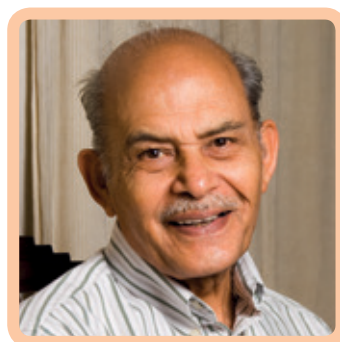
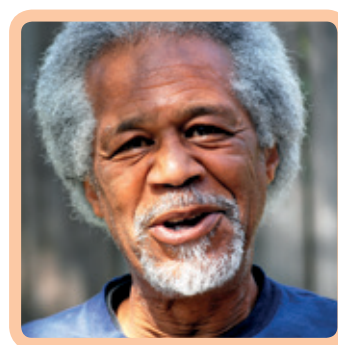


Our Dementia, Our Rights



A brief guide co-produced by The Dementia Policy Think Tank
(member group of DEEP) & Innovations in Dementia CIC

Authored by Philly Hare (Winter 2016)



This booklet is dedicated to Peter Ashley, who lived with dementia for 15 years until his death in 2015. He was one of the UK's first campaigners for the rights of people with dementia.



Innovations in Dementia (iD) is a community interest company. We work nationally with people with dementia, partner organisations and professionals with the aim of developing and testing projects that will enhance the lives of people with dementia.

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The guide has been authored by Philly Hare on behalf of the Dementia Policy Think Tank. This group was set up in 2016 by a number of people with a diagnosis of dementia who have a particular interest in promoting rights and influencing policy issues. The group is a member of the UK wide DEEP network¹, which is facilitated by Innovations in Dementia².

The following have all contributed their time and extensive expertise, providing incisive and constructive comments on the various versions of this guide.

Members of the Dementia Policy Think Tank



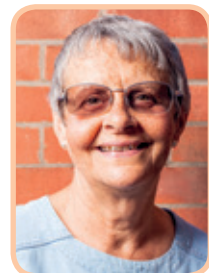
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1 <http://dementiavoices.org.uk/>

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Accessible summary

Living with dementia is a challenge, and you may well need support.

But getting the services and help you need is not always easy.

This booklet explains why it can be helpful to know—and talk about—your rights.

Rights can help us to uphold shared values in challenging circumstances.

The language of rights can help you feel more confident and empowered.

Although rights and laws are about everyday life, they can feel complicated.

However, there are services, helplines and advocates who can help you to ask for what you need, and to challenge decisions when they seem to ignore your rights.

The more we talk about and use the rights of people with dementia, the more our services, culture and attitudes will change for the better.

Case Study: Margaret's care home

Derek and his wife Margaret have been married for over 60 years. Margaret was diagnosed with Alzheimer's disease several years ago and they were coping well at home. Over the last few months though Derek and Margaret are beginning to really struggle, their social worker suggests that it may now be the time for Margaret to move into a care home. Derek reluctantly agrees as he knows that he cannot provide her with the care that she needs.

The care home will be funded by the local authority. There is a care home in the small village that they live in and Derek asks if she can move there, but he is told it is too expensive. Instead he is informed that they will only fund a care home that is nearly 30 miles away from their home.

Due to his health Derek can no longer drive. They live in a very rural place and so there are hardly any buses and he would need to take 2 buses and walk for over a mile to see his wife and his own mobility is bad. Derek is very concerned that he will not be able to see his wife much and wonders what he can do.

Following some advice, the couple speak to the local authority and ask them to reconsider the decision. In the conversation Derek mentions that under the Care Act people are meant to have more control and choice over their lives and their care and support – this is under the 'well-being' principle. He feels that this should mean that he and his wife have a choice over the care home that Margaret is placed in. He also mentions to the local authority that he and his wife have a right under the Human Rights Act to family life (Article 8) and moving her so far away that they cannot see each other is violating this right.

The outcome in this case was that the local authority provided Derek and Margaret with a list of care homes in the area that they would fund. There was a care home only a few villages away that would only require one short bus journey. Derek and Margaret asked for this home instead and she moved there.



1 Introduction

Many people with dementia have experienced significant discrimination in their day to day lives. But over the past few years there has been a lot more talk about the rights of people with dementia. This is largely driven by people with dementia themselves.

2016 has been called “*a watershed moment for people with dementia across the world.*”³ In this year, Alzheimer’s Disease International (ADI) committed its 83 national Alzheimer Associations to a human rights-based policy. This followed strong representation from Dementia Alliance International (DAI), a worldwide, non-profit, association of people with dementia at all ages.

But there is still confusion and ignorance about what these rights actually are.

The purpose of this accessible guide is to bring together in one place the facts about some of the key rights relating to dementia in the UK.

In doing this we hope to empower people with dementia, their carers and their advocates to use their rights.

It is not easy to simplify complex laws and rights We are aware that the information might feel overwhelming. Do read it slowly and in short chunks if that helps.

If you prefer a **very short, easy-read guide to human rights**, the Equality and Human Rights Commission (EHRC) has produced ‘*The United Nations Convention on the Rights of People with Disabilities What does it mean for you?*’⁴. (There is also a fuller version).

³ Dementia Alliance International. 2016. The Human Rights of People Living with Dementia: from Rhetoric to Reality

⁴ <http://bit.ly/29WvgxA>



The British Institute of Human Rights (BIHR) also has an accessible guide ‘*Mental Health, Mental Capacity: My human rights*’⁵.

Our guide should be useful for:

- People with dementia
- Carers, family members, supporters and advocates
- Organisations, volunteers and professionals concerned with rights issues relating to dementia, ageing, disability and carers
- Service providers and commissioners

So if you are any of these, read on – and we hope to give you a better understanding of what rights you have and why they matter.

Disclaimer: *This guide contains general legal information, not legal advice. The information is not advice, and should not be treated as such.*

We recommend you get advice from a specialist legal adviser who will help you with your individual situation and needs (see Section 11).

⁵ <http://bit.ly/2bGssq8>

2 Why do rights matter?

Why people with dementia can miss out

People with dementia can be affected not only by the symptoms and impairments caused by the condition, but by many other things, including:

- The stigma associated with the condition
- Lack of knowledge among professionals, staff and other people they have contact with
- Services cutting corners to save money
- Lack of training and poor leadership in services
- Their own lack of ability to challenge and report their concerns. This may be due to cognitive or impairment issues, lack of energy or lack of confidence or knowledge of what to do

Paternalistic attitudes and services also play a huge part in discrimination. As a result, people with dementia are often rendered passive.

In practical terms, this can all translate into losing out on the help and support which can enable them to participate in social and community life—a right which is protected in the UN Convention on the Rights of Persons with Disabilities (Art.19).

Discrimination

Many people with dementia – and their families – say they find it hard to get the services or support they need, or to know their entitlements. They can face **discrimination** and treatment that contravenes their human rights.

People with dementia often face indirect, rather than direct, discrimination and so need to be able to tell the difference. In

equality law, there's an important distinction. **Direct discrimination** means treating someone less favourably because of certain attributes of who they are. **Indirect discrimination** occurs when an organisation's practices, policies or procedures have the effect of disadvantaging people who share certain characteristics.

Here are some examples of likely indirect discrimination that have been experienced by people with dementia:

- Denied a Blue Badge for parking, because dementia alone is not seen as a disability
- Denied a stair lift, because of their dementia
- Denied a personal assistant, because of their dementia
- Denied exemption from the 'Work Capability Assessment' process
- Pressured into leaving work when diagnosed with dementia, without an assessment
- Forced to move into a care home against their wishes (especially when they have been admitted to hospital for other reasons)

People with dementia often feel powerless against such discrimination and unable to insist on getting what they are entitled to by law. At the same time, they may be reluctant to frame their issues in terms of rights, even if they know them.

Finally, people with dementia from specific groups may also face double (or multiple) discrimination, for example:

- Ageism (most people affected by dementia are older, but younger people can also be affected)
- Sexism (this can be careless assumptions about either men or women)
- Discrimination on sexual orientation (e.g. no hospital visiting rights for same sex couples, or involvement in decisions for partners)



Rights and the law

Discrimination is prohibited by law. The Human Rights Act brings human rights into UK law. It acts as a lens for all other legislation, which all needs to be compliant with the Human Rights Act.

Understanding their rights can give people **greater legal protection** and **clarity about entitlement** to services. Human rights laws can be simple tools that can be used to make or challenge everyday decisions – as Helen Wildbore of the British Institute of Human Rights (BIHR) explains in a great blog⁶.

Challenging decisions

Human rights laws enable us to **challenge situations** and give us the power to improve things – as individuals or as members of an influencing group. This has worked well for other groups, such as those with physical disabilities, women and minority ethnic groups. A basic knowledge of rights, and the willingness to gently articulate that knowledge, can make a lot of difference. If we know about the rights to which we are entitled, it is easier for us to speak up and protect ourselves from poor treatment or practice, or to remind public bodies that they have obligations to us.

As Dementia Alliance International (2016) states: *“A right gives you authority to speak for yourself and to join with others whose rights are not respected or abused⁷.”*

Rights can provide a safety net—especially when services are being cut. They are an important tool which can be used to hold public authorities to account and ensure they are being fair.

The British Institute for Human Rights (BIHR) has a new resource for service users and advocates about how to use human rights to negotiate with services: *Mental Health, Mental Capacity: Raising a human rights issue⁸*.

6 <http://bit.ly/2aa9pPj>

7 <http://bit.ly/2a5jjUh>

8 <http://bit.ly/2bGssq8>

Moving towards a rights-based culture

Talking about rights can also support a **positive cultural shift** in the way that dementia is perceived and understood (including by people with dementia themselves). This booklet is not focused on the Human Rights Based Approach (HRBA) – but please see more information on this, if you are interested, in Appendix 2.

Human rights, and the laws that uphold these rights *do matter*, because they help people to get the support they need in the way they want it.

“

People with dementia face widespread discrimination for a number of reasons. There remains a significant misunderstanding and stigma attached to dementia that manifests itself in widespread discriminatory attitudes. Abuses and serious infringement of our human rights have significant impact on our quality of life.

(Tommy Dunne BEM, co-chair Liverpool SURF group.)



”



3 Is dementia a disability?

Many people find it hard to think of their dementia as a disability, and are understandably reluctant to take on another 'label'.

The fact is that dementia is *counted as a disability* if it causes “a physical or mental impairment which has a substantial and long-term adverse effect on your ability to carry out normal day-to-day activities” (Equality Act 2010).

Likewise, Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) states that “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments, which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.”

The word 'disability' is therefore not a stigmatising label imposed upon individuals (as a paper by the Mental Health Foundation explains)⁹. It is just a means to an end, a tool.

Another group—people with mental health difficulties—don't consider themselves as disabled either, but they have made very good use of the UN Convention to claim their rights.

So, even if you don't think of dementia as a disability, the law does define the impairments it may cause in this way—and this can be to your benefit.

⁹ <http://bit.ly/2a8vwrS>



Case Study: Tom's job

Tom has always worked as a car mechanic and for the last 15 years he has been working at a local garage close to his home.

Tom is now 53 and, after noticing some changes, he visits his GP. After various tests he is diagnosed with Alzheimer's disease.

He chooses to inform his employer as he feels that he will support him at work. But his employer doesn't offer him any support as such, and suggests that he takes early retirement. Tom feels that with some support he could stay in work. He tries to stay in work, but over the next few months feels that his work colleagues are stigmatising him. They are starting to act very differently around him and are also suggesting that he shouldn't be there. Although he mentions this to his boss, nothing changes and he feels that he may have to leave, even though he wants to carry on working and knows that he can.

A friend of Tom suggests that the way he is being treated is not right and so he should get some advice. He then speaks to a local advocate, and together they decide to complain to his employer. Within this complaint they mention Tom's rights under the Equality Act. This includes Tom's right to not be discriminated against by his employer, and in the workplace, and his employer's duty to look into this. The complaint also argues that his employer should agree to reasonable adjustments.

Tom's boss suggests that they meet to discuss this and Tom takes his advocate with him. They manage to work a way forward in which Tom will take more, but shorter, breaks. It's also agreed that Tom will drop some of the supervisory elements of his role and concentrate more on the mechanics, which is something he is more confident with. The employer will look at some form of dementia awareness training for the workforce, to enable Tom's colleagues to understand dementia more and for them to know that they cannot discriminate against him.

These changes are put in place and Tom is able to continue working for longer.



4 What are these rights?

People with dementia have the same civil and legal rights as everyone else. The laws around these vary to some extent across England, Scotland, Wales and Northern Ireland (so the relevant countries are highlighted below in blue).

Below is a summary of some of the *key laws and Conventions* that protect the rights of people with dementia. More details about each of the key acts is to be found in Appendix 1.

Human rights and equality

Human rights are universal to all and are based on shared values. Some are absolute, some can be limited or restricted, but none can be taken away completely. All law should be applied through the lens of human rights.

- **The European Convention on Human Rights (ECHR) 1951 (UK)**. Its Articles apply to everyone—including of course people with dementia.
- **The Human Rights Act (HRA) 1998 (UK)**. A framework law which places on public authorities in the UK a duty to respect its rights in everything that they do. It brought 16 of the ECHR rights into UK law, which means that everyone in the UK can bring human rights cases to UK courts under certain circumstances.
- **The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2006 (UK)**. Promotes and protects the rights of the person with a disability (including people with dementia, see Section 3 on page 7).
- **The Equality Act 2010 (England, Wales and Scotland)**. Makes it illegal to discriminate against people on account of their disability, age, ethnicity, sexual orientation and five other ‘protected characteristics’.

- **The Disability Discrimination Act 1995 (Northern Ireland).**
Gives people with disabilities the right to not be discriminated against.

The Equality and Human Rights Commission (and its counterparts in the devolved authorities) are independent of government and prepare reports on the implementation of all national human rights legislation and international treaties. They will play a key role in the reporting on the implementation of CRPD by the UK government in 2017.

Case Study: Raj's stairlift

Raj is 78 and lives at home with his wife Fatima. He has recently had a stroke leading to vascular dementia, and the stroke also affected his mobility. Following a short stay in hospital Raj returns home, his wife and family are now providing him with more support. Due to the decline in his mobility he is increasingly finding it difficult to use the stairs, and at times his 2 sons and wife have to help him to get up and down them. They ask the local authority for a stair lift.

The local authority state that they do not provide stair lifts to people with dementia, and so will not come out and assess Raj. They instead suggest that the family convert part of the downstairs into a bedroom for Raj, and offer a commode and an adapted bed for Raj. The family's home is open plan and so this would mean that Raj would be sleeping, eating, going to the toilet and dressing in the current living/dining room.

The family are not happy with this response and following some advice decide to put in a complaint. Within the complaint they mention that they feel the policy stating that someone with dementia cannot have a stair lift is discriminatory and against the Equality Act. They also state that they believe this is an infringement of Raj's right to a private and family life under Article 8 of the Human Rights Act.

The local authority then looked into the family's complaint and agreed to come out and assess Raj for a stair lift.



Mental capacity

- **The Mental Capacity Act (MCA) 2005 (England and Wales)**. Supports the rights of people who are cognitively impaired to make decisions for themselves wherever possible. Within the MCA, the **Deprivation of Liberty Safeguards (DOLS) 2009** are in place for people who lack capacity to make decisions about their care or treatment, and who are deprived of their liberty to protect them from harm.
- **Adults with Incapacity (Scotland) Act 2000**. The Act states that when a person cannot make a decision, another person can have powers conferred on them to make relevant decisions for that person. This helps uphold the rights that people with dementia have.
- **Mental Health (Care and Treatment) (Scotland) Act 2003**. This wide ranging Act contains rights-based principles that professionals must apply in carrying out the functions of the Act.
- **The Mental Health Act 1983** is the law in **England and Wales**. In **Northern Ireland** the **Mental Capacity Act 2016** brings mental capacity and mental health together.

Care

- **The Care Act 2014 (England only)**. Promotes individual wellbeing in regard to personal dignity, protection from abuse, control by the individual over their day-to-day life, physical health, mental health and emotional wellbeing, and the individual's contribution to society.
- **Social Services and Well-being (Wales) Act 2014**. Any authorities exercising duties in relation to adults must act to promote their well-being.
- **Social Work (Scotland) Act 1968**. Established an overall duty to promote social welfare by providing advice, guidance and assistance. In pursuing this, local authorities can provide a variety of services to people in need (including people who

have care needs as a consequence of disability or mental health of increasing age).

These are the key laws which can help you to ensure your rights and be protected from discrimination. *All* laws must be compliant with the Human Rights Act.

More detail about each is to be found in Appendix 1.

“

Where, after all, do human rights begin? In small places, close to home – so close and so small that they cannot be seen on any map of the world. Yet they are the world of the individual person.

(Eleanor Roosevelt, 1958)

”



5 Understanding and communicating

It won't be easy for you to get the help to which you are entitled if you don't understand the information that service providers give you, or if you cannot communicate your needs or wishes.

All organisations that provide NHS or publicly funded adult social care must conform to the **Accessible Information Standard (England only, though the expectation is there in Scotland and Wales)**. This includes NHS Trusts and Foundation Trusts, GP practices and local councils. The NHS has produced a short accessible overview to the Standard¹⁰.

This Standard tells organisations how they should ensure that people **with all types of disabilities** (and that includes people with dementia) receive information in formats that they can understand and that they receive appropriate support to help them to communicate. This includes:

- Asking people if they have any information or communication needs, and finding out how to meet their needs.
- Recording those needs in a set way.
- Highlighting a person's file, so it is clear that they have information or communication needs, and clearly explaining how those needs should be met.
- Sharing information about a person's needs with other NHS and adult social care providers, when they have consent or permission to do so.
- Making sure that people get information in an accessible way and communication support if they need it (for example, in print using Readability measures, or by email or letter rather than by phone).

¹⁰ <http://bit.ly/2c1FCv3>

Understanding information and communicating your needs is vital if you are to make decisions and plan ahead, as discussed in the next section.

This is also very important for people who may lack mental capacity – the second principle of the Mental Capacity Act (MCA) says people must be given appropriate support and information to make decisions.

If you can't understand the information provided by a health or care organisation, or if you have specific communication needs, you can cite the Accessible Information Standard, and ask them to make improvements.

“

The voices of people living with dementia and those who care for them need to be heard in a meaningful way.

”

(Rosa Cornfeld Matte 2015. The first independent expert on enjoyment of all human rights by older people for the UN Human Rights Council)



6 Decision making and planning ahead

Dementia is a progressive condition which brings with it the need to adapt to new challenges and to think about the future. An understanding of your rights is very important in planning ahead.

Your affairs

Mental capacity law states that people have the **right to make decisions** for themselves wherever possible. If you do not have the mental capacity to make decisions for yourself, it outlines what you can do to plan ahead, how you can ask someone else to make decisions for you, and who can make decisions for you if you have not planned ahead.

One of the things you may want to think about is who takes care of your financial and/or personal affairs, such as health or social care decisions, if and when you no longer can. While you have capacity, you have the right to appoint **an attorney**, to make these decisions for you for a time when you have lost capacity.

Treatment

Article 8 of the Human Rights Act protects people's autonomy and right to participate in decisions about their care/treatment. You may also have views about treatments that you would not wish to have in the future. **In England and Wales, you can make an advance decision to record these which is legally binding for refusals of treatment: in Northern Ireland this is covered under an advance directive.** You could also **make an advance statement (often referred to as a 'living will' in Northern Ireland)**. This covers a wider range of issues and is not legally binding, but should ensure that your wishes and feelings are consulted if and when you lose capacity.

Work

If you are in work and have been diagnosed with dementia, you will need to make some important decisions about your future. You could for example ask your employer to reallocate a task to another employee, move your desk to a quieter area, agree a change of working hours or levels of responsibility, provide rest periods, or adapt physical features of the buildings, fittings or equipment. These are called 'reasonable adjustments' (under the Equality Act (England, Wales and Scotland) and the Disability Discrimination Act (Northern Ireland)).

All aspects of employment should be considered when thinking about adjustments, including recruitment and selection, promotion, professional development review, transfers, training, career development and retention¹¹.

The Alzheimer's Society has some useful factsheets on creating a dementia friendly workplace and on employment rights.^{12 13}

11 <http://bit.ly/292Y6fB>

12 <http://bit.ly/1MPtUT5>

13 <http://bit.ly/2aklJi6>

7 Public services and benefits

Local Authorities (local councils) must enable people to participate as fully as possible in decisions about them and must provide the information and support necessary to do this.

If you don't receive information and support when you have asked for it, or in a format that works for you, you should make it clear that this is your right.

If you are using a care service, the Care Act (England) and Social Services and Well-being (Wales) Act affords you the right to **personal dignity** and to **protection from abuse**. This might include being treated unkindly by a care worker who does not understand your needs (for example, forced to eat too quickly, or having your meal removed before you have finished).

The right under the Care Act (England) and the Social Services and Well-being (Wales) Act to '**control** by the individual over their day-to-day life' could also apply to situations such as:

- having to get up, go to bed or eat at times you do not wish to
- being allowed visits from relatives at certain times only

Some people believe that **rights to health and social care** are the same. They are not, and they also vary across the UK. There is a universal right to free healthcare at the point of need in the UK. But rights to publicly funded social care, housing, and welfare benefits, are more conditional. They depend on the financial situation of the individual, severity of need etc. Legislation relating to these entitlements must be compliant with human rights legislation (though it is true that this remains largely untested).

Many people with dementia have to depend on **welfare benefits**. These are very complex and vary across the four countries. We do

not cover benefits in this booklet, but the Alzheimer's Society¹⁴ and Age Scotland¹⁵ provide useful factsheets.

There are many potential situations in which people with dementia are treated unfairly or discriminated against. Knowing how the law applies will not prevent them all—but it is a powerful tool with which to challenge such practices.

14 <http://bit.ly/1PPDRur>

15 <http://bit.ly/2bbEpOW>

Case Study: Fred the 'bed-blocker'

Fred has had an operation and has been ready to go home for twelve weeks. His house is ready and has been checked by social services. His daughter has arranged to have special leave from work to help Fred settle back into his home. However, social services and the health board cannot agree who will pay for Fred's ongoing care package. They will not discharge him until it is agreed. Fred's daughter overheard a nurse refer to her dad as a 'bed-blocker'.

Fred has dementia and has become very depressed. He does not want to be in hospital but his repeated requests to go home are ignored. His family say that he has changed and they want him home as soon as possible. His Article 8 rights (private and family life) are affected because an administrative matter between two public authorities is preventing him from returning home and to his family. It is likely that the public authorities are breaching Section 6 of the Human Rights Act because they are not upholding Fred's human rights, which is something they must do.



8 How can you use your rights?

Saying that you have a right to something can be very helpful. It does not mean that you are being difficult or confrontational. It simply means that you are aware of the law, and are prepared to stand up for a legal right.

Stating your rights

Knowing where you stand is important if fairness matters to you. Understanding your rights can give you the **confidence** to ask for something to be changed, and to use legal terms. For example, if your employer does not seem to realise that you may be able to continue working with dementia, you could talk about ‘reasonable adjustments’. This will show that you know what you are talking about.

Making a complaint

Understanding your rights also means that you can make a more **effective complaint**. All organisations should have a complaints process. This usually has a number of stages, each with its own time limit. It is always best to put your complaint in writing, so that you have a record and it is taken seriously. When writing a letter of complaint, it helps to state clearly which of your right(s) you think have been breached – or which will be breached e.g. if a new policy is put in place. The Equality Advisory Service has produced some useful template letters¹⁶, though these are not specific to dementia. BIHR’s resources include information on how to spot and raise a human rights issue, practical flowcharts, and worked-through examples with sample letters¹⁷.

The next tier of complaints is the Ombudsman. This is a person who has been appointed to look into complaints about an organisation.

¹⁶ <http://bit.ly/29Z3Naq>

¹⁷ <http://bit.ly/2bGssq8>

Using an Ombudsman is a way of trying to resolve a complaint without going to court. You must have tried the internal complaints system first, and there is usually a time limit for the Ombudsman, so don't leave it too long. Depending on where you live, you will need to contact the [Scottish Public Services Ombudsman](#)¹⁸, the [Northern Ireland Public Service Ombudsman](#)¹⁹, the [Public Services Ombudsman for Wales](#)²⁰, and relevant Ombudsmen in England depending on the sector²¹.

Campaigning together

If you are part of an action group (e.g. one of the UK's many DEEP dementia groups²²), a knowledge of rights can help you to **campaign** collectively for something specific. You might also consider joining the global network Dementia Alliance International²³. You can use your knowledge of rights to lobby policy makers, and to insist on the right of people with dementia to participate as equals in the development of policy.

The more we use our rights on an individual basis, the more we can change services, attitudes and culture for the better.

Knowing something about rights – and being prepared to show that you do – can be very helpful when you are challenging a decision, making a complaint, or taking a case further.

18 <http://www.spsso.org.uk/>

19 <https://nipso.org.uk/nipso/>

20 <http://www.ombudsman-wales.org.uk/>

21 <http://bit.ly/2ce7L4a>

22 <http://dementiavoices.org.uk/>

23 www.joindai.org

9 Support and advocacy

Many people with dementia will not feel able to pursue their rights without help and support. But they do have a statutory right to free and independent **advocacy**. Advocacy services can help you get your voice heard if you feel let down by your local services or feel you are facing disadvantage or discrimination with regard to care or treatment.

Statutory advocates

There are a number of different types of statutory advocate provided under different laws. These are all funded by government and delivered through local commissioning arrangements, sometimes by local authorities and sometimes by Clinical Commissioning Groups (CCGs) in partnership. Statutory advocacy services are regulated and the specification and criteria are set out in statute law by parliament.

- **Independent Mental Health Advocates (IMHAs)** are independent advocates who are trained to work within the framework of the Mental Health Act 1983 to support people to understand their rights under the Act and participate in decisions about their care and treatment²⁴. ([England and Wales only](#))
- **Independent Mental Capacity Advocates (IMCAs)** are a legal safeguard for people who lack the capacity to make specific important decisions: including making decisions about where they live and about serious medical treatment options. IMCAs are mainly instructed to represent people where there is no one independent of services. They can be a family member or friend, who is able to represent the person²⁵. ([England and Wales only](#))

²⁴ <http://bit.ly/2an4D4t>

²⁵ <http://bit.ly/2a5tJGU>

- **Care Act Advocates (CAAs):** If it appears to the authority that a person has care and support needs, then a judgement must be made as to whether that person has substantial difficulty in being involved and if there is an appropriate individual to support them. An independent advocate must be appointed to support and represent the person for the purpose of assisting their involvement if these two conditions are met²⁶. ([Care Act \(England\)](#), and [Social Services and Well-being \(Wales\) Act](#))

These services are often delivered by voluntary sector groups under contract.

Other types of advocate

Additionally, there are many types of citizen and lay advocacy organisations. These are independent and impartial, usually run by the voluntary sector, and almost always free.

Generic issue-based advocacy is available through a variety of organisations in most localities, such as Citizens' Advice Bureaux.

There are also generic problem solving advocacy groups, peer and self advocates.

A new toolkit for advocates is being published by the British Institute of Human Rights (BIHR)²⁷, with flowcharts to help decision-making.

If you need help or advice in understanding your rights and making them known, try to get the support of an advocate.

²⁶ <http://bit.ly/29Z4mAP>

²⁷ <https://www.bihhr.org.uk/>

10 Considering legal action

There is a lot people can do (with the support of an advocate if necessary) to challenge and negotiate for better treatment/decisions without going to court. Simply using the language of rights can open many doors.

Pursuing legal action should be seen as a last resort, and should not be undertaken lightly. Access to the law is very tightly constrained and there are many obstacles that may prevent or frustrate you. The cost of instructing a solicitor or briefing a barrister is considerable and usually beyond the means of most ordinary people.

Pursuing rights through the courts in person is particularly problematic for individuals with dementia. The legal process requires them to produce sufficient evidence to support the claim in order to have an initial hearing.

The next step is to assemble more evidence to prove there has been a breach or an offence. Evidence from the appellant (the person bringing the case) is then exchanged with the respondent or the defendant (person/organisation the case is being brought against); the other party will almost always produce an alternative explanation and set of facts.

All this takes place before a hearing is scheduled, to see whether there is a valid complaint to pursue and to test whether that case can be pursued in the terms of the relevant law.

However, all this does not mean it is not worth going forward. Cases can be challenged successfully in the lower courts and tribunals – especially if related to welfare or employment matters.

It may be possible, in some cases but not all, to enlist an organisation which wants to support the complaint as a **test case** to establish legal precedent.

Access to the **UK Supreme Court** and **European courts** can only be attempted after all the local court procedures have been exhausted – so it can take a long time. However, there have been some successes and these have often led to changes in practice.

The advice must be to think hard before launching into legal action. If you do decide to do so, try to find an advocacy organisation which will support you.

“

People with dementia can not only be capable of advocating for themselves but can band together to form their own campaigning groups... and to clamour to the powers-that-be for recognition and respect.

James McKillop

”



11 Practical resources

Here is a list of practical resources and organisations which can give you more detailed guidance:

- Age UK. 2015. *Our Rights Our Voices*. An excellent toolkit—not dementia specific²⁸.
- Alzheimer Society of Ireland. *I have dementia...I have rights*²⁹ and *A Charter of Rights for People with Dementia*. April 2016³⁰.
- British Institute of Human Rights (BIHR): lots of practical guides on rights³¹, including a new resource aimed at dementia practitioners, '*Dementia and Human Rights: A practitioner's guide*' and one for service users, '*Mental Health, Mental Capacity: My human rights*'. Also a current project '*Care and Support: A Human Rights Approach to Advocacy*' which is working with six groups to ensure people with mental health and capacity issues have increased control and autonomy over treatment decisions, and make sure they are treated with dignity and respect³². BIHR does not provide advice or casework.
- Charter of Rights for People with Dementia and their Carers in Scotland³³.
- Declaration of Rights for Older People in Wales³⁴.
- Dementia Alliance International. 2016. *The Human Rights of People Living with Dementia: from Rhetoric to Reality*. Brief guide – not UK specific³⁵.

28 <http://bit.ly/1gSVlgb>

29 <http://bit.ly/2a4mawb>

30 <http://bit.ly/1oIIDDT>

31 <http://bit.ly/1Gb5Nra>

32 <http://bit.ly/2bGssq8>

33 <http://www.dementiarights.org/charter-of-rights/>

34 <http://bit.ly/2bIU1eJ>

35 <http://bit.ly/2a5jjUh>

- Disability Rights UK. Lots of resources on rights, though not dementia-specific³⁶.
- Equality Advisory Service: provides free information and guidance on discrimination and human rights issues, via their helpline (0808 800 0082) and website, and has a selection of useful template letters³⁷.
- Equality and Human Rights Commission: has an easy read guide *The United Nations Convention on the Rights of People with Disabilities What does it mean for you?*³⁸. Also a web-based tool that you can click through to find out your rights in a specific situation.
- OPAAL (Older People's Advocacy Alliance UK) can tell you if there are advocacy services for older people in your area³⁹.
- Scottish Human Rights Commission 'Care about rights' project⁴⁰.

Helplines:

- Alzheimer's Society⁴¹ ([England & Northern Ireland](#)): 0300 222 1122
- Alzheimer [Scotland](#)⁴²: 0808 808 3000
- Equality Advisory Support Service: 0808 800 0082
- Liberty: 0203 145 0461
- [Wales](#) Dementia Helpline⁴³: 0808 808 2235
- Dementia UK⁴⁴: 0800 888 6678

36 <http://www.disabilityrightsuk.org>

37 <http://www.equalityadvisoryservice.com/>

38 <http://bit.ly/29WvgxA>

39 <http://opaal.org.uk/>

40 <http://www.scottishhumanrights.com/careaboutrights>

41 <http://bit.ly/1SRybmn>

42 <http://bit.ly/29WsTuH>

43 <http://bit.ly/29WsybF>

44 <http://bit.ly/2a1mKcz>

12 Some background reading

Books by people with dementia (as recommended by Dementia Alliance International)

Bryden, C., 2015. *Nothing About Us Without Us*. London: Jessica Kingsley.

Rohra, H.,(2016) *Dementia Activist: Fighting for Our Rights* (translated from German original). London: Jessica Kingsley.

Swaffer, K., 2016. *What the Hell Happened to My Brain? Living beyond dementia*. London: Jessica Kingsley.

Taylor, R., 2007. *Alzheimer's from the Inside Out*. Baltimore, Md: Health Professions Press.

Other resources

Alzheimer's Society. *Equality, discrimination and human rights*⁴⁵
A webpage explaining their position on these issues.

Alzheimer Scotland. 2009. *Charter of Rights for People with Dementia and their Carers in Scotland*⁴⁶.

McGettrick,G. and Williamson,T., 2015. *Dementia, rights, and the social model of disability*. Mental Health Foundation⁴⁷.

This paper describes the social model of disability in relation to dementia, as well as national and international law that is informed by it or that it connects with. It goes on to describe tools that can be used to apply the model through policy, practice, service and community development.

45 <http://bit.ly/2apPwWa>

46 <http://www.dementiarights.org/>

47 <http://bit.ly/2a8vwrS>

Miller, O., 2016. Blog: *Human Rights are not an Abstract Concept*. SCVO⁴⁸.

Rahman, S., 2015. *Living better with dementia: good practice and innovation for the future*. London: Jessica Kingsley⁴⁹.

Wildbore, H., 2015. Blog: *The Difference It Makes: Putting Human Rights at the Heart of Health and Social Care*. British Institute of Human Rights⁵⁰.

“

How great it is to see the experience of dementia being framed as a disability rights issue.

”

Jenny Morris, disability writer/researcher

48 <http://bit.ly/2bE16jH>

49 <http://bit.ly/2agS62N>

50 <http://bit.ly/2aa9pPj>



Appendix 1: Key laws and conventions

Human rights and equality

Human rights are legally protected by the **European Convention on Human Rights (ECHR)**, which came into force in the UK in 1953. This gave effect to certain rights stated in the **Universal Declaration of Human Rights** and made them binding. Since 1966, people in the UK have had the right to take a case to the European Court of Human Rights in Strasbourg.

In 2000 the **Human Rights Act (HRA) 1998** brought 16 of the European Convention on Human Rights (ECHR) rights into UK law. This gives legal duties to core public authorities (and also private or voluntary bodies performing ‘public functions’) to respect, protect and fulfil these rights, meaning that people can use it at local level to negotiate with services. It also means that people in the UK can currently bring human rights cases to UK courts as well as to the European Court in Strasbourg.

The European Convention on Human Rights (ECHR) and the Human Rights Act apply to everyone. Of over 60 Articles, those that are most applicable to supporting people with dementia to have their rights upheld are:

- Article 2 – the right to life (with virtually no exceptions)
- Article 3 – prohibits inhuman or degrading treatment or punishment (with no exceptions or limitations)
- Article 5 – everyone has the right to liberty and security of person (subject to lawful arrest or detention, which can include people with mental disorders)
- Article 8 – the right to private and family life (subject to certain restrictions that are “in accordance with the law” and “necessary in a democratic society”). This includes rights around privacy at home and in correspondence, as well as the right to access personal information such as medical records

- Article 12 – insists on supported decision-making and is opposed to all forms of substitute decision-making
- Article 14 – freedom from discrimination, including on the grounds of disability (but only in respect to the person’s rights under the Convention, so a case cannot be brought in under Article 14 alone).

Laws, government policy, and the decisions, actions and behaviours of government and public authorities (including the NHS and local government) must comply with the Human Rights Act.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) 2006 is an international treaty which promotes and protects the rights of the person with a disability. The rights enshrined in national and international human rights law and conventions do not distinguish between different illnesses and conditions. Instead, they use the language of ‘disability’ – the physical, psychological and cognitive impairments that arise from illnesses, diseases and health conditions (see Section 4).

The treaty defines disability as including “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”. This would include people living with dementia.

It aims to ensure their enjoyment of human rights and equality under the law and represents a legal framework for applying generic human rights legislation in a way that is meaningful for people with disabilities.

The general principles are:

- Respect for dignity, autonomy, freedom to make choices, independence
- Non-discrimination e.g. age, gender, race, disability
- Full participation and inclusion in civil society



- Respect for difference; acceptance of disability as part of human diversity
- Equal opportunity
- Accessibility

The UK has ratified the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), which means that national laws and government policies should comply with it.

The **Equality Act 2010** (England, Wales and Scotland) makes it illegal for people to be treated less favourably because of their age, disability, gender, race, religion or belief and sexual orientation or transgender. It requires public bodies to fully consider the impact that changes in policy, such as the closure of a service, have on people with “protected characteristics” such as disabilities. In addition, the Act continues the duty of service providers and employers to make “reasonable adjustments” to ensure that people with disabilities are not disadvantaged.

The nine protected characteristics under the Act include disability and age.

Disability: The Act defines disability as a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on a person’s ability to do normal daily activities. The Government’s own guidance states that ‘a disability can arise from a wide range of impairments’, and it names ‘forms of dementia’ in this list.

Age: The Act also includes a ban on age discrimination in services (including the provision of goods and facilities), public functions and associations (unless this is covered by an exception from the ban, constitutes positive action, or a good reason can be shown for the differential treatment.) Both older and younger people with dementia can face age discrimination.

People who fall under the scope of the Act receive full protection against all forms of discrimination that are unlawful under it, including a right to ‘reasonable adjustments’ by the providers of

goods and services. Employers are also required to make reasonable adjustments for people with disabilities, including people with dementia, to ensure they are not disadvantaged at work.

Note: The Disability Discrimination Act (DDA) 2005 remains in place in Northern Ireland, and some elements remain in force in the whole of the UK.

Mental Capacity

Note: The Mental Capacity Act (MCA) covers England and Wales. Scotland has the Adults with Incapacity (Scotland) Act 2000. The Mental Capacity Act (Northern Ireland) 2016 is not yet in force.

The **Mental Capacity Act (MCA) 2005** Supports the rights of people who are cognitively impaired to make decisions for themselves wherever possible. Within the MCA, the **Deprivation of Liberty Safeguards (DOLS) 2009** are in place for people who lack capacity to make decisions about their care or treatment, and who are deprived of their liberty to protect them from harm.

Mental capacity legislation also has a role in enforcing rights for people with disabilities who are cognitively impaired. The Mental Capacity Act (MCA) supports the rights of people to make decisions for themselves wherever possible. If you cannot make decisions for yourself because you do not have the mental capacity to make them, the Act tells you what you can do to plan ahead, how you can ask someone else to make decisions for you and who can make decisions for you if you have not planned ahead.

The Act says you have these rights:

- You will be assumed to have capacity to make a decision, unless you have had an assessment showing you do not in *that specific situation* (global judgements about an individual's capacity should not be made).
- You should be given information and support in an appropriate way to enable you to make a decision and just

because others don't agree with your decision should not be automatically used as a way of saying you lack capacity.

- All decisions made for you when you have lost capacity should be made in your best interests – where possible you and those caring for you should still be involved in the decision. Best interests decisions should be as least restrictive as possible.
- Your liberty can only be taken away from you in very specific situations – this is called a deprivation of liberty (often shortened to DOLS), and it should only be used if it is the least restrictive way of keeping you safe or making sure you have the right medical treatment.
- You may have the right to get support from an advocate in certain circumstances. This is someone who listens to what you want and can speak for you, if you want, but does not have the legal authority to make financial or personal decisions for you.
- A deputy is a person appointed by the court to make financial or personal decisions for you, once you have lost capacity to make those decisions for yourself.
- If there are any doubts as to what an advance decision means, or what an attorney under a lasting power of attorney or a deputy is allowed to do, you can contact the Office of the Public Guardian or the Court of Protection can make a decision about these things.

The Act also tells you how you can plan ahead:

- You can appoint an attorney. This is a person you appoint, while you have capacity, to make financial or personal decisions for you for a time when you have lost capacity.
- You can make an advance decision. These cover refusals of treatment only and are legally binding. You could also make an advance statement. Advance statements cover a wider range of issues and are not legally binding, but your wishes and feelings should be consulted once you have lost capacity.



Amongst other things, the **Adults with Incapacity (Scotland) Act 2000** states that when a person cannot make a decision, or decisions, another person can have powers conferred on them to make relevant decisions for that person. This helps uphold the rights that people with dementia have.

Mental Health (Care and Treatment) (Scotland) Act 2003. This wide ranging Act contains rights-based principles that professionals must apply in carrying out the functions of the Act.

The **Mental Health Act 1983** is the law in **England and Wales**. In **Northern Ireland** the **Mental Capacity Act 2016** brings mental capacity and mental health together.

Care

***Note:** The Care Act 2014 only applies in England. In Wales, the Social Services and Well-being (Wales) Act is now in force. Scotland and Northern Ireland are in the process of amending their respective social care legislation and are including a wellbeing principle.*

The **Care Act 2014 (England only)** promotes individual wellbeing in regard to personal dignity, protection from abuse, control by the individual over their day-to-day life, physical health, mental health and emotional wellbeing, and the individual's contribution to society.

The Care Act is particularly relevant for people with dementia and their carers. Its overarching principle is one of individual wellbeing in regard to:

- personal dignity
- protection from abuse
- control by the individual over their day-to-day life
- physical health, mental health and emotional wellbeing, and the individual's contribution to society.

Local Authorities must enable the individual to participate as fully as possible in decisions about them and to be provided with the information and support necessary to do this, including advocacy services.

And they must ensure that any restriction on the individual's rights or freedom of action is kept to the minimum necessary.

In Wales, the **Social Services and Well-being (Wales) Act 2014** requires that any authorities exercising duties in relation to adults must act to promote their wellbeing and must have due regard to the United Nations Principles for Older Persons adopted by the General Assembly of the United Nations on 16 December 1991.

In Scotland, the **Social Work (Scotland) Act 1968** established an overall duty to promote social welfare by providing advice, guidance and assistance. In pursuing this, local authorities can provide a variety of services to people in need (including people who have care needs as a consequence of disability or mental health of increasing age).

The National Health Service and Community Care Act 1990 (Scotland) imposes on local authorities a duty to assess the individual care needs of people – such needs assessments should include and address issues of culture, sexuality, etc.

The Patient Rights (Scotland) Act 2011 states that patients have a right to care which is patient-focused and takes account of their individual needs. The Act also asserts the right of every patient to give feedback, raise concerns and make complaints. The Act places a duty on Scottish Ministers to publish a charter of Rights and Responsibilities for Patients.

The Social Care Self Directed Support (Scotland) Act 2013 gives people a range of options for how their social care is delivered, beyond just direct payments, empowering people to decide how much ongoing control and responsibility they want over their own support arrangements. The Act places a duty on councils to offer people choices as to how they receive their social care support.

Case Study: Constance Simon's will

(With kind permission to reproduce from Kingsley Napley LLP)

Constance Simon made a new Will at her 88th birthday party in 2005 which benefitted all four of her children equally. Her estate included 16 shares in the family company. Each of the four children had an equal number of shares and the purpose of Mrs Simon's modest holding was to prevent deadlock.

She had made four previous Wills. The most recent, in 1996, had left the shareholding to her son Robert because she felt it was right that he should have control of the company.

At the tail-end of the birthday party, when the discussion turned to death and taxes, Mrs Simon was told that her existing Will did not benefit her children equally. She did not know why this was and was adamant that she wanted to make a new Will then and there, which she did. Mrs Simon had dementia at the time.

The medical evidence did not really assist the Court because it seemed that Mrs Simon had good days and bad days and, of course, the question was whether she had capacity at the time she signed her Will. The Court was persuaded that she did have capacity based on the evidence of the various witnesses who were present, who were found to be credible and consistent. Based on the same evidence, the Court held that she also knew and approved the contents of the Will, which were read back to her a number of times.

Robert had appealed this finding on first instance. His main argument was that his mother must have lacked capacity because she couldn't remember her reasons for benefitting him to a greater extent in her earlier Will. The Court did not agree. The judges drew a neat analogy with remembering the kings and queens of England when you are younger and having to look it up when you are older. It was simply a fact she had forgotten, which she could look up if she chose.

So in this case (*Simon v Byford & Ors* ([2014] EWCA Civ 280) it was held that her failure to remember why she had made a previous Will in the terms she had did not mean she lacked capacity.



Appendix 2: Using a Human Rights Based Approach (HRBA)

Some people have negative perceptions of Human Rights law and fail to see that Human Rights apply to them. They can find the Human Rights Act difficult to navigate. This is why a Human Rights Based Approach is applied – to bridge the gap between law and practice. Talking about rights can support a **positive cultural shift** in the way that dementia is perceived and understood (including by people with dementia themselves).

Since 2003, the United Nations has been developing a Human Rights Approach (HRBA) across the whole of its work.

Scotland has led the way in showing how to introduce a HRBA into national dementia policy.

When the UK government ratified the UN Convention on the Rights of Persons with Disabilities in 2009, Scotland adopted a Charter of Rights for People with Dementia in Scotland based on the **PANEL Principles**:

PARTICIPATION in decisions, which affect their human rights

ACCOUNTABILITY of those responsible for the respect, protection and fulfillment of human rights

NON-DISCRIMINATION AND EQUALITY

EMPOWERMENT to know their rights and how to claim them

LEGALITY in all decisions through an explicit link

Scotland is the first country to have included people with dementia in its implementation of this Convention. In 2002 it appointed a Scottish Dementia Working Group of people with dementia, which advises the government, with the support of Alzheimer Scotland.



There is currently no significant steer from the English Government to promote a Human Rights Based Approach (HRBA). However, the Prime Minister’s Challenge on Dementia 2020⁵¹ does commit to “a greater understanding and protection of the human rights of those living with dementia around the world.” There are some notable examples of HRBA initiatives in England, such as the Mersey Care and Human Rights project. Over the last ten years Mersey Care has worked in partnership with the British Institute of Human Rights to embed human rights based approaches and subsequently the PANEL principles in a range of initiatives and services⁵².

Similarly, the Care Quality Commission (CQC) uses a rights and values framework explicitly in its assessment guidelines. In order to pass CQC regulation inspections, the care and health services it registers and inspects must now demonstrate that they centre around human rights and equality.

Wales also has human rights principles embedded in legislation and its Declaration of Rights for Older People.

Now that Alzheimer’s Disease International has adopted a human rights-based approach, it is hoped that many other countries will follow suit.

51 <http://bit.ly/1xvD0wK>

52 <http://bit.ly/2bZVNdN>



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The voices of people living with dementia and those who care for them need to be heard in a meaningful way.

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Innovations in Dementia (iD) is a community interest company. We work nationally with people with dementia, partner organisations and professionals with the aim of developing and testing projects that will enhance the lives of people with dementia.

For information about **iD** or the **DEEP network**, please contact [**ideas@innovationsindementia.org.uk**](mailto:ideas@innovationsindementia.org.uk)

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A brief guide co-produced by The Dementia Policy Think Tank (member group of DEEP) & Innovations in Dementia CIC