

Mental Health, Mental Capacity: Raising A Human Rights Issue

Workbook

Finding your way around

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Who is this workbook for?

This workbook is for anyone with mental health or mental capacity issues, to be used with the support of your advocate if necessary. It gives you tips on how you can identify whether an issue you have with your care or treatment is a human rights issue, and if so, how to raise it using human rights.

Unlocking your rights

This workbook should be used with our booklet 'Mental Health, Mental Capacity: My Human Rights' available at www.bihhr.org.uk/health

That booklet gives you information about

- what your human rights are,**
- who has duties to uphold your human rights, and**
- how your human rights are protected.**



What is this workbook?

If you have a mental health or mental capacity issue, this workbook aims to give you tips and tools about how you can use human rights to help you to have more control over your own life and be treated with dignity and respect.

The focus of this workbook is on your human rights when you are receiving health and care services, e.g. at your GP, in hospital, community care, care homes etc. Most of the information will also apply to other situations like education, housing or involvement with the police, but we do not cover these areas in this workbook.

This workbook gives you tips and tools about how to use your human rights in practice to challenge poor practice or decisions about your care or treatment that have a significant impact on you.

This workbook is written by the British Institute of Human Rights (BIHR), in partnership with six other organisations:

These organisations are working with BIHR on a project called 'Care and Support: A Human Rights Approach to Advocacy'. The project aims to ensure people with mental health and mental capacity issues have increased control and autonomy over treatment decisions, and make sure they are treated with dignity and respect. The project is funded by the Department of Health, therefore the information in this workbook focuses on English law and bodies.

BHA Leeds Skyline
for equality in health and social care

healthwatch

Mind in Brighton and Hove

n|compass Advocacy Service

ansun
network for mental health

WISH

We would like to thank the Department of Health for their grant which supported the production of this workbook. The BIHR staff team would also like to thank all those organisations and individuals who helped to produce this workbook, particularly the Human Rights Leads from our partner organisations for their ideas, advice and guidance.

BIHR's advocacy resources aim to empower people to have their rights respected. If our materials have helped you use human rights in practice, as an individual or an advocate, we would love to hear your story. You can contact us on info@bihr.org.uk

What is advocacy?

Advocacy is about helping you to express your views or concerns, to explore your choices, to access information and services and to protect and promote your rights. An advocate is independent and there to represent you. Advocacy can be helpful in all sorts of situations, including if you are worried that you are not being listened to by services or professionals.

Instructed advocacy

is when you are able to express your views and an advocate acts on this and helps you to be heard and access services and information.

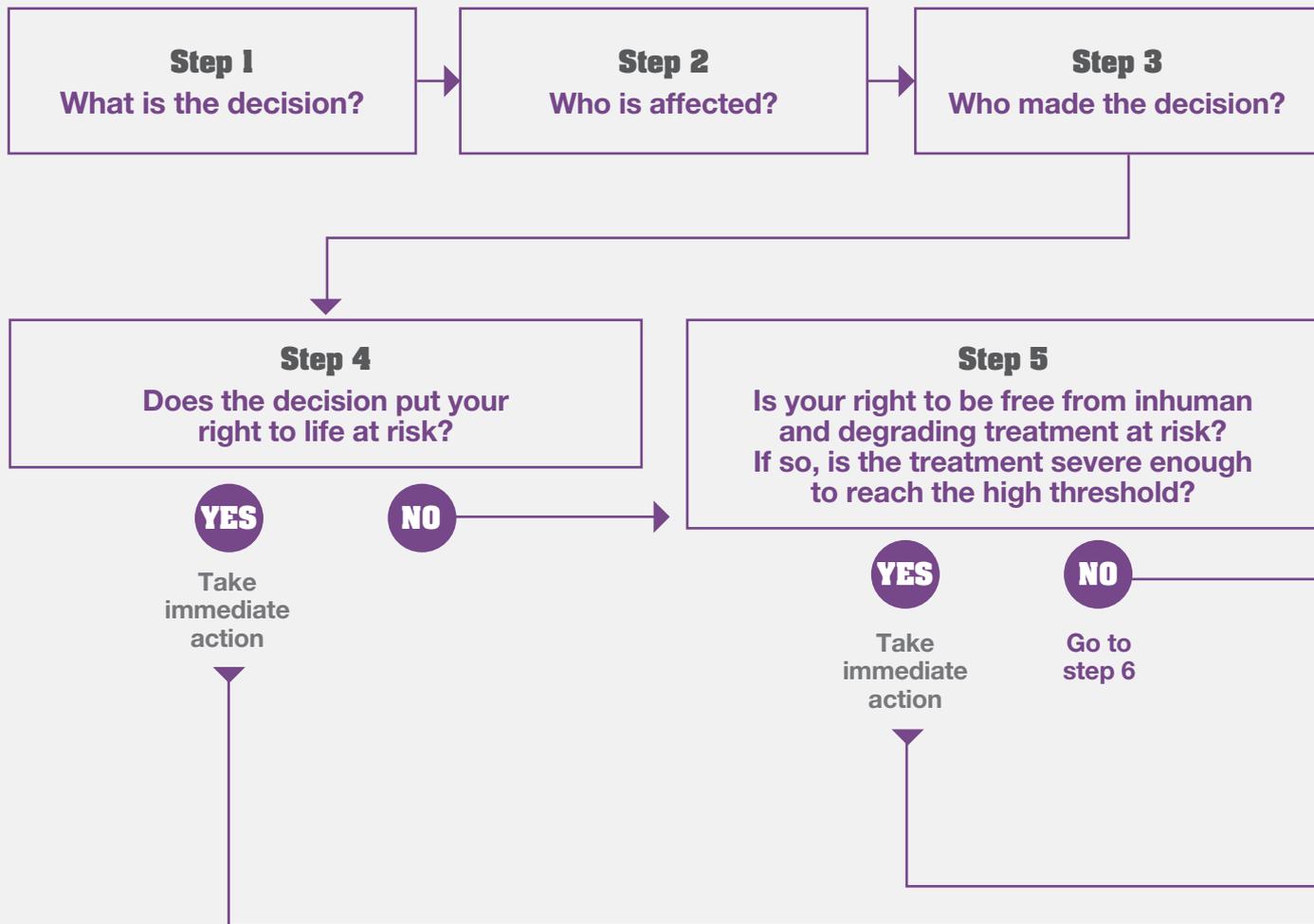
Non-instructed advocacy

is when an advocate acts on your behalf when you are not able to communicate what you want in a particular situation.

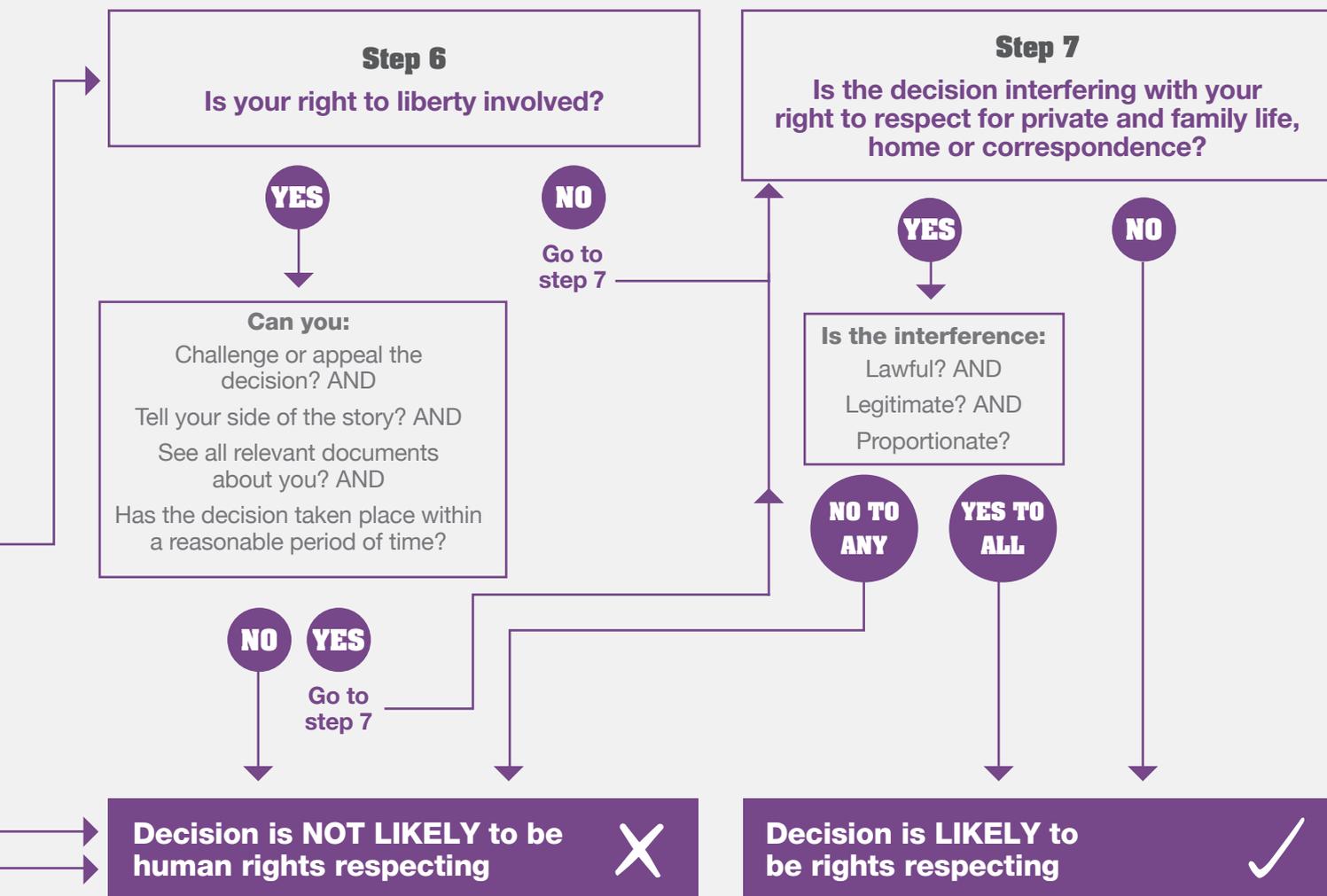
There are some **legal rights to advocacy**:

- If you do not have capacity and there is no one to speak on your behalf, the Mental Capacity Act says an **Independent Mental Capacity Advocate** should be appointed to support you in certain situations.
- If you have mental capacity issues and you are deprived of your liberty in hospital or a care home (ie. if you are not free to leave and kept under constant supervision and control), the Mental Capacity Act says that you should have **someone to support you through the process of a ‘Deprivation of Liberty Authorisation’** and afterwards. This could be a family member, friend or an advocate.
- In some situations the Mental Health Act says you have a right to an **Independent Mental Health Advocate** (IMHA). An IMHA should support you to understand and exercise your legal rights. The authority detaining you should give you information about IMHAs.
- In some situations the Care Act says that you have a right to **an independent advocate, if you have ‘substantial difficulty’ in being involved in decisions about your care** and you don’t have an appropriate individual to support you. The independent advocate will support you and represent you to be involved in decisions about, for example, your needs assessment or your care plan.

Using human rights: is my issue about human rights?



This flowchart gives you information to help you identify whether an issue with your care or treatment is a human rights issue. The flowchart takes you through some of your key rights in the Human Rights Act, so remember to have a copy of our booklet **‘Mental Health, Mental Capacity: My Human Rights’** with you, as it gives you information on what is covered by each of these human rights.



Using human rights: Is my issue about human rights? Explaining the flowchart steps

Step 1

What is the issue/ decision?

What happened, when and where? Be clear about the details of your situation. Then clearly identify what it is you want to challenge. Is it the way you have been treated, a specific decision that has affected you, or a policy affecting a number of people?

TIP: think about the main issue that you think is impacting on your rights and the main thing you want to change.

Step 2

Who is affected?

Does the decision affect you or a number of people? How has it affected you? Think about the impact it has had on you, and include any relevant information about personal circumstances or characteristics (for example, age, health, gender etc.) that are relevant, particularly the impact on your mental health.

Step 3

Who made the decision?

Public authorities have a legal duty to respect and protect your rights in everything that they do, including designing and delivering services. Importantly, private companies and charities delivering health and care services also have a legal duty to uphold your rights where your care is arranged or paid for (in any part) by the local authority. This duty means public officials - people working in public services - have to uphold your human rights. This includes:

- NHS staff
- Local authority staff e.g. social services, housing etc
- Private health and care providers where your care is arranged or paid for (in any part) by the local authority
- Police / prison staff
- Courts and tribunals, eg the Mental Health Tribunal, the Court of Protection

This is not a full list, just examples of who has duties to uphold your rights. This booklet focuses mainly on the duties of those providing health and care services.

If you are receiving your care from a private individual, or you're not sure whether your care provider has duties to uphold your human rights, and you are concerned your rights are being infringed with, you should contact someone working in a public authority like a social worker, your GP, your council, the Care Quality Commission, or for serious concerns the police. Once they know your rights are at risk, they will have a duty to act and take steps to protect your rights. This is sometimes called a **'positive obligation'**.



More information on this is available in our booklet 'Mental Health, Mental Capacity: My Human Rights' on page 10.

Step 4

Does the decision put your right to life at risk?

If your life is at immediate risk you should contact the police by telephoning 999. If a decision about your care or treatment has been made by a public official which puts your right to life at risk, this could potentially violate your right to life under Article 2 in the HRA. You should raise this straight away. If your right to life is at risk from another person, like a member of your family or a patient, it is important that you let a public official know about this as soon as possible. They can then take steps to try and protect your right to life.



See our booklet 'Mental Health, Mental Capacity: My Human Rights' page 13 for more information.

Step 5

Is your right to be free from inhuman and degrading treatment at risk?

This is an 'absolute' right, which means public officials cannot restrict it under any circumstances. This right protects against very serious abuse and neglect. You will need to show there has been a very serious impact on you for this to be 'inhuman or degrading' treatment.



See our booklet 'Mental Health, Mental Capacity: My Human Rights' page 15 for more information.

It is important to remember that most of the other rights in the HRA are non-absolute and can be restricted in certain circumstances.

Step 6**Is your right to liberty involved?**

Detention under the Mental Health Act will restrict your right to liberty. This will not be an unlawful deprivation of liberty if it meets the safeguards and requirements of Article 5 in the HRA (see the mini-checklist in the flowchart). If these safeguards have not been followed the detention may not be human rights compliant.

If you have mental capacity issues and you are told that you are not allowed to leave a place like a care home or hospital, or are physically prevented from leaving, this may be a restriction of your right to liberty. If so, the safeguards under Article 5 (see the mini-checklist in the flowchart) will have to be followed and the public official will need to obtain a 'Deprivation of Liberty Authorisation'. Otherwise the deprivation of your liberty may not be human rights compliant.



See our booklet 'Mental Health, Mental Capacity: My Human Rights' page 19 for more information.

Step 7**Is your right to respect for private or family life, home or correspondence being restricted?**

If so, a careful balancing act must be applied by the public official to make sure any restriction of this right is **lawful, legitimate and proportionate**. These three criteria have a specific meaning. **It is important you read** our booklet 'Mental Health, Mental Capacity: My Human Rights' pages 22-27.

There are other rights in the HRA which can also be restricted and where the same balancing act needs to be carried out (right to free expression, to protest and to freedom of thought, conscience and religion).

Decision is LIKELY to be rights respecting

If you have followed the flowchart and the decision seems not to restrict your rights in the Human Rights Act, you can still think about:

- if any of your other rights are involved (see back page), such as your right to freedom of thought, conscience or religion.
- has the decision/action of the public official discriminated against you (which is protected by Article 14 in the Human Rights Act and the Equality Act)?
- if you are not sure, it may be necessary to get some advice or support (see page 33).
- things may change and you may need to use the flowchart again in future.

Top tips for identifying a human rights issue

The stronger your claim is from a human rights point of view, and the stronger your arguments are, the better. It is worth remembering that a weak claim, or one that is not sound from a human rights point of view, can sometimes be counter-productive. Preparing the ground is important!

- ✓ Think about and record the **impact** of a decision/policy/treatment on you.
- ✓ Do you need to ask for more **information** from the public official (e.g. about how they made their decision)?
- ✓ Try to think about what the public official will say to your human rights points by thinking about and weighing up the choices they have had to make. This will help you prepare. For example, can you think of an **alternative** response to suggest?
- ✓ Be clear about what you want to **achieve** (e.g. are you trying to reverse a decision or are you only asking for a policy to be applied flexibly to you?)
- ✓ Remember any process of negotiation may involve a bit of compromise, think about the **minimum** you believe needs to be changed and what it would take to achieve that.
- ✓ Using human rights language **does not have to be confrontational**, in fact it can help frame discussions in a constructive way. For example thinking about what a proportionate response would be can help you think of an alternative to suggest to the public official. This approach can avoid putting the public official on the back foot and can help create a spirit of cooperation and help find solutions.
- ✓ Whether you are having an informal chat or a formal meeting, **practice** your human rights points to help you talk about the issues as confidently as possible.
- ✓ Remember **if the situation is urgent** or your right to life or to be free from inhuman or degrading treatment are at risk, **raise the issue immediately** and you may need to get help or support or legal advice

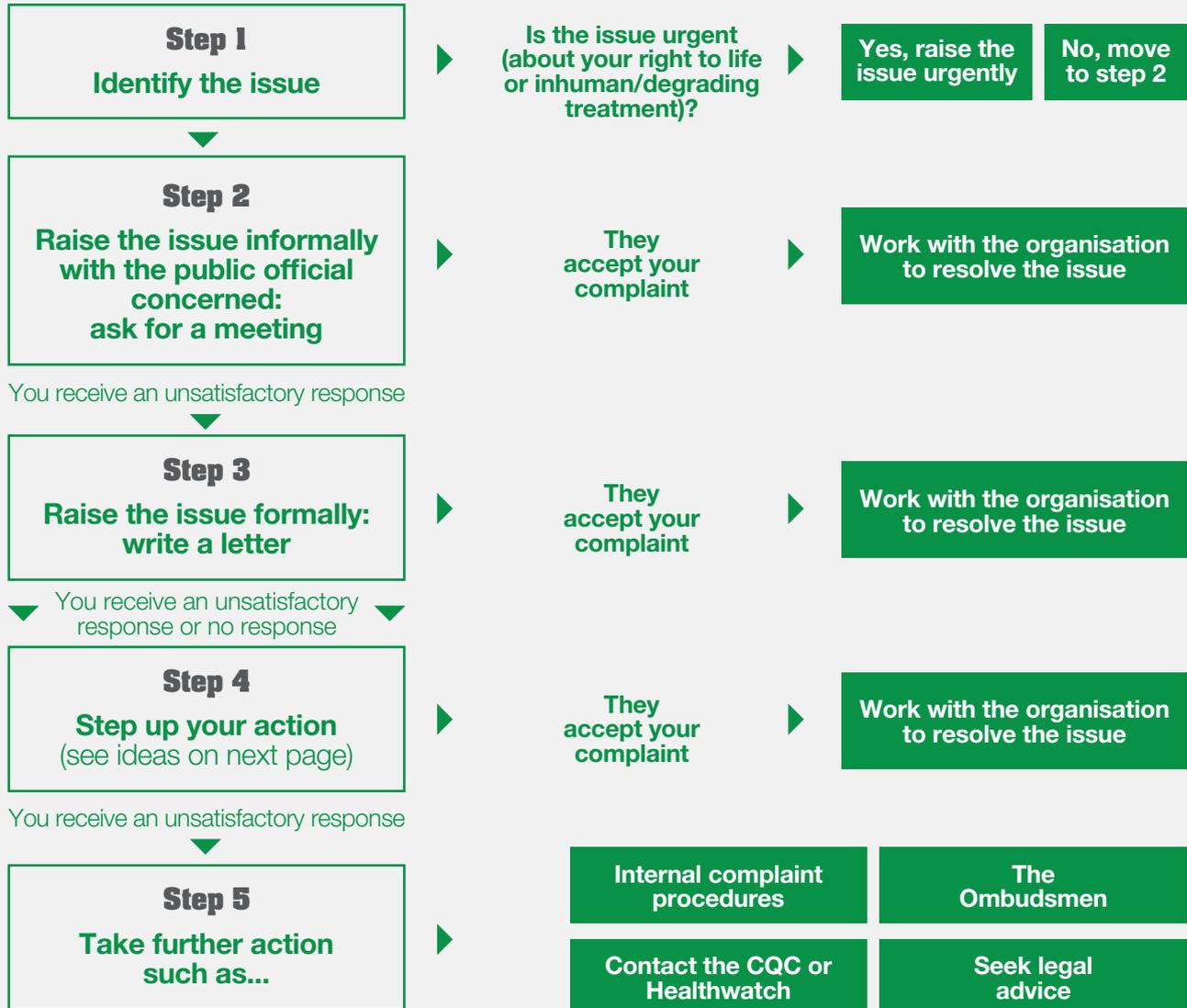


Where can I get more information and support? on page 33

Using human rights: Flowchart for action

This flowchart gives you information and tips about how to take action and raise human rights concerns.

Flowchart



Explaining the steps in the flowchart for action

Step 1

Identify the issue

This is what the first flowchart on page 6 and 7 helps you to do.

If the issue is urgent and there is a risk to your right to life, call the police immediately on 999. See the 'Where can I get more information or support' section on page 33.

Step 2

Raise the issue informally

It can be useful to raise the problem with the public official you believe has interfered with your rights. You could arrange a meeting with them or with their managers.

If your issue is urgent (for example about your right to life or inhuman/degrading treatment) you may want to ask for an urgent meeting.

Step 3

Raise the issue formally: write a letter

If you cannot resolve the matter informally, you may want to consider writing a letter of complaint. The service provider should give you a written reply setting out their response to your concerns.

No response? Depending on the severity and urgency of your issue, you can follow up with a phone call to check your letter has been received. If it hasn't, re-send the letter and ask to be told when they've received it, making a firm request for a response by a certain date. You could send it by registered post or deliver it by hand.

If the letter has been received but the official is vague about when you can expect a response, or does not appear to take the issue seriously, you can resend a copy to the management (e.g. the chief executive or head of the service) with details of your previous letter and the lack of response. You could send a letter to the original person telling them you have written to the managers.

If your issue is urgent (for example about your right to life or inhuman/degrading treatment) you may want to skip this step and move straight to step 4.

Explaining the steps in the flowchart for action

Step 4 Step up your action

There are a number of different ways that you could step up your action, including:

✔ Strengthening the human rights arguments in a follow-up letter.

For example:

- How strongly did you make your case before?
- Did you outline the rights?
- Did you explain the service has a legal duty to protect your rights?
- Are there any positive obligations you could make clear?
- Are there more proportionate responses that could be put in place?
- Did you specifically refer to the rights and duties in the Human Rights Act?

✔ Asking for an immediate meeting to discuss the response

✔ Warning that you may have to take more serious action if the issue is not resolved.

✔ Writing directly to the next level management as in step 3.

If you have received a response which you do not agree with, you could **request an explanation of the public official's decision**. Any follow-up letter or meeting should also ask the public official to explain how they came to the decision which has led to your concern.

By asking the public official to do this, they may reconsider the issue in light of the law and this can lead to a more satisfactory response. It is also useful to have their full reasoning before taking further action, as it makes it easier to think about how best to challenge the decision.

If your issue is urgent (for example about your right to life or inhuman/degrading treatment) you may want to take some of this action urgently, such as asking for an urgent meeting with management.

Step 5 Take further action such as...

There are a number of ways that you can follow up a failure at Step 4, either on your own or with the support of your advocate or someone else.

1. Internal complaints procedure

Most public authorities will have an internal complaints procedure. You can usually find these on the authority's website or you can ask the staff for information about the complaints procedure.

Since 2009 there has been a single complaints system for all health and adult social services in England. The system covers complaints against local authorities, NHS hospitals, and independent providers. These are known as "responsible bodies". Your advocate also has a right to make a complaint on your behalf. There are two stages to the complaints system; the first step is called 'local resolution'.

Key things to know about the 'local resolution' complaints process:

- A complaint must be made within 12 months (unless there are good reasons for delay).
- It can be made verbally, in writing, or electronically.
- The responsible body must acknowledge receiving the complaint within 3 working days.
- The responsible body must offer to discuss with you how the complaint is to be handled, and how long it will take to investigate and provide a response.
- The responsible body must investigate the complaint as quickly and efficiently as possible and keep you informed of progress.

- Once the investigation is complete they must send you a written response, telling you how the complaint has been considered, what they decided and why and any action they have or are going to take.
- If the responsible body fails to send you a response within 6 months of making the complaint, they must explain why and respond to you as soon as possible.

If the internal complaints procedure does not resolve your issue, or you are not satisfied with the response you receive, you may ask one of the Ombudsmen to investigate.

Explaining the steps in the flowchart for action

Step 5 Take further action such as...

2. Ombudsmen

The **Health Service Ombudsman** can investigate complaints about health services. The **Local Government Ombudsman** can look at social care. If your complaint raises issues in both areas the Ombudsmen can jointly review the case.

The Ombudsman is independent of the NHS, local authorities and Government. The Ombudsman does not have a duty to investigate every complaint referred to them. Usually they will not take on a case until after the local resolution complaints procedure (explained on page 15).

Key things to know about making a complaint to the Ombudsmen:

- The Ombudsman will not investigate a complaint if the issue is also part of a legal case.
- A complaint must be made within 12 months of the date of the relevant events (unless there are special reasons for the delay).
- The Ombudsman can investigate complaints about an organisation when they have not acted properly or fairly, or have provided a poor service.
- The Ombudsman can request an organisation to provide an explanation and acknowledgment of what went wrong, and take action to put the matter right, including giving an apology.
- Where the Ombudsman finds serious faults with the organisation they can also make recommendations to the organisation to ensure changes are made.
- The Ombudsman does not have any formal power to enforce their recommendations but they are almost always followed.

Step 5 Take further action such as...

3. Contact the CQC

The **Care Quality Commission (CQC)** is the independent regulator responsible for making sure health and social care services in England meet national standards of quality and safety, this includes human rights. The CQC also monitors the use of the Mental Health Act and has duties to protect the interests of people who have had their rights restricted under the Act.

The CQC can investigate complaints from, or about, people who:

- are, or have been detained in hospital,
- are subject to Community Treatment Orders or
- subject to guardianship.

Anyone can make a complaint to the CQC about how the Mental Health Act is being used including staff, patients and the public.

Contact Healthwatch

Healthwatch England is an independent consumer body that acts as the ‘patient voice’ within health and social care. You can raise your concerns with your Local Healthwatch.

They have the power to ‘submit views’ (in the form of reports and recommendations) to an organisation they believe is handling complaints poorly, and the organisation is legally required to consider these views.

Local Healthwatch also have the power to ‘enter and view’ health and social care services. Following this Healthwatch England can recommend that the CQC takes action, if appropriate.

Explaining the steps in the flowchart for action

Step 5 Take further action such as...

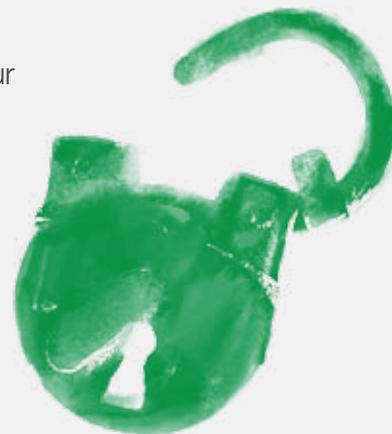
4. Seeking legal advice

Many cases may be resolved without needing to go to court, by taking the actions outlined in the previous steps of the flowchart. But sometimes a court case will be the only way to get your issue addressed. If you think this may be the only solution, you should seek legal advice as soon as possible.

Going to court and/or seeking legal advice and representation from a solicitor usually costs money. You can contact the Legal Aid Agency for more information about getting help with legal advice and representation.

Other avenues of support to help with legal advice and proceedings include Trade Unions, University Law Clinics, and Pro Bono Law Centres, your local Law Centre or Citizen's Advice Bureau.

Remember, taking a case to court is usually a last resort. It is often much easier, quicker, and cheaper to try and resolve issues before they end up in court.



Points to remember if you are considering taking a legal case:

- You have **12 months** from the date of the alleged violation to bring a legal challenge. This time limit applies to a “stand alone” human rights claim. If you are also using another bit of law to take action – like the Equality Act – other time limits will apply. Speak to your legal advisor about this.
- If you are already involved in legal proceedings against a service provider, such as a negligence case, you can add human rights to this, provided it is within 12 months of the alleged violation of human rights.
- You can also take a human rights claim as part of a special type of legal case called a **judicial review**. This is a way of challenging decisions made by public authorities because they are unlawful, irrational, unfair or disproportionate. Judicial review claims must be brought as soon as possible, and usually no later than **3 months** after the decision you want to challenge (there may be shorter time limits for some issues, speak to your legal advisor about this).

What the courts can do if you take a human rights case:

- The Human Rights Act says that a person whose human rights are violated must be provided with a **remedy** that is necessary, just and appropriate.
- The remedies the court can provide include making a declaration that the policy or decision breaches human rights, making an order to stop something or to make something happen, and awarding financial damages.
- If you are worried about how a part of law, such as the Mental Health Act or Mental Capacity Act, is affecting your human rights, you can ask the higher courts to look at this. **They can decide if there is an unlawful restriction and whether that part of the law needs to be changed.** If so they will issue what is called a ‘Declaration of Incompatibility’. It is then down to the Government to decide whether to suggest a new law, before asking Parliament to pass the new law or not. There are lots of examples of how the Mental Health Act has been updated to remove or change parts that are incompatible with people’s rights. For example, when there are concerns about who the law says should be a patient’s ‘nearest relative’, the patient can raise this and staff can select a different person.

The flowcharts in practice: a worked though example

MENTAL health EXAMPLE

This section takes ‘Siobhan’s story’ and shows how you can work through the steps in the flowcharts, finishing an example of the kind of letter you could send to try and resolve the situation.

Siobhan is 21 and has been detained in hospital under the Mental Health Act and is receiving treatment. She has recently self-harmed and has attempted suicide in the past. Siobhan is currently under 24 hour observation. She is very distressed after being told by staff that she can’t close the door to her room, or use the bathroom on her own.

This has caused conflict with staff on the ward. Lisa, a nurse on the ward, feels under particular pressure, because management are very happy with the policy. They believe the observation must continue in order to keep Siobhan safe. However, Siobhan has become very angry with Lisa on several occasions and Lisa sometimes feels worried about her own safety.

Clare, Siobhan’s psychiatrist, has assessed her on a number of occasions. She believes Siobhan will attempt to harm herself again and, if she feels she has the opportunity, may attempt suicide. She is also concerned, however, that the constant observation is causing Siobhan considerable distress and may harm Siobhan’s recovery.

Siobhan has told her advocate, Ben, that she feels the staff are invading her privacy and this is making her feel more unwell. She feels the staff are monitoring her as a form of punishment and has not been told how long the 24 hour observation will continue. Ben would like to talk through the issue with Siobhan and the staff. However he is finding it difficult to engage with hospital staff. All Ben hears from the staff is that not allowing Siobhan any privacy is for ‘her own safety’.

Working through the flowchart: identifying a human rights issue

Step 1: What is the decision?

To keep Siobhan under 24 hour observation due to a history of self-harm and a current high risk of attempting suicide. This includes the requirement to ensure that Siobhan is never out of sight when occupying her own room or going to the bathroom so the doors must be kept open.

Step 2: Who is affected?

Siobhan will be directly affected by having little or no privacy. Think about the impact this will have:

- What is the impact on Siobhan, considering also her age and mental health issue? What effect has it had on her health, emotional well-being and relationships with other patients/staff on the ward?
- How are the staff treating Siobhan, are they sympathetic to her needs/concern?
- Are any other patients affected? Can other patients see into

Siobhan's room or the bathroom when she is using it? Is 24 hour observation putting additional pressure on staff time?

Step 3: Who made the decision?

The mental health hospital, which is detaining Siobhan under the Mental Health Act. If the hospital is local authority/NHS/social services run, it will have duties under the Human Rights Act to uphold her rights. If the hospital is run by a private company, charity or other type of body, they will also have duties under the Human Rights Act to uphold her rights if the care is arranged or paid for (in any part) by the local authority.

Step 4: Does the decision put Siobhan's right to life at risk?

No. Siobhan is at high risk of attempting suicide, so her right to life is potentially at risk from her own actions. The hospital staff have placed Siobhan under

24 hour observation and are restricting her right to private life in order to protect her right to life. The hospital's duty to Siobhan includes an obligation to take steps to ensure this right is protected.

Step 5: Is the right to be free from inhuman and degrading treatment at risk?

The interference with Siobhan's private life is unlikely to be severe enough to be considered inhuman or degrading treatment, which has a very high threshold. The decision has been taken by the hospital due to concerns about self-harm, which protects her right to be free from inhuman and degrading treatment. The hospital's duty to Siobhan includes an obligation take steps to ensure this right is protected.

Steps 6: Is the right to liberty involved?

Yes, Siobhan has been detained under the Mental Health Act. The hospital has to show that her detention is justified because Siobhan has a specific and recognised mental disorder and it is necessary for her health or safety. As Siobhan is at risk of self-harm and suicide, her detention may be justified but to be lawful it would need to comply with the safeguards set out in the right to liberty, including the checklist in Step 6 of the flowchart. For more information on this, see our booklet 'Mental Health, Mental Capacity: My Human Rights' page 19.

Step 7: Is the decision interfering with Siobhan's right to respect for private and family life, home or correspondence?

Yes, placing Siobhan under 24 hour observation is interfering with her right to respect for private life. Siobhan has no private space whatsoever and she is unable to perform intimate personal care tasks such as using the toilet without being observed. This may be a cause of anxiety and humiliation impacting on Siobhan's well-

being and impeding her recovery. This interference with her private life must be justified as:

- **Lawful** – is there a law which allows the hospital to restrict Siobhan's private life? Yes, the Mental Health Act allows the hospital to keep Siobhan in a restrictive environment for her safety (provided the requirements for detaining her have been met).
- **Legitimate** – what is the legitimate aim the hospital is trying to achieve? It is trying to ensure Siobhan is safe and not able to self-harm or take her own life. They also have to consider the rights of others, including other patients and staff if Siobhan is being violent or threatening to harm others (such as the ward nurse, Lisa).
- **Necessary** – is the way the hospital is going about achieving that aim **proportionate**? In other words, is it the only way to achieve that aim, or are there other options open to the hospital which would respect Siobhan's rights more?

Think/ask about:

- ✓ Have staff considered Siobhan's rights and/or the other patients' rights?
- ✓ Do they need to restrict Siobhan's right to private life in order to protect her other rights?
- ✓ Is the risk of self-harm or suicide high enough to justify 24 hour observation?
- ✓ How long is this level of supervision likely to be required?
- ✓ Is it necessary to require that all doors be kept open at all times, including Siobhan's own room and her bathroom?
- ✓ Have they considered other options open to them which are less restrictive of those rights? Have they come up with the best solution?

Working through the Flowchart for Action

Step 1: Identify the issue

This is what we've done on pages 21-22 by working through first flowchart.

Step 2: Raise the issue informally

Using the information you have identified through the steps above, you can now consider raising the issue informally with the public official concerned. Siobhan could ask for meeting with Lisa and Clare to raise her concerns, with the support of Ben if necessary, and asking them when the 24 hour observation will end and if they have considered other options more respectful of her right to privacy.

Step 3: Raise the issue formally

If meeting with Lisa and Clare doesn't resolve the issue, Siobhan could step up her action and write to the ward or hospital manager to raise it formally. A sample letter is on the following page.



Ward manager
Sunnyside Hospital
Cherry Tree Lane
Newtown, NI 1AA

01 February 2017

Dear Mrs Smith,

I am a patient at your hospital and am detained under the Mental Health Act. I am being kept under 24 hour observation. I am unable to close the door of my room and I cannot use the bathroom alone. I am becoming increasingly distressed by this decision, since I feel like my privacy has being interfered with and it is making me feel more unwell.

As an NHS hospital, you have a legal duty under the Human Rights Act (HRA) to respect and protect my rights. I believe that constantly monitoring me and refusing to allow me to use the toilet alone amounts to an interference with my right to respect for private life protected by Article 8. My psychiatrist, Clare, agrees that the constant observation is causing me considerable distress and may detrimentally impact my recovery.

Although I appreciate your commitment to maintaining my safety, the HRA requires you to make sure any interference with my private life is proportionate. Perhaps the hospital could consider a less invasive way of monitoring me? Have you considered other options such as allowing me to use the bathroom with the door closed whilst a staff member remains outside? I have also not been told how long this supervision will continue for, which I find distressing as I feel like I am being punished for something. I do not feel staff have properly spoken to me about the decision as they are happy to continue with the supervision as it is.

I would like you to respond to my letter within the next two weeks as I would like to resolve this matter as soon as possible. If we are not able to find a solution, I would like information about how to make a formal complaint.

Yours sincerely

Siobhan



In real life: right to privacy

Siobhan's story is based on a real life example

The real 'Siobhan' (we changed her name) was very distressed by the 24 hour observation by the mental health hospital. Siobhan's advocate explained to her that the hospital had a positive obligation to protect her right to life, because of the risks she presented to herself, and this is why they were restricting her privacy, but the restriction still needed to be proportionate. Siobhan (supported by her advocate) asked for a meeting with the treatment team. She explained the distress the 24 hour observation was causing her. She asked the team to explain why she was under observation, how long it would last and if there were any changes that could be considered.

The team agreed Siobhan could close the bathroom door to give her more privacy if staff could make sure she had no objects to harm herself with, and they could wait outside. This was a way of protecting her right to life while being less restrictive of her right to private life, and one which Siobhan was happy with. After being given a chance to express herself, Siobhan felt much more comfortable with the observation process. She told her advocate that she realised it was not a form of punishment but designed to protect her human rights.

This is an example from BIHR's publication called
'The Human Rights Act: Changing Lives'.

The flowcharts in practice: a worked though example

MENTAL capacity EXAMPLE

This section takes ‘Liam and Pamela’s’ story and shows how you can work through the steps in the flowcharts, finishing with an example of the kind of letter you could send to try and resolve the situation.

Liam, 28, and Pamela, 35, are residents in a home for learning disabled adults run by the local authority. Pamela is new to the home and she forms a close friendship with Liam within two months of moving in.

Staff are concerned by the influence Pamela has on Liam. They believe that she encourages him to make unwise financial decisions. Recently the two did not return from a planned trip to town until very late which staff consider to be completely out of character for Liam.

Staff have banned Liam and Pamela from spending time together unsupervised. A new placement for Pamela is one option being considered if she continues to exert this negative influence on Liam.

Working through the flowchart: identifying a human rights issue

Step 1: What is the issue/ decision?

Staff have made the decision to interfere in the friendship between Liam and Pamela because they do not think it is good for Liam.

Step 2: Who is affected?

Liam and Pamela are affected by the decision. Their freedom to engage in a friendship is being limited and they are threatened with separation.

Think about the impact this will have on Liam and Pamela, this could include:

- Think about their age, personal circumstances and the impact this decision has had on them – has it impacted on their emotional well-being and their friendship?

- How are the staff treating them – are they being patronising or speaking to them in a disrespectful way about their friendship?

Step 3: Who made the decision?

Staff at the residential home have made the decision. Because the local authority runs the home, the staff have a duty under the Human Rights Act to respect and protect the rights of the residents. If the care home was run by a private company, charity or other type of body, they would also have duties under the Human Rights Act to uphold Liam and Pamela's rights if their care was arranged or paid for (in any part) by the local authority.

Step 4: Does the decision put their right to life at risk?

No.

What if the relationship is sexual?

If Liam and Pamela are assessed as having the capacity to decide about consenting to have sex, then it would be unlawful for anybody to interfere with their decisions. **Sexual relationships are a part of the right to private life protected by Article 8 in the HRA.**

If Liam or Pamela are assessed as lacking the capacity to make the decision about consenting to have sex and the care home wants to restrict this relationship, the issue should be referred to the Court of Protection.

In most cases concerning personal welfare matters, best interest decisions can be made by staff on behalf of people who lack capacity. However consent to sex is one of the few exceptions to this rule. The Mental Capacity Act does not allow a person to make a decision on behalf of somebody else about consenting to have sexual relations.

Step 5: Is the right to be free from inhuman and degrading treatment at risk?

The interference with Liam and Pamela's private life is unlikely to be severe enough to be considered inhuman or degrading treatment, which has a very high threshold.

Step 6: Is the right to liberty involved?

No. Although staff have restricted Liam and Pamela from spending time together unsupervised, this is unlikely to be an extreme restriction on their movement so wouldn't fall within the right to liberty. It is more of an issue under the right to respect for private and family life.

Step 7: Is the decision interfering with Liam and Pamela's right to respect for private and family life, home or correspondence?

Yes, the decision will restrict Liam and Pamela's right to respect for private and family life, which covers forming and maintaining private relationships and friendships. This restriction must be justified as:

- **Lawful** – it is lawful for staff at the home to use the Mental Capacity Act to make decisions in the best interests of residents who lack capacity to make those decisions themselves. However, this is only lawful if staff have carried out a mental capacity assessment with Liam to assess his capacity to make an independent decision about whether or not to have unsupervised contact with Pamela. If Liam has capacity to make this decision, he is able to make what others might think of as an unwise decision.

- **Legitimate** – what is the legitimate aim the home is trying to achieve? The staff are trying to protect Liam's well-being and ensure he is not being exploited or harmed by Pamela's influence.
- **Necessary** – is the way the home is going about achieving that aim **proportionate**? In other words, is it the only way to achieve that aim, or are there other options open to the home which would respect Liam and Pamela's rights more?

Think/ask about:

- ✓ **Have staff considered Liam and Pamela's rights?**
- ✓ **Have they taken into account their freedom to make what might be considered unwise decisions?**
- ✓ **Are there other ways to approach this, rather than imposing restrictions on their rights?**

Working through the Flowchart for Action

Step 1: Identify the issue

This is what we've done on pages 27-28 by working through the first flowchart.

Step 2: Raise the issue informally

Using the information you have identified through the steps above, you can now consider raising the issue informally with the public official concerned. Liam and Pamela could ask for meeting with the staff at the home to explain how they think their rights are being restricted.

Step 3: Raise the issue formally

If a meeting with the staff at the home doesn't resolve the issue, Liam and Pamela could write to the manager of the home to raise it formally. A sample letter is opposite:

Manager
Apple Lodge Home
Long Acre Road
Addleton, AD3 5JX

01 February 2017

Dear Mr Thomas,

I am a resident of Apple Lodge Home and my friend, Pamela and I are unhappy with staff's attempt to separate us. We like spending time together and staff are considering moving Pamela to a different supported house. We believe that these actions are restricting our right to respect for private life.

The staff have said that they are concerned by Pamela's influence on me because we do things like not returning home until late. However, as the home is run by a local authority, you and the staff have duties under the Human Rights Act to respect and protect the rights of the residents. We believe that trying to separate us interferes with our right to respect for private and family life, which covers forming and maintaining private relationships and friendships.

We understand that our right to form friendships and relationships can be restricted in certain circumstances if it is lawful, legitimate and necessary. Even if the staff believe that they are acting in my best interests, I don't believe that separating us is the fairest or most proportionate way to achieve this. Staff could allow us to remain in the same home and enable us to spend time together privately.

Yours sincerely

Liam (and Pamela)

Human rights in real life



This section provides some real life examples where people with mental health or mental capacity issues have used the Human Rights Act to challenge poor treatment, with the support of their advocates. The examples show how using human rights language can help change the way services treat you.

These examples are all from BIHR's Care and Support project

Woman in mental health hospital successfully challenges using a bucket as a toilet

Lorraine was detained under the Mental Health Act in hospital. On admission, no bedrooms were available so the hospital turned a meeting room into an extra bedroom. Lorraine was placed in this unfinished room. The room had a window on the door, with no curtain, so staff (and other patients) could see into her room.

Unlike the other bedrooms on the ward, there was no bathroom in the room. Lorraine had continence problems which meant she needed to use the toilet throughout the night. The communal toilet for the ward was locked at night for safety reasons. This meant Lorraine had to call the

night staff to take her to the toilet and wait outside. As night staff were not happy about this, they gave Lorraine a bucket to use as a toilet in her room.

Lorraine was very embarrassed and distressed about the situation, especially as she had to empty and clean the bucket herself (as she was too embarrassed to ask staff to do it). She had to carry the bucket to the communal toilet in view of staff and patients in the corridor.

Lorraine had an advocate, Rajesh, supporting her. Rajesh had received training on human rights from BIHR. With Lorraine's

consent, Rajesh raised this at the ward review with the responsible clinician and the primary nurse, using Lorraine's right to be free from inhuman and degrading treatment (protected by Article 3 in the Human Rights Act). It hadn't occurred to staff that it was a human rights issue, but once Rajesh raised it as such, the staff agreed and immediately acted.

Staff moved Lorraine to another room with a toilet (which had since become free) and didn't use the meeting room as a bedroom again until a toilet had been installed. Rajesh also wrote a letter to the modern matron, to make sure that concerns raised were on record.

Woman uses human rights to receive treatment

Moira was in her 40s and had suffered with severe tinnitus and deafness in one ear for three years. This caused an incessant loud noise in her head which was having a significant impact on her mental health. Moira's consultant thought that she could benefit from a cochlear implant but the Clinical Commissioning Group (CCG) refused to fund it.

Moira and her family were severely depressed by this. Moira had thought of taking her own life but

stopped because of her family. She felt totally hopeless as she had no quality of life. She felt that her life was no longer worth living.

Moira was in touch with Saul, an advocate. Saul had attended human rights training by BIHR. He supported Moira to go back to her GP to explain the impact of the CCG's decision. With some research that showed how someone in a similar situation had benefitted from the implant, Moira used her right to be free

from inhuman and degrading treatment (protected by Article 3 in the Human Rights Act) and told her GP that she thought it would be inhumane to leave her suffering when treatment was available.

The GP called Moira the next day and told her that they had secured funding for her treatment from an alternative source and she was booked in for the implant. Moira felt that she was getting her life back.

Mental health patients successfully challenge ban on their relationship

Christine is detained in a mental health hospital and is in a relationship with another patient, Anthony. Christine asks her doctor, Simone, if she can meet with Anthony inside the hospital. Simone refuses, saying that she thinks the risks are too high as it might be detrimental to their well-being. The hospital's policy is based on risk management and prohibits any sexual activity.

Christine is upset and feels it is detrimental to her well-being not to see Anthony. She has an Independent Mental Health Advocate, Daniel, who had

been trained by BIHR. Daniel speaks to Simone, explaining that the decision is interfering with the couple's right to private and family life (Article 8 in the Human Rights Act). Whilst this right could be restricted by the hospital to protect their well-being, the response still needs to be proportionate. Daniel points out that the decision to refuse all meetings seems disproportionate and that the relationship could improve Christine's well-being. Simone dismisses this and refers back to the hospital's policy.

Daniel meets the Clinical Service Manager to discuss the couple's human rights. As a result the hospital agree to reassess their decision. Balancing the risk to the couple's well-being and their right to private and family life, it is agreed that the couple can meet on the ward. They can have physical contact during the meetings and this could increase over time (working towards joint leave away from the hospital). The hospital also changed its policy on relationships. It now refers to balancing human rights and risk.

Older couple supported to stay at home and family carer gets support



Barbara and Jerry are married and in their late 70s. They both have health issues. Their daughter, Susan, lives elsewhere but provides all of their care.

A Carer Support Worker, Lemar, visits them to conduct a Carers Assessment. Barbara, Jerry and Susan disagree about their care and Susan's strong views are causing conflict with her parents. Lemar is concerned that Susan is speaking on behalf of her parents and making decisions for them. Lemar has attended training on human rights from BIHR and is concerned about Barbara and Jerry's right to autonomy (protected by Article 8 in the Human Rights Act).

Lemar gently asks Susan to step out of the meeting so that he can speak to her parents. Lemar explains to Barbara and Jerry that they have a right to autonomy; to make their own decisions and have their views respected. Jerry's health is deteriorating and he'd like to move into care so he can spend his last days comfortably. Barbara wishes to stay at home but tells Lemar that Susan wants both parents to stay at home so she can care for them. Neither are speaking up for themselves because of a fear of Susan's views, which is causing stress and anxiety.

Lemar speaks to Susan and explains about her parents' right to autonomy. Susan accepts that she needs to hear and respect their views. Susan is struggling to cope as the primary carer and needs some support, so Lemar speaks to Susan about her rights as a carer.

The family and Lemar discuss the situation. Barbara and Jerry decide to trial having paid carers at home, realising they would find it hard to live apart. Lemar refers the couple for an assessment of need by the local authority, and Susan for a Carers Assessment so that they can receive the support they need.

Woman with learning disability removed from inappropriate care home



Gemma is in her late 40s and has a learning disability. She had been living with her mum but after her mum passed away, the local authority paid for Gemma to be placed in a care home. The home was inappropriate for Gemma as it was for older people and didn't provide the support she needed.

The home had a locked door, to prevent people affected by dementia from leaving without the correct support. Gemma

wasn't able to come and go from the home freely as she had done when living with her mum. Gemma was distressed by this but didn't want to raise it directly with the home so she contacted her local Healthwatch.

Healthwatch staff had attended training by BIHR and decided to arrange 'Enter and View' visits to five local care homes, so as not to identify Gemma. They talked to staff and residents about whether

they were able to come and go, which is part of their right to liberty (protected by Article 5 in the Human Rights Act).

The report by local Healthwatch uncovered that Gemma was living in an inappropriate setting. As a result, the local authority now support Gemma to live independently in her own flat where she is much happier.

(Healthwatch Blackburn with Darwen example)



Where can I get more information and support?

If you need some advice or support about challenging a decision involving your human rights, below are some organisations who can help with this, and contact details for the bodies mentioned in this workbook:

Liberty

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

www.yourrights.org.uk

Phone: 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.

Citizens Advice

Provide advice in person, over the phone and by web chat.

www.citizensadvice.org.uk

Find your local Citizens
Advice: 03444 111 444
Text phone: 03444 111 445

Advice UK

This is not an advice giving organisation but has a directory of advice services. Find a service on their website.

www.adviceuk.org.uk

Local Healthwatch

Find your Local Healthwatch through Healthwatch England

[www.healthwatch.co.uk/
find-local-healthwatch](http://www.healthwatch.co.uk/find-local-healthwatch)

Phone: 03000 683 000
Monday to Friday, 8:30 a.m. to 5:30 p.m.

Care Quality Commission

If you have a concern about care, in the first instance you should report it to the NHS Trust or local authority. However you can also share your experience with the Care Quality Commission.

www.cqc.org.uk

Phone: 03000 61 61 61

Monday to Friday, 9:00 a.m. to 5 p.m.

Health Ombudsman

If you do not hear anything following a complaint to the individual NHS organisation or Healthwatch, you can take your complaint to the Health Ombudsman. The Ombudsman's website also has the option of BSL sign video live.

www.ombudsman.org.uk

Phone: 0345 015 4033

Monday to Friday, 8:30 a.m. to 5:30 p.m.

Local Government Ombudsman

The Local Government Ombudsman can investigate complaints about local authorities, including complaints involving adult social care, provided you complain to the council involved first. Complain by phone or online.

www.lgo.org.uk

Phone: 0300 061 0614

Monday to Friday, 8:30 a.m. to 5:00 p.m.

Legal Aid Agency

Some people who are challenging decisions involving their human rights may qualify for legal aid. The Legal Aid Agency may be able to tell you if you qualify.

www.gov.uk/government/organisations/legal-aid-agency

Email:

contactcivil@legalaid.gsi.gov.uk

Civil general enquiries:
0300 200 2020

Crime general enquiries:
01158 526 000

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

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 over 1000 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.

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
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)