supported to live independently at home. Following a recent hospitalisation with pneumonia, Eleanor was discharged from hospital into a rehabilitation centre without any consultation with her or her family. A person-centred approach was not applied when planning her care; she did not have the opportunity to participate in the planning of her care and her personal preferences were not taken into account. Eleanor does not know how long she will be in the rehabilitation centre. She is worried that when she returns home she will not receive the same level of care with the same people who had been supporting her previously.
- Martha lives in a residential centre for older people and shares a room with another resident. Martha would like to keep her possessions and clothes in her own room but there isn't enough space. Martha's possessions and clothes are kept in a storage room down the hall and staff choose Martha's clothes for her. Martha cannot access her possessions when she wishes. She would like to be able to personalise her room and choose her own clothes every day but she is not supported by staff to do so.

### 3. Equality

Equality means people having equal opportunities and being treated no less favourably than other people on the grounds set out in legislation. These grounds include: sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or any other status.

Equality in health and social care means making sure people using services have equal access to care and support, equal outcomes from care and support, and are supported to take part in society. It is important to remember that some people using services may need additional support because of their status or characteristics, such as a person with a disability or an older person. Discrimination occurs when someone is treated in a different way to someone else in a similar situation, or where people in very different situations are treated the same. A human rights-based approach means that no person is discriminated against because of their status or characteristics.

The principle of equality relates to Article 14 of the European Convention on Human Rights – prohibition of discrimination.

#### 3.1 How I uphold equality in my day-to-day work<sup>+++</sup>

##### Communicating respectfully

- I communicate respectfully with all people using my service and ensure that each person is provided with information in a way that is tailored to their needs regardless of who they are or their communication ability.

##### Providing quality care and support for all

- I support people who use my service to get the care and support they need regardless of sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or any other status. The quality of care and support I provide is the same for everyone.
- I do everything I can to meet the more complex and varying needs of some people to ensure they can achieve the same outcomes as those with fewer or less serious needs. I do this by ensuring that: longer appointments are provided when necessary and possible; relevant information is accessible to everyone;

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<sup>+++</sup> This is not an exhaustive list but provides an indication of how equality can be supported and promoted.

everyone has information about and access to relevant population screening programmes if they choose to avail of them.

### **Presuming and supporting capacity**

- I recognise that I must always presume that a person has capacity and that I never judge a person's decision-making ability based on sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or any other status.
- I recognise that I cannot presume that a person lacks capacity in relation to a certain matter or decision on the basis that they make a decision that seems unwise to me.

### **Promoting participation in society**

- I take effective and appropriate steps to facilitate and promote a person's full inclusion and participation in society, for example supporting them in having relationships and participating in political, religious, social and self-help or advocacy organisations.

### **Encouraging equality and a human rights-friendly service**

- I recognise the importance of there being a culture of equality within my service where all people achieve equal access to and equal outcomes from care and support.
- I am aware that there should be no blanket policies, conditions or rules in place in my service that can impact people's human rights, for example their right to liberty.

### **Facilitating access to representation**

- I support the right of people to access legal representation of their choosing when needed.
- I support the right of people to access independent advocacy representation of their choosing when needed.

### 3.2 Equality in real life

The following examples illustrate real-life situations where the principle of equality has been upheld and not upheld.

#### Equality is upheld

- Sharon is an adult with an intellectual disability and wishes to have a sexual relationship with her boyfriend. Sharon's support workers recognise Sharon's right to a private and family life. However, they want to make sure that she understands the decision she is making. They conduct an assessment to determine her capacity. Sharon demonstrates her capacity to make this decision as she shows a clear understanding of personal and sexual relationships and she can clearly distinguish between relationships that are abusive and non-abusive. She also understands the risks involved, including sexually transmitted infections and pregnancy. She is aware of various methods of contraception and how to access them if she chooses. Sharon knows that staff are there for her if she needs their support or if she has any questions. By supporting Sharon in her decision, staff have taken the appropriate steps to ensure her right to respect for private and family life – including her sexual and reproductive rights – are not discriminated against because of her disability.
- Annan is a Hindu. He is receiving care in an acute setting. Annan's condition has taken a turn for the worse and staff inform Annan's family that he is dying. Staff are aware of Annan's beliefs and discuss with his family how they can respect these beliefs. Just before death, Annan's family inform staff that he must be removed from his bed to the floor in keeping with his beliefs. Staff uphold the principle of equality and ensure Annan's religious beliefs are facilitated and respected.

#### Equality is not upheld

- Sam is in his nineties and is living in an older person's residential centre. He likes to be able to walk down to the local shops and pub. In the centre, there is a policy in place to keep the front door locked in case residents with cognitive impairments leave the centre unattended. Sam does not have a cognitive impairment and feels this blanket policy impacts on his right to liberty. Sam is presumed to lack capacity because of his age. He feels he is being discriminated against and is frustrated that he has to ask for permission each time he wishes to go outside.
- English is not Nadia's first language and she often brings her 22-year-old son, who speaks fluent English, with her to healthcare appointments to interpret and ensure she doesn't miss any important details. On one occasion, Nadia had a hospital outpatient appointment. However, her son was not available to attend the appointment with her. Nadia phoned ahead to ask for an interpreter for the appointment but was told by the clinic secretary that this would not be possible. Nadia felt discriminated against. She felt no attempt was made to access an interpreter for her. As a result of not having an interpreter, Nadia did not understand everything that was discussed with her. Nadia's right to a health outcome equal to someone who speaks fluent English was impacted.

## 4. Dignity

Dignity means treating people with compassion and in a way that values them as human beings and supports their self-respect, even if their wishes are not known at the time.

Dignity is central to the idea of human rights and all human rights are connected to human dignity. Lack of dignity is a common theme in examples of abuse and neglect in health and social care settings, including malnutrition and dehydration; physical, psychological or sexual abuse; ignoring calls for help; unchanged bed sheets; not feeding people properly; bed sores; poor hygiene; being made to wear incontinence wear when unnecessary; restrictive practices; and bullying, patronising and condescending attitudes. A lack of dignity can result in feelings of insecurity, guilt, shame, worthlessness, anger, frustration, lack of confidence, inadequacy and reduced motivation, reduced quality of care and support, and decreased satisfaction among staff. When human dignity is upheld in health and social care settings, it improves working relationships and can result in positive outcomes for staff and people using services.

The principle of dignity relates to the following articles set out in the European Convention on Human Rights: Article 3 – prohibition of torture, and Article 8 – the right to respect for family and private life.

### 4.1 How I uphold dignity in my day-to-day work<sup>\*\*\*</sup>

#### Meeting basic needs

- I ensure people using my service have their basic needs met, for example food, clothing and personal hygiene.
- I ensure that they have access to appropriate food and hydration so that they do not suffer from malnutrition or dehydration. I ensure that food and drink is always within a person's reach and offer assistance if support is required to eat or drink.
- I ensure that people are not neglected or treated in any way that is likely to cause harm. For example, I make sure that no one is left in a soiled state.

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<sup>\*\*\*</sup> This is not an exhaustive list but provides an indication of how dignity can be supported and promoted.

## **Maintaining privacy**

- I make sure to respect the privacy of people when supporting them to undress, bathe and dress.
- I discuss a person's health and care in a private setting or, in a situation where there is no private space available, I lower my voice.
- I make sure to properly drape a person during a physical examination or when I am assisting them in cleaning themselves.
- I avoid rushing a task in a way that might impact their privacy and dignity.

## **Communicating effectively**

- I address people who use my service by their preferred name.
- I communicate with people in a way that acknowledges and respects their individuality, dignity and personal identity. I do this whether or not the person is able to communicate verbally. If a person is unable to communicate verbally, I work with other team members, the person's family, their friends or their nominated person to understand the best way to communicate with them. I strive to make sure that they understand me and that I understand them.
- I take care not to patronise or be condescending towards a person regardless of their age or any other status.
- I ensure that a person's dignity is maintained even if they are unconscious, and unable to communicate.

## **Supporting a person's preferred lifestyle**

- I always enquire about a person's preferred lifestyle, including routines, pets, clothing preferences, religious and cultural preferences, and facilitate their lifestyle as much as possible. This can be something as simple as enabling them to wear their own clothing.

## **Avoiding restrictive practices**

- If there are no fully justifiable reasons for the restriction of movement, I ensure that a person is supported to move around as they wish and are not confined to a bed or chair when this is unnecessary.

## 4.2 Dignity in real life

The following examples illustrate real-life situations where the principle of dignity has been upheld and not upheld.

### Dignity is upheld

- Fiona is pregnant and has started to experience depression. She has been referred to a midwife with mental health expertise in her local maternity hospital. Fiona does not want others finding out about her depression. The mental health midwife ensures that her privacy is respected at all times. When Fiona is called for her appointment, although the room is a few minutes' walk from the waiting area, the midwife ensures they are in the consultation room and cannot be overheard before they begin talking.
- Graham has an intellectual disability and is on an end-of-life pathway. He is receiving care in his own home. Graham is weak and has difficulty swallowing. Staff ensure that Graham is supported to eat and drink. Staff have taken time to get to know Graham and they learn that his favourite drink is whiskey and coke. On the occasions when he requests it, Graham is supported to have his favourite drink with thickener. Staff have upheld Graham's dignity by ensuring that his basic needs for food and hydration are met. They have also taken time to get to know him and his preferences.

### Dignity is not upheld

- Daniel has difficulties communicating verbally and is admitted to hospital with complications associated with his diabetes. The healthcare practitioners do not speak to Daniel about what care they are providing to him or what interventions are being carried out, because he cannot communicate verbally. In addition, staff do not assess whether Daniel can understand them and if there are other ways to communicate with him. Daniel is not provided with additional support to help him to communicate with staff and therefore is not involved in any decisions regarding his care.
- Rebecca is an 80-year-old woman with severe arthritis. She lives in a residential centre. Rebecca needs support to get out of bed and is often told to relax and to have her breakfast in bed. Rebecca knows this is because there is not enough staff to help her to the dining room. On one occasion, low staffing in the centre led to Rebecca not being facilitated to leave her bed for an entire day. Rebecca was told they couldn't get her out of bed because of staff shortages and was given an incontinence pad to wear. She becomes very upset as she is able to use toilet facilities with assistance and feels her dignity has been compromised.

## 5. Autonomy

Autonomy is the ability of a person to direct how they live on a day-to-day basis according to personal values, beliefs and preferences. In a health and social care setting, autonomy involves the person using a service making informed decisions about their care, support or treatment.

In a health and social care setting, people may require different levels of support to assert their autonomy and make their own decisions. This means staff have a key role in this process. The ability to be autonomous, and make decisions, can and must be supported and developed. Respecting and supporting autonomy is important in health and social care as it is a fundamental aspect of person-centred care and support.

The principle of autonomy relates to the following articles set out in the European Convention on Human Rights: Article 5 – the right to liberty and security, and Article 8 – the right to respect for family and private life.

### 5.1 How I uphold autonomy in my day-to-day work<sup>§§§</sup>

#### Seeking consent

- I make sure that I communicate clearly and effectively with the person using my service. I use language or other means of communication that they can understand and do not use medical or social care jargon to discuss their health or social care issue. I always support the person in their decision-making process in relation to their care and support.
- I make sure that the person is provided with complete and relevant information about their care and support options, including the advantages and disadvantages of each option, to ensure they can make a fully-informed decision.
- I openly discuss risk management in a positive and proactive manner.

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<sup>§§§</sup> This is not an exhaustive list but provides an indication of how autonomy can be supported and promoted.

## Understanding and respecting a person's will and preferences

- I make sure that I understand the will and preferences of a person to ensure that I can promote and support their autonomy when assisting in or supporting their decision-making process.
- In order to make sure a person's autonomy is upheld, I support their choice in relation to care and support regardless of whether or not I believe it is the right decision.

## Supporting capacity and responding accordingly

- I always presume a person has capacity and work to fully support them to make a decision for themselves.
- If a person has been formally assessed<sup>\*\*\*\*</sup> as lacking capacity under the Assisted Decision-Making (Capacity) Act 2015 in relation to a certain matter or decision and if an intervention is urgent and it is unlikely that the person will recover capacity to make a decision in the short term, I ensure that any action I take is proportionate to the seriousness of the issue at hand and minimises any restrictions to their human rights.
- If a person has been assessed as lacking capacity in relation to a particular matter or decision, I make every effort possible to ensure that their past and present will and preferences have been determined. This includes considering the views of any person named by the person themselves, whether a family member, a friend, or independent advocate, and consider any written documentation (such as an advance healthcare directive) and ensure that any decision made takes these into account.
- Although a person might have been assessed as not having capacity to make a decision at a particular moment in time, I understand that when it is relevant and possible for me to do so, I should make sure that their capacity is reviewed and that changes are made accordingly.

## Minimising restrictive practices

- I always make sure to explore options other than restrictive practices when a person displays behaviour that challenges or is disruptive. I also make sure that when a restrictive practice is used, it is proportionate to the behaviour it is being

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\*\*\*\* The Functional Test is a formal test, set out in the Assisted Decision-Making (Capacity) Act 2015, for the assessment of a person's capacity where concern exists.

used to restrict; is the least restrictive; is applied for the shortest possible time; and is subject to a timely review.

### **Supporting participation**

- I encourage the participation of people in the assessment, planning, delivery and evaluation of their care and support.

### **Supporting independent living**

- I make sure that I support people as much as possible to maintain or develop their capacity to live independently and develop the skills necessary for community living when they are being discharged from care.

## 5.2 Autonomy in real life

The following examples illustrate real-life situations where the principle of autonomy has been upheld and not upheld.

### Autonomy is upheld

- Jane has a physical disability and had been living in a residential centre. However, she wishes to live at home. Following discussion and assessment, her support team in the residential centre felt that this was not ideal as she was considered to be a person with high needs. Jane and the team discussed this and she understood and agreed that she would not receive the same level of care at home that she would have in a hospital or nursing home. Jane's wishes were respected and she was supported to take a measured risk. This was not about discharging Jane from the service, but about supporting her to transition from the residential centre and continuing to provide her with care in a different setting. Staff supported Jane in exercising her autonomy by understanding and respecting Jane's will and preferences and supporting her to live independently.
- Kieran had a stroke a number of years ago and is being cared for in a residential centre. Since then, he has had difficulty swallowing and communicating verbally. Medical advice was to introduce percutaneous endoscopic gastrostomy (PEG) feeding, where he would be fed through a tube into his stomach. All information relating to Kieran's treatment options were explained to him in an accessible way over a six-month period. He was facilitated to ask questions and express his choice of treatment throughout this time. Ultimately, Kieran fully understood all of his options. He did not want PEG feeding to be introduced as he felt it would impact on his enjoyment of the social aspect of eating and mealtimes. As a result, the procedure did not go ahead. Instead, staff in the residential centre arranged extra support for him when he was eating. Through correctly seeking consent and supporting Kieran to make a fully informed decision regarding his preference for eating, staff have upheld his autonomy.

Autonomy is not upheld

- Richard is a long-term inpatient due to complications associated with Parkinson's disease. Richard likes to eat quickly and on more than one occasion he has nearly choked on his meal. Staff assessed Richard's situation and prescribe that Richard's food be cut up. Richard was not consulted regarding this decision. He was not provided with information in the right format to ensure his understanding of the process and he was not consulted with regarding the next steps in his care plan. Richard does not want his food to be cut up and wishes he had been involved in the decision-making process and supported to participate in the planning of his care.
- John has severe heart failure and is currently in hospital with shortness of breath. He is aware of the seriousness of his condition and has no problems listening to and understanding the information he is given by the staff. However, he tells his daughter that, in the event of a cardiac arrest, he does not want cardiopulmonary resuscitation (CPR) or ventilation to be performed. John responds to treatment and returns home. John did not receive any information about making an Advance Healthcare Directive while he was in hospital, and there is no more discussion with John in relation to cardiopulmonary arrest, the issue of resuscitation, or his future options if this occurs. A few months later, John experiences a cardiac event and is transferred to hospital; he is unconscious but is accompanied by his daughter. Staff are unaware of John's wishes on resuscitation and do not consult with John's daughter to determine what his will and preferences are; they are therefore unaware of the views he has expressed in the past. All attempts are made to resuscitate him. No efforts were made to ascertain John's known past will and preferences, and the principle of autonomy has not been upheld.

## 6. Extended case studies

### 6.1 Jim

Jim has dementia and lives in a residential centre for older people. Patrick is a nurse and has just begun working in the residential centre. He is responsible for caring for Jim.

On the first day, Patrick introduces himself to Jim and greets him warmly. He sits with Jim and asks him how he is. He speaks slowly to Jim and uses simple language. Throughout his first week at the centre, Patrick familiarises himself with Jim's notes. He recognises the importance of being fully up-to-date on the current care plan, and to have knowledge of Jim's history, for truly individualised care. Through Jim's notes, Patrick reads about the hobbies Jim once engaged in, the role he had within his family, and the outlook he once had on life. Patrick does additional research on dementia online. The literature suggests various techniques which could be used in order to make Jim as comfortable as possible, such as reminiscence therapy and art therapy. Patrick speaks to Jim's family and friends and listens to their opinions on the various interventions that may help Jim.

Patrick attends multidisciplinary team (MDT) meetings where all the people using the service are discussed. The MDT's shared knowledge ensures that people using the service receive the best available care. This takes place in a private meeting room and information about Jim is discussed on a need-to-know basis. The meetings give Patrick the opportunity to raise issues about Jim's care.

Patrick wants to develop a collaborative and therapeutic relationship with Jim but this can be challenging especially when Jim becomes confused and angry. This occurred on one occasion when Patrick assisted Jim in changing his clothes and Jim became frustrated with the process and demonstrated this by climbing into bed and refusing to speak to him. Although Patrick was under time pressure, he respected Jim's decision and gave him time before trying again. Patrick ensures Jim's privacy is protected when performing intimate-care tasks such as supporting Jim to bathe and dress.

Patrick notes that Jim's entire case notes contain a wealth of important information but it takes a lot of effort to find the details. Jim raised this issue with the MDT and it was decided to summarise the notes into a smaller 'book'.

This is an example of **respect** in practice where Patrick takes the time to introduce himself properly to Jim when they first meet. He speaks to Jim in a way that Jim can understand. Patrick ensures Jim's human rights are respected.

This is an example of **autonomy** in practice, by making sure that Jim is fully supported as a person with individual needs and preferences. Patrick makes every effort to determine Jim's will and preferences by talking to his family and friends and listening to their suggestions based on their personal knowledge of Jim.

This is an example of Patrick also ensuring that Jim's **dignity** is respected when he is supported to undress, bathe and dress. He does not rush tasks that affect Jim's personal privacy and thus upholds the principles of dignity and respect.

This is an example of **fairness** in practice. Patrick ensures that there is comprehensive and accessible information on Jim's treatment options, care providers and status.

In this way, while a complete set of notes will still exist, there will also be a succinct account of who Jim is and what methods of care have been tried in the past. The book will be written in plain English and will be useful to new members of staff. It will also be useful to Jim's family and those advocating on his behalf.

By spending time with Jim, Patrick begins to understand him more – learning about his history, what works for him, what has not worked for him, and what makes him sad, angry or happy. Jim's notes reveal that he enjoys company and Patrick finally understands how to interact with him on a level he feels comfortable with. Patrick initially engaged with Jim as he would with any other person using the service, in terms of making conversation. However, this had put a lot of strain on Jim. Every subsequent interaction Patrick has with Jim involves him being present and caring, but not necessarily vocal. Jim likes art and once a week Patrick arranges an outing with him to a local art gallery. Patrick occasionally makes remarks about general things, making sure not to call attention to confuse or upset Jim. Patrick places no onus on Jim to answer him, as his remarks never take the form of a question. These short interactions allow for Patrick to build a more trusting relationship with Jim.

This is an example of **equality** in practice. It is important to understand the impact that treating Jim the same as everyone else would have on him. Patrick understands that this could lead to indirect discrimination.

Jim's **dignity** is respected throughout his care pathway. Jim is communicated with in a way that indicates his individuality, dignity and personal identity are acknowledged and respected.

## 6.2 Claudia

Claudia is in her late fifties and has a physical disability. She lives in a residential care centre. She recently saw an advertisement on TV about BreastCheck and wondered why she had not yet received a letter regarding this.

Claudia asked the nurse on duty why she had not received a letter and even though the nurse did not know, she did not follow up on Claudia's query. Claudia found it upsetting that her query was not taken seriously and spoke to her support worker, Fiona, about her concerns. Fiona found out that the centre had received the letter but had discarded it. Claudia arranged an appointment with the resident GP to discuss the matter. At Claudia's request, Fiona accompanied Claudia to her appointment.

Claudia explained what had happened, but her GP did not offer any information as to how it had happened or how it could be rectified. Claudia was upset after her visit to the GP as she felt she had not been listened to or taken seriously. She felt that her health had potentially been put at risk.

Claudia wanted to make a complaint about not receiving the letter but did not know how to do this as there was no information available in the centre. She asked for assistance from Fiona, who helped her write a letter of complaint to the centre manager. The centre manager sent a letter of apology to Claudia, explaining what had happened to her letter from BreastCheck and stating that all efforts would be made to ensure she received a date for her screening appointment as soon as possible. Claudia was also reassured that procedures would be put in place to prevent this from happening to anyone in the centre again.

This is an example where **respect** was not shown to Claudia. Claudia's Nurse and GP did not provide adequate answers to her questions and did not provide her with information on the options available to her. She was not supported to access and realise her rights.

Claudia also felt her **dignity** was not upheld when she was not taken seriously by her GP.

This is an example where Claudia's care did not promote **equality** of outcomes. It is important that her will and preferences are respected in the same way as others, regardless of her characteristics or status.

This is an example where **fairness** was upheld in that Claudia was supported in making a complaint by her care worker. The centre manager upheld fairness by making efforts to rectify the situation by putting proper procedures in place.

This case study is an example of **autonomy** in practice. Claudia is supported throughout the process by her support worker who ensures her will and preferences are central to it.

### 6.3 Mark

Mark is an 80-year-old adult living in a community nursing unit. Over the past number of years, Mark's sight has deteriorated and he is now legally blind. Mark's wife died a number of years ago and he doesn't have any children. He is close to his niece, Marie, who visits him regularly. Mark attends his resident GP, as he is experiencing severe abdominal pain and vomiting. His GP sends him to the emergency department for further tests, and Mark is diagnosed with appendicitis.

The plan is to proceed with surgery to remove Mark's appendix. Mark's doctor, James, meets with him in his six-bed ward when Marie is visiting him. James introduces himself and asks Mark if he would like anyone to be with him when he receives information about his surgery. Mark says that he would like his niece to stay with him when discussing his care. James closes the curtains halfway around his bed. He assumes that Mark has difficulty hearing on account of his age and speaks loudly to Mark explaining that he will need surgery. Mark has very good hearing and is conscious that his information is being shared with all other patients in the room.

James ensures he follows the necessary guidelines for good practice in seeking consent to treatment. He explains to Mark the benefits and risks of the proposed surgery and the consequences of not having surgery. He explains the procedure using simple language and avoids complex medical terminology where possible. He asks Mark how he would like to receive the information. As Mark has difficulties with his sight, he is provided all relevant written information about the procedure in large bold print which he is able to read. Mark is fully informed and actively involved in the process. James encourages him to ask questions and he checks Mark's understanding throughout the discussion. He gives Mark time to reflect on the information and to think of further questions to ask.

Mark is anxious about the surgery and has a number of questions. Mark's doctor spends time answering these questions clearly, which eases his fears. Mark gives his consent to undergo surgery for his appendicitis. James is confident that he has capacity to make this decision regarding his treatment as he was able to communicate his consent clearly, has shown that he understands his condition and treatment options, and is able to retain this information. James is also aware that Mark came to this decision by himself.

Mark was treated with **respect** and was provided with information about his condition and treatment, and had his questions answered in a way he understands.

**Equality** was upheld when Mark's will and preferences were respected regardless of his characteristics or status. However, equality was not upheld when it was assumed he had hearing difficulties.

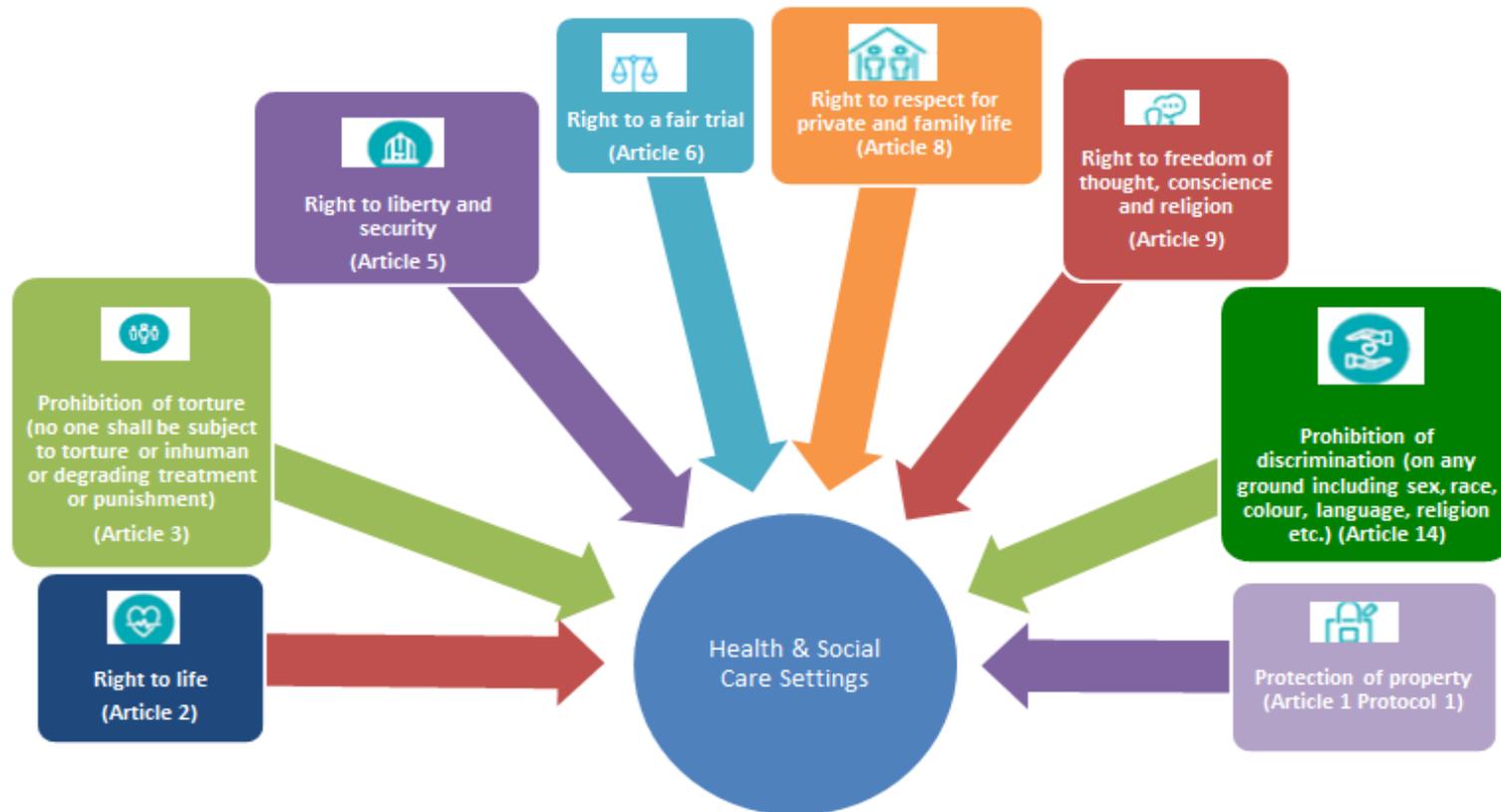
Mark's **dignity** is respected where he was communicated with in a way that acknowledged his personal identity and individuality. However, by speaking loudly and not closing the curtain fully, his physical privacy and privacy in relation to his information was compromised.

**Fairness** was upheld as there was a clear and fair process in place governing informed consent and Mark was provided with accessible information on his treatment options. Mark was supported to participate in the decision-making process.

Mark's right to **autonomy** was upheld throughout this process resulting in him making an informed decision to consent to surgery freely and without duress.

### Resource 1: Key human rights relevant to health and social care settings

This resource describes the key human rights set out in the European Convention on Human Rights Act 2003 which are relevant to health and social care settings.



## **Right to life (Article 2)**

This covers situations where a person's life may be at risk and decisions are being made to withdraw life-sustaining treatments or not to resuscitate a person. It can also relate to a person experiencing suicidal thoughts or posing a risk to other people's lives.

## **Prohibition of torture (Article 3)**

This is relevant where a person is at risk of serious harm including where a person is neglected or cared for in a way that causes serious harm or suffering. It can be relevant where someone receives continuing treatment that causes serious harm and suffering or where a person's need for pain relief is not assessed and responded to.

## **Right to liberty and security (Article 5)**

This prevents restrictions being placed on people's movement except in specific circumstances, such as when procedural safeguards can be applied according to the law. Even where a restriction on liberty is for a lawful reason, human rights safeguards must be in place.

## **Right to a fair trial (Article 6)**

This covers all aspects of procedural fairness. It is relevant when other rights, such as the right to liberty or the right to respect for private life, are at issue. It includes the right to participate effectively in proceedings and in some cases a public hearing, and the right to legal representation.

## **Right to respect for private and family life (Article 8)**

Private life can be interpreted to include personal choices, relationships, physical and mental wellbeing, access to personal information and participation in community life. It includes confidentiality and privacy of medical information.

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

This right protects everyone's right to freedom of thought, conscience and religion. It includes the right of people to put thoughts and beliefs into action either alone or in a community with others. Both religious and non-religious beliefs are protected as is the right to change religion or belief. For a belief to be protected under this article, it must be serious, concern important aspects of human life or behaviour, be sincerely held, and be worthy of respect in a democratic society.

### **Prohibition of discrimination (Article 14)**

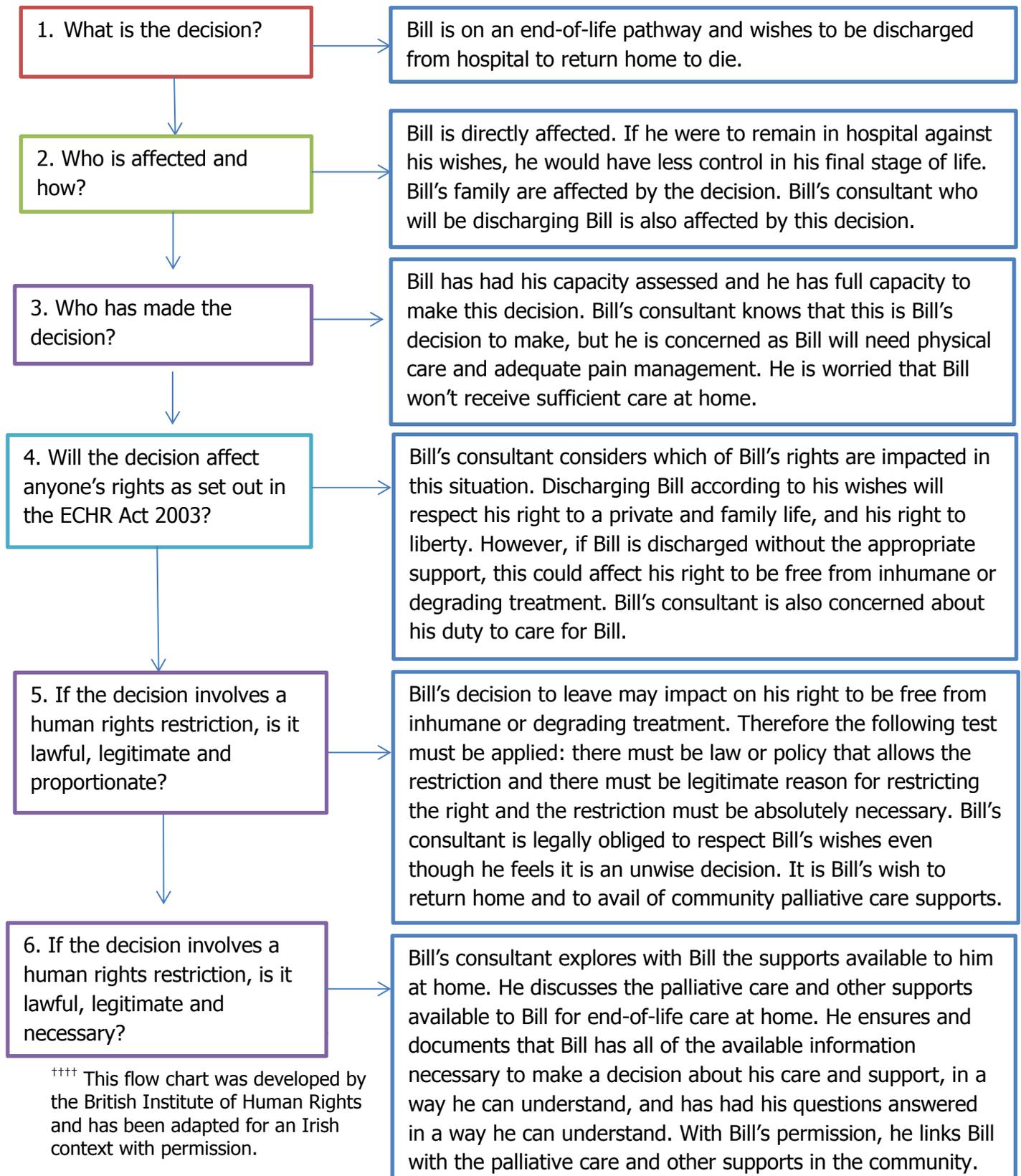
This can relate to situations where a person is denied access to services or treatment on any ground such as sex, race, colour, language, religion, political or other opinion, national origin, association with a national minority, property, birth or other status. It also relates to people being treated differently to others under comparable circumstances on account of their characteristics, or where people with very different characteristics are treated the same. This can lead to unequal outcomes.

### **Protection of property (Article 1 of Protocol 1)**

A person is entitled to the peaceful enjoyment of their possessions. Possessions and property have a wide meaning, including land, houses, leases, money and personal property. A person's property or possessions and the way they use them cannot be interfered with except in the public interest and when subject to the conditions provided for by law.

## Resource 2: Decision-making flow chart<sup>++++</sup>

This flow chart is a helpful tool for staff when making decisions in relation to a person's care. The case study below relates specifically to a situation that can arise in services for end-of-life care, but the process is adaptable across settings.



<sup>++++</sup> This flow chart was developed by the British Institute of Human Rights and has been adapted for an Irish context with permission.



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