

Shining a light on human rights

Dementia and Human Rights:

A practitioner's guide

The British Institute of **Human Rights**

bihr.org.uk



About this booklet

This booklet is about human rights and dementia care. It is aimed at professionals working in dementia care settings, in hospital or in the community (we've used the term 'practitioner' throughout to capture this). Lots of information in the booklet may also be useful for people using dementia care services, their family or carers.

This booklet was written by the British Institute of Human Rights (BIHR), in partnership with **Bristol's Dementia Wellbeing Service (Devon Partnership NHS Trust and the Alzheimer's Society)**. This service is currently working with BIHR on our project called **Delivering Compassionate Care: Connecting Human Rights to the Frontline**. The project aims to place human rights at the heart of mental health services, helping to ensure frontline staff have the knowledge and skills to fulfil the vital role they can play in upholding the dignity and human rights of people using services. The project is funded by the Department of Health, therefore the information in this booklet focuses on English law and bodies. BIHR would like to thank the practitioners at Bristol Dementia Wellbeing Service for their help in producing this booklet, particularly the Human Rights Leads for their ideas, advice and guidance.

This booklet should be read in conjunction with our other resource '**Mental Health, Mental Capacity and Human Rights: A practitioner's guide**'. That resource contains more information about how UK law protects human rights, key rights for mental health/capacity services and where to find more information/support.

Dementia and human rights

Many of the aims of dementia care/support services align with human rights values. This includes supporting people affected with dementia to:

- have as much control as possible over their own lives, care and treatment
- be treated with dignity and respect in their interactions with services
- live as independently as possible, for as long as possible

Independence, control and autonomy are key human rights values and are protected by the **right to respect for private life** (Article 8 in the Human Rights Act 1998). This booklet aims to give practitioners the knowledge and confidence to use human rights in practice in order to design and deliver rights-respecting dementia care services. It's arranged around three key issues for dementia care services, identified by our partner.

 This booklet is for information purposes only. It is not intended, and should not be used, as legal advice or guidance.

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Responding to a (potential) crisis in the community

With appropriate care and support people affected by dementia can continue to live their lives well within the community long after they have received a diagnosis. However, people may sometimes experience acute issues while in the community which require an urgent response. There may also be instances when concerned friends, family members and others contact services expressing their concerns about a person's behaviour or appearance because they think a person is in crisis or needs assistance when intervention is not required or appropriate.

This part of the booklet is about how to use a human rights approach when dementia practitioners are deciding whether a concern raised by a member of the public should be referred/acted upon as a safeguarding issue.

"I was recently able to challenge poor practice around planning the care pathway of a client using a human rights approach. The client's own wishes to live in her own home were not given appropriate weight and getting people to think about the range of human rights involved meant she was given a much more dignified, respectful pathway to be supported to live in her own home."

Lisa, Senior Dementia Practitioner, from BIHR's Delivering Compassionate Care project

Potential human rights issues for practice

- blanket responses by practitioners to intervene in the lives of people affected with dementia based on reports by friends, family members or others about perceived concerns
- a person affected with dementia chooses to continue to live independently in their own home but family members consider this to be too risky
- overriding the choices and wishes of a person about where they want to live when they have capacity to make that decision for themselves
- trying to place restrictions on a person's movement due to concerns about their safety, without applying the legal safeguards (the Deprivation of Liberty Safeguards)
- raising safeguarding concerns which lead to a person assessed as lacking capacity being removed from their own home, without supporting them to be involved in the decision and failing to inform or consult their family/carer

Key rights for responding to a (potential) crisis in the community

Right to be free from inhuman and degrading treatment

(protected by Article 3 in the Human Rights Act)



This right protects people from being treated in a way which causes them serious mental or physical harm, or humiliates them. This is an absolute right which means there can never be a lawful reason to treat someone in this way. It includes:

- serious harm arising as a result of a lack of care/support or self-neglect
- severe abuse or ill-treatment by others (which could include practitioners, family members, carers, other individuals)

Relevant practitioners' duties:

- ♥ to respect this right: not breaching in any circumstances
- 🛡 to protect this right: taking action to protect someone from a known and immediate risk of serious harm, often called **safeguarding**

📖 See our other booklet **'Mental Health, Mental Capacity and Human Rights: A practitioner's guide'** page 12 for more information, including your other duties.

Right to liberty

(protected by Article 5 in the Human Rights Act)



This right prevents extreme restrictions being placed on people's movement, except in specific circumstances (such as a Deprivation of Liberty (DoL) Authorisation). Even if a restriction on liberty is for a lawful reason, there are still human rights safeguards which must be in place and the correct processes need to be followed.

This might be relevant when practitioners are considering taking steps to prevent a person from leaving their home for their own safety, which could amount to a deprivation of liberty where:

- the person is under continuous supervision or control
- and
- the person is not free to leave a place
- and
- public officials are involved in the funding, arrangement, planning and/or delivery of the person's care

(Cheshire West and Chester Council v P, 2014)

In such circumstances, whatever the aim of the deprivation, the right to liberty requires that the person must have access to the relevant legal safeguards, such as the DoL Safeguards.

Relevant practitioners' duties:

- ♥ to respect this right: not interfering where possible
- 🛡 to protect this right: applying the procedural safeguards written into the right

📖 See our other booklet **'Mental Health, Mental Capacity and Human Rights: A practitioner's guide'** page 15 for more information, including your other duties.

Right to respect for private life, family life, and home

(protected by Article 8 in the Human Rights Act)



The right to **private life** protects people's **privacy, autonomy** and **well-being**. This includes:

- a person being able to participate in decisions about their care or treatment, including concerns about their safety
- respecting the ability of people with capacity to make decisions and take risks, even when others consider those decisions to be unwise – the law (the Mental Capacity Act 2005 and the Human Rights Act) is clear that people with capacity have the right to make unwise decisions, and that an unwise decision in itself is not evidence of lack of capacity
- protecting a person from abuse and neglect (serious abuse/neglect will be covered by Article 3, see page 4)
- a person being able to participate in the life of their community
- a person having their private information (including diagnosis) kept confidential and being in control of information shared about them, except where an identified risk of harm outweighs this

The right to respect for **family life** includes a person being able to maintain family and personal relationships.

The right to respect for **home** includes supporting a person to make choices about where they want to live.

Relevant practitioners' duties:

- ♥ to respect this right: not interfering where possible unless it is lawful, for a legitimate reason and proportionate
- 🛡 to protect this right: taking action to protect where necessary

📖 See our other booklet **'Mental Health, Mental Capacity and Human Rights: A practitioner's guide'** page 17 for more information, including your other duties.

Right to non-discrimination

(protected by Article 14 in the Human Rights Act)



Practitioners should also consider whether a person's right to enjoy their human rights without discrimination (Article 14) is an issue. For example are they being deprived of their liberty on the grounds that they are affected with dementia rather than because of safety issues?

📖 See our other booklet **'Mental Health, Mental Capacity and Human Rights: A practitioner's guide'** page 20 for more information, including your other duties.

"Human rights helps people understand why we have safeguarding – where it comes from and what its about."
Practitioner on BIHR's Delivering Compassionate Care project

In real life: failing to respect rights in removing person from own home

Joan is 81 and has recently been diagnosed with advanced dementia. Her son Kieran cares for her at home, with financial support from the local authority. Concerns are raised about bruises and scratches that Joan is unable to explain. While Kieran is out shopping a social worker asks Joan to go with her to a care home. Four days after Joan is removed from her home, the local authority applies for a standard deprivation of liberty authorisation, which is given ten days later (no emergency authorisation was sought). The following day the local authority applies to the Court of Protection. The court decides 18 days after the application is made (just over a month after Joan is removed from her home) that it is in Joan's best interests for her to remain at the care home and the court authorises any further deprivation of liberty.

Kieran is not told where his mother is until 19 days after she is first removed from her home, when his solicitor writes to the local authority. Allegations of abuse by Kieran are referred by the local authority to the police. For 18 months Kieran's contact with his mother is restricted because of these allegations. The police and the local authority decides not to pursue the abuse allegations.

A case is brought against the local authority challenging their decision-making processes. The court decides that for the time that no deprivation of liberty authorisation was in place, the local authority have breached Joan's right to liberty. The court also rules that removal from her home led to a disproportionate interference with Joan's right to respect for private and family life and her home. It is decided that Joan will remain in the care home, as there is no alternative place for her to be cared for at this stage. The court cannot see any reason for continued restrictions on visits between Joan and Kieran. The local authority agrees to fund the reasonable costs of contact between them, and Kieran agrees to take a manual handling course to better support his mother on their outings.

(Milton Keynes Council v RR & Others, 2014)

“Using a human rights approach has revolutionised decision making. Staff are thinking differently and making decisions differently. It needs to be rights based, not just risk based.”

Paul Hill, North Essex Partnership University NHS Foundation Trust, from BIHR's Delivering Compassionate Care project

A human rights approach to responding to a crisis in the community

This could include:

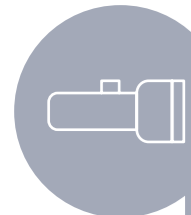
- ✓ assuming that the person has capacity to make decisions about where and how they want to live as the starting point and carrying out a capacity assessment only where you have genuine concerns about their safety (using the Mental Capacity Act)
- ✓ where a person is assessed as not having capacity to make a decision, supporting them to be as involved in the decision as possible
- ✓ ensuring that a person's privacy is maintained unless they have given permission for their diagnosis to be discussed with others such as friends, family, carers, neighbours or other practitioners, except where the risk of harm to the person outweighs their privacy
- ✓ recognising that the wishes of a person's family cannot supersede the person's own wishes and/or their best interests
- ✓ with a person's permission, supporting friends, family and neighbours to distinguish between a crisis and non-harmful issues and/or behaviours
- ✓ exploring all options with a person to support them to live independently and manage risk, with intervention as a last resort
- ✓ limiting any intervention to the least restrictive course of action required to ensure a person is safe from serious harm or ill-treatment

“In our safeguarding meetings I have been able to use the human rights framework, including the language of dignity and respect, to give a sharper, harder edge to our concerns around issues of neglect. It has helped us express our concerns as being relevant as a matter of law, something concrete. It has helped, in difficult times, to give us back our social work values in a meaningful way.”

Practitioner on BIHR's Delivering Compassionate Care project

Responding to a (potential) crisis in the community

This flowchart is for practitioners deciding whether to raise a serious concern about someone's safety as a safeguarding issue



Flowchart information: Does the concern raise any safeguarding issues?

If you are unsure of whether the concern raises a safeguarding issue, consider the criteria for adult safeguarding in law. Adult safeguarding duties apply to any adult who:

- has care and support needs; and
- is experiencing, or is at risk of, abuse or neglect (includes self-neglect) and is unable to protect themselves because of their care and support needs (Care Act 2014 section 42(1) and see also Care and Support Statutory Guidance chapter 14)

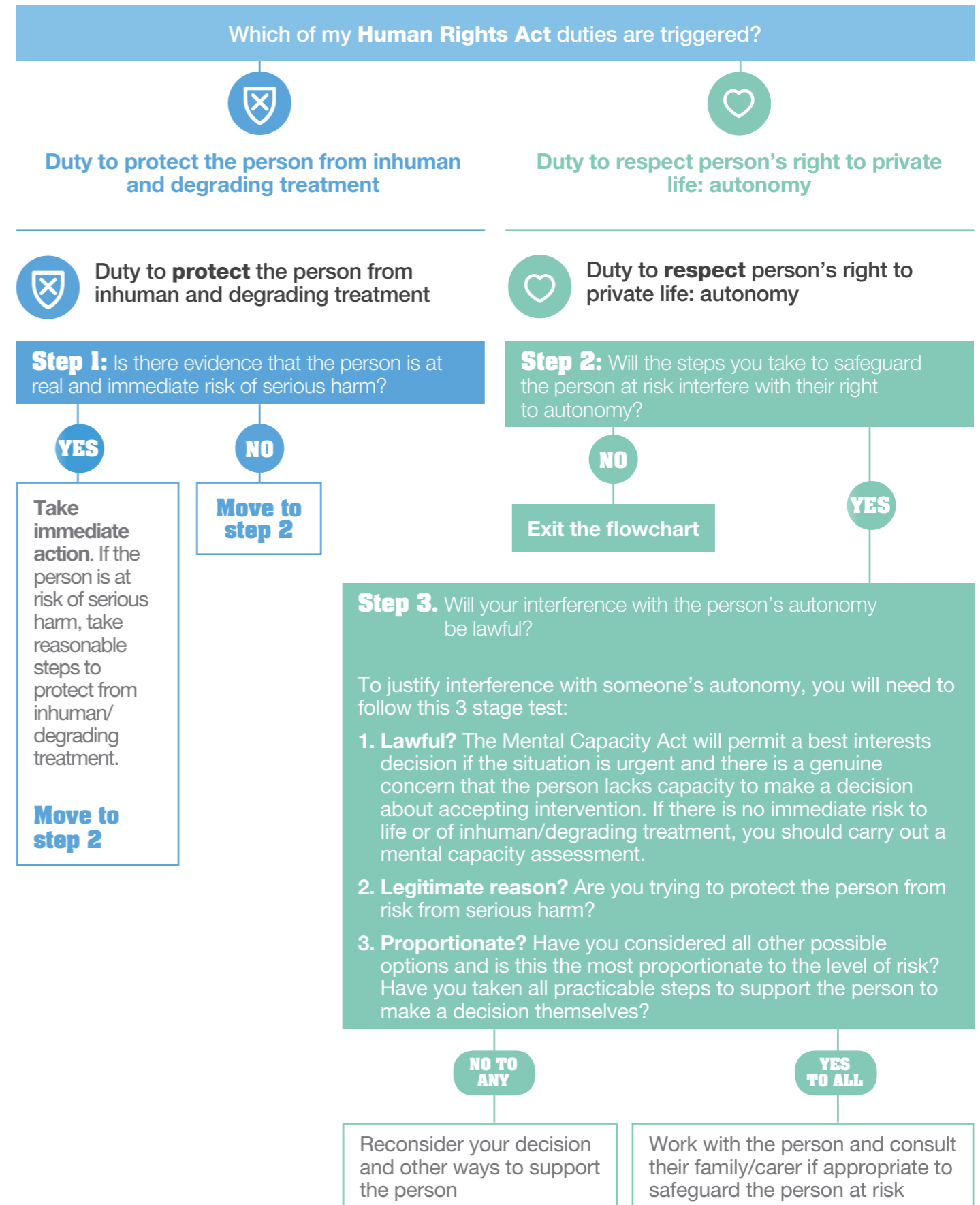
Evidence that this criteria has been met will trigger the local authority's duty to make enquiries under section 42 of the Care Act 2015.

When deciding whether or not somebody is at risk of abuse, keep in mind that abuse can include (but is not limited to) organisational abuse (through neglect or poor professional practice as a result of the structure, policies, processes and practices within an organisation),

neglect and acts of omission (including ignoring medical, emotional or physical care needs, failure to provide access to appropriate health, care and support or educational services, the withholding of the necessities of life, such as medication, adequate nutrition and heating) and self-neglect (Care and Support Statutory Guidance chapter 14.17).

The right to be free from inhuman and degrading treatment (Article 3) and the right to respect for private life (Article 8) are the two rights most likely to be relevant to raising a safeguarding issue. Other rights in the Human Rights Act might also be relevant, for example the right to life (Article 2) in extreme circumstances, or the right to liberty (Article 5) if you are considering restricting someone's movements and you will need to ensure correct legal safeguards are in place (such as Deprivation of Liberty Safeguards). See our other booklet 'Mental Health, Mental Capacity and Human Rights: A Practitioner's guide' page 10 and page 15 for more information.

ONE: Decision-making flowchart



ONE: Explaining the steps in the flowchart



Step 1. Is there evidence that the person is at real and immediate risk of serious harm?

The right to be free from inhuman and degrading treatment protects against serious harm (caused by abuse or neglect). To decide whether a safeguarding issue meets the high threshold for inhuman and degrading treatment you could consider:

- is the risk current, or potential?
- does the evidence suggest that serious psychological or physical harm to the person is likely?
- is it possible to speak to the person at risk to find out more about the impact of the treatment on them and what they would like to happen?

If the risk of harm is not serious enough to reach the high threshold of 'inhuman or degrading', the right to respect for private life (Article 8) includes well-being and protects people from less serious harm caused by abuse or neglect. See our other booklet 'Mental Health, Mental Capacity and Human Rights: A practitioner's guide' page 17 for more information.



Step 2 Will the steps you take to safeguard the person at risk interfere with their right to autonomy?

The right to private life protects people's autonomy, which includes:

- a person making their own decisions about their life, care and treatment
- this includes being able to make decisions others might think unwise
- where a person is assessed as lacking capacity to make a decision, they should still be supported to be involved and make decisions as much as possible

The right to private life also includes:

- a person's right to live in their own home and to participate in the life of the community
- a person's right to privacy and to be in control of information shared about them



Step 3. Will your interference with the person's autonomy be lawful?

You will need to decide whether your interference with the person's private life in order to protect them from risk of serious harm will be proportionate. You should consider all practicable steps to support the person to make a decision themselves.

That might include exploring all options with the person to support them to live independently and manage risk, deferring the decision until another time, involving an Independent Mental Capacity Advocate etc.

two

Assessment and diagnosis: respecting private life

A dementia diagnosis can have a significant impact on a person's physical and mental well-being, and on their sense of personal identity. Both of these are protected by the **right to respect for private life** (Article 8 in the Human Rights Act). At the same time, a diagnosis of dementia is often necessary for people to access the appropriate care and support services required to maintain their mental and physical well-being. Dementia practitioners may be working with GPs to help diagnose people with dementia. People may sometimes express a wish not to be given such a diagnosis. They may also become extremely distressed if a diagnosis is given to them insensitively or without adequate warning, especially if they have attended a healthcare service for an unrelated reason.

This part of the booklet is about how to use a human rights approach when carrying out an assessment to identify if a person has dementia and how to give feedback about the results.

Potential human rights issues for practice

- a person who presented to a practitioner with an unrelated health issue but symptoms that may indicate they have dementia are observed
- a person who has symptoms of dementia but who does not want an assessment or full diagnosis
- screening a person for dementia without informing/consulting them first
- sharing information about the diagnosis with other relevant agencies or other people without permission
- telling a person that they are at high risk of developing dementia in the near future by letter

"Using a human rights approach is very enabling and there have been many light bulb moments - it's turned decision making on its head."

Practitioner on BIHR's Delivering Compassionate Care project

Key right for dementia assessment and diagnosis

Right to respect for private life

(protected by Article 8 in the Human Rights Act)



This right protects a person's **privacy, autonomy** and **well-being**. For people being assessed/diagnosed with dementia this could include:

- participation in decisions about care or treatment, including consent to be being assessed for dementia and referred for further care and treatment
- maintaining the confidentiality of information about a person's care and treatment
- a person's right to determine their own identity and live accordingly

Relevant practitioners' duties:

- ♥ to respect this right: not interfering where possible unless it is lawful, for a legitimate reason and proportionate
- 🛡️ to protect this right: taking action to protect where necessary



See our other booklet '**Mental Health, Mental Capacity and Human Rights: A practitioner's guide**' **page 17** for more information, including your other duties.

A human rights approach to dementia assessment and diagnosis

This could include:

- ✓ making clear to a person that they have a right to know their diagnosis, but that they also have a right not to be told if they do not want to know, except where this is outweighed by a risk of harm in not knowing (e.g. not being able to access treatment to relieve pain or suffering)
- ✓ promoting communication; enabling the person to have support from relatives where they want it, interpreters or advocates
- ✓ ensuring that the assessment process and care pathway is explained to a person sensitively, in a language that they can understand
- ✓ seeking a person's consent prior to involving any friends or family in the diagnosis and assessment process
- ✓ discussing in a sensitive way how a person would like to proceed in the future should they lack capacity to make decisions about their care and treatment and agreeing a care plan in advance

Worked example: dementia assessment and diagnosis

Keith is 75 and is visiting his GP, Dr Hussein, with his partner Adam for a follow-up appointment two weeks after a hospital procedure to remove a mole on his arm. When Dr Hussein asks how Keith is feeling, he takes a little while to respond, eventually saying that he has been feeling foggy and slow, perhaps because of the painkillers. Adam jokes that Keith's forgetfulness started well before the operation on his arm.

Dr Hussein is aware that confidentiality is an important part of Keith's right to respect for private life, and that he should be consulted about how to proceed with any further investigations and who to involve. She suggests Keith should attend a memory clinic for a full assessment. She checks whether Keith is happy for her to ask Adam some questions about his memory and ability to concentrate and carry out day-to-day tasks. Keith does not want Adam to be involved at this stage. He thinks that Adam will be very distressed and unable to cope with the uncertainty of the assessment process. Keith is happy for Dr Hussein to call his sister Frieda to ask her the relevant questions about his day-to-day functioning and memory, which Dr Hussein does.

A week later, Keith attends his appointment at the memory clinic with Frieda where a dementia practitioner asks him to do a series of tests. She explains that Keith will be offered an appointment with a consultant later that week to find out the outcome. The dementia practitioner asks Keith whether, should a diagnosis of dementia be found, he would like to be informed or not. The dementia practitioner also asks Keith whether he would like his partner Adam to be involved in his care and treatment at that stage. Keith decides that he would like to be informed, and for Adam to be told at that stage too, so that they can put plans in place for the future. Keith is particularly concerned that at some point he may need to move out of his home. He wants to look into residential care placements that will accommodate him and Adam as a couple. The dementia practitioner reminds Keith that he is still early on in the assessment process. She signposts him to a local mental health support group, to assist with any anxiety of waiting for a diagnosis.

When Keith and Adam attend the follow-up meeting with the consultant Keith is told that his memory function seems to be normal. This will need to be reviewed in three months' time. The consultant suggests Keith may be showing symptoms of depression, and recommends he speaks to his GP about so that it can be investigated.

"Although we are a values based service, I really needed to know how to put human rights into practice. We needed that integrity."

Practitioner on BIHR's Delivering Compassionate Care project

Autonomy and memory (grief and loss)

Interference in people’s personal freedom and autonomy in relation to memory, particularly around grief and loss, can raise human rights issues. People living with dementia who are experiencing memory loss may not be able to recall certain information, such as the fact that certain loved ones have died. They may ask those around them, including dementia care practitioners, where that person is or how they are. Practitioners can take a number of approaches to this:

- a reality orientation approach involves reminding the person that the individual they are asking for has died
- a validation approach acknowledges and empathises with a person’s beliefs and feelings, and avoiding factual disputes about whether or not a particular individual has died

Whatever approach a practitioner takes, the **right to respect for private life** (protected by Article 8 in the Human Rights Act) will be relevant because it protects people’s autonomy and their physical and psychological integrity.

Right to respect for private life (protected by Article 8 in the Human Rights Act)



This right protects people’s **privacy, autonomy, and well-being**, including:

- having control over their own life, care and treatment
- participating in decisions about their care or treatment
- well-being (both mental and physical), including distress caused by disorientation or confusion arising from living with dementia or from certain aspects of dementia care

Potential human rights issues for practice

- challenging a person’s beliefs about a loved one who is no longer alive, causing them severe distress
- validating a person’s (inaccurate) beliefs about their life and surroundings, potentially undermining their dignity
- consulting a person’s family/carer about what therapeutic approach to take when responding to memory loss, and managing divergence between the family’s views and those of practitioners involved
- supporting a person’s family/carer to take part in the therapeutic approach adopted by practitioners

Relevant practitioners’ duties:

- to respect this right: not interfering where possible unless it is lawful, for a legitimate reason and proportionate
- to protect this right: taking action to protect where necessary

See our other booklet **‘Mental Health, Mental Capacity and Human Rights: A practitioner’s guide’ page 17** for more information, including your other duties.

A human rights approach to autonomy and memory

This could include:

- ✓ discussing with a person in advance how they would like issues of grief and loss to be approached should their condition change in the future
- ✓ ensuring the emotional harm a particular approach may cause is proportionate to the likely benefits
- ✓ consulting with family/carers, acknowledging their views and wishes, explaining the rights engaged in different therapeutic approaches and working together on the agreed approach

“Better literacy on human rights can inform better care planning.”

Practitioner on BIHR’s Delivering Compassionate Care project

Worked example: autonomy and memory (grief and loss)

Enora has been diagnosed with dementia and has been living in a residential care home with her husband Alfie for the last six months. Until recently staff and Alfie had adopted a reality orientation approach with Enora. They gently reminded her of the time, date and her surroundings. This seemed to help Enora remain aware of what was happening around her, avoiding distress and confusion.

Recently, however, Enora has been asking to see Elsie, her younger sister who died when she was an infant. On at least two occasions staff have informed Enora that Elsie has died, and she has become very distressed. Alfie, however, wants staff to continue to tell Enora the truth because he thinks it is infantilising to lie to her.

The staff at the home are concerned about the distress that their current approach is causing Enora, and meet to discuss her care plan. They note that she is losing interest in activities that she used to enjoy, and becoming more withdrawn after they explain to her that Elsie has died. Enora’s consultant highlights that at their last appointment, Enora was diagnosed with advanced dementia.

Her dementia practitioner believes a reality orientation approach at this stage is probably of limited benefit.

The staff at the home decide that it may be a disproportionate interference with Enora’s well-being to continue to inform her that Elsie has died. They believe there are other less distressing ways to acknowledge her questions about her sister.

Staff meet with Alfie and Enora and explain that while they recognise that Enora has a right to autonomy, they also have a duty not to interfere with her physical and mental wellbeing as far as possible. Given that Enora’s condition is deteriorating despite the reality orientation approach staff have adopted so far, they think that it is disproportionate to repeatedly inform Enora of Elsie’s death, given the distress that this is causing her. They agree together with Alfie that in light of the change in Enora’s condition, they will support him in a validation approach with her in the future.

The rights protected by our Human Rights Act:



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
(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 be discriminated
against in relation to any of
the rights contained in the
Human Rights Act
(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)

This booklet 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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