

Dementia and Hope:

Our vision for dismantling the barriers which disable a million people in the UK

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One Dementia Voice



Make
breakthroughs
possible



Front cover photo of Dr Wendy Mitchell, who lives with dementia, taken by her daughter Sarah Mitchell

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1. Summary

This document sets out the vision of a group of dementia organisations in the UK who have come together as One Dementia Voice. The vision is that:

We must focus not only on the medical aspects of dementia, but also on the many other barriers which disable those affected.

We must address these societal and environmental barriers proactively, thinking more about rights, citizenship, inclusion and equality.

In this way we can each play our part in bringing more hope and meaning to the lives of those of us who live with this condition.

To achieve this, we must understand that we all have the power to change or minimise these barriers, by making adjustments both to the physical environment and to our attitudes and behaviours, and by adopting a rights-based approach.

There are many benefits to this approach, including:

- **Hope and empowerment:** Recognising dementia in terms of disability rights and citizenship can empower, and give hope to, those who are diagnosed and their families.
- **Equity and inclusion:** This approach helps us all to focus on how the disabilities associated with dementia connect with social, attitudinal and environmental factors; with the strengths, resilience and abilities of people with dementia themselves; and with the principles of solidarity and inclusion.
- **Access and adjustment:** This approach should help people with dementia to access everything that others, with or without disabilities, access. Society can also learn from them what the barriers are and redouble its efforts to minimise them through what the law calls reasonable adjustments /accommodations.

This document sets out our starting point and the key benefits of the approach. It addresses many frequently asked questions (FAQs) and provides suggestions on how to embed 'Dementia and Hope' into your organisation. There are also many personal stories and examples of how 'reasonable adjustments' can and should be made for people with dementia.

Our vision is about people and the barriers they face. It's about hope, enablement and positivity. Here are some of the people we have in mind:

Anwar, 81

Anwar was diagnosed three years ago with fronto-temporal dementia. Anwar finds rail travel difficult because he is unsure about catching the right train or finding his destination from the station. Loud or unexpected noise also disturbs him and this makes going out difficult. Consequently, he has stopped travelling to meet friends and family, and rarely visits his local town.

Alastair, 56

Alastair has lived with Alzheimer's disease for seven years. His driving licence was taken away immediately after diagnosis, on the recommendation of his GP. Alastair's employer did not support him to help him continue in work, so he also lost his job. He often forgets why he has gone into a shop, or how to get home, and local people have come to know and help him. He used to enjoy meeting friends for a drink and a chat. However, he has lost his confidence and is spending almost all his time at home, on his own.

Annie, 97

Annie has had dementia for a number of years. She lives in a care home and is now very poorly. The Activity Coordinator puts on lively sessions for other residents in the communal lounge – but Annie, though a sociable person, is no longer well enough to follow what is happening, nor can she see much because of her cataracts. The Activity Coordinator, recognising that she has as much right to her time and attention as anyone else, spends time with Annie individually every day in her room, playing her beloved brass band CDs and reading her favourite poetry aloud.

Section 1

Our vision

“

It is new for me to actually look at it this way – to separate those impairments and disabilities. And it's *really, really interesting*.

”

George Rook (*living with dementia*)

1. Our vision

This booklet sets out the vision of One Dementia Voice - a collaboration of a number of organisations driving change in dementia support. Together we are building links between our activities, promoting the rights of people living with this long-term condition, and making sure people affected by dementia have the strongest possible voice with decision makers.

The organisations are (in alphabetical order):

Alzheimer's Research UK
Alzheimer's Society
Dementia UK
Innovations in Dementia
John's Campaign
Lewy Body Society
Rare Dementia Support
Together in Dementia Everyday (tide)
Young Dementia Network

Our shared vision is that...

We must focus not only on the medical aspects of dementia, but also on the many other barriers which disable those affected.

We must address these societal and environmental barriers proactively, thinking more about rights, citizenship, inclusion and equality.

In this way we can each play our part in bringing more hope and meaning to the lives of those of us who live with this condition.

To achieve this, we must understand that we all have the power to change or minimise these barriers, by making adjustments both to the physical environment and to our attitudes and behaviours, and by adopting a rights-based approach.

One Dementia Voice organisations are committed to ensuring that we accept, understand, talk about, advocate for and act on the disabilities and inequalities which people with dementia experience. Since early 2022 we have been finding new ways to bring the vision to life within our own work. You can find many examples in Section 6.

We invite you and your organisation to share the vision and take active steps to embed it into all your work. We hope that this document will help you to act in a proactive and positive way to instigate change.

Hilary Evans	Alzheimer's Research UK	
Kate Lee	Alzheimer's Society	
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Philly Hare	Innovations in Dementia	
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Jacqui Cannon	Lewy Body Society	
Sebastian Crutch	Rare Dementia Support	
Samantha Bolam	tide	
Tessa Gutteridge	Young Dementia Network	

Personal story: Peter

For the last few years Peter, his wife and adult daughters and their families have celebrated New Year's Eve together, often going to local events and firework displays. They all appreciate having a decent quality meal together to bring in the New Year. Since Peter was diagnosed with dementia a couple of years ago, his symptoms have become more noticeable, and he struggles with too much background noise.

Peter is keen to still celebrate in the New Year with family and they decide to buy tickets for an event at their local pub – a place Peter knows well and which has a separate restaurant that will be doing a special menu for the occasion. When buying the tickets, his daughter Suzan asks if it's possible for them to be sat in the back corner, so that there wouldn't be as much background noise for her Dad. She also asks about whether they can stay indoors to watch the fireworks. The landlord asks why and she explains that her Dad has vascular dementia.

The landlord informs her that, due to her Dad having dementia, he will not be able to give him a ticket. If they served him he would lose his licence.

Suzan speaks to the local Alzheimer's Society to ask if this is really the case as it seems a little odd. She is informed that the landlord is being discriminatory, which is unlawful under the Equality Act. An advocate speaks with the landlord, and it is clearly a misunderstanding as he believed that if he served someone with dementia that he would lose his licence. Once presented with the facts and the law, he accepts he is wrong, he also agrees to attend a Dementia Friends session. Since then, he has hosted a regular dementia lunch group in his pub. By way of apology he offered the family their New Year's Eve tickets for free with an extra bottle of bubbly!

Section 2

Our starting point – how we frame dementia

“

Some people are really struggling, having a hard time, because they're of the generation where you don't make a fuss, so you don't question the authorities.

”

Mary (carer)

2. Our starting point – how we frame dementia

There is more than one way of looking at dementia. How we look at it as a society shifts and evolves over time and is constantly contested. How we look at it as individuals depends on our upbringing, education and culture, our personal experiences, our openness and exposure to ideas, and the context in which we work.

But how we choose to ‘frame’ dementia and those affected by it – the ‘model’ we use – is very important. It affects how we talk about it, how we react or respond to people who live with it, how we campaign and fund-raise, how we make policy, how we provide care and treatment, and how we prioritise our actions.

Over the years various models have been developed which can help (or perhaps hinder) us. This is a complex area, and here is not the place to analyse and evaluate these in academic detail, especially as many others have done so. However we describe them briefly below.

The medical model

The medical model regards disability as an impairment, as a deviation from ‘normal’ health status. Exclusion of disabled people from society is regarded as a personal tragedy and an individual problem, and the reasons for exclusion of the person are attributed to the impairment¹. The focus is on neurodegeneration and brain pathology, and the central message is that the dementias resulting from this need to be treated, cured, fixed or at least rehabilitated.

Following this model, dementia is often still framed as an incurable, hopeless illness/disease – the symptoms of which come almost to define the whole person... and which leads to death. Though very pervasive, this model is widely viewed as outmoded and much too narrow. We know that, because of it, many people are reluctant even to seek a proper diagnosis (which could unlock the support they need).

¹ Degenier, T A human rights model of disability (2014)

Little attention is given to the many potentially good years which may pass between diagnosis and the end of life, or to the fact that life, even with dementia, can still be meaningful, with the right support and adjustments. One consequence is that, in the research world, there is an overriding focus on finding a cure (though no real hope that this will come any time soon). And in the public, media and health/care spheres there is a preoccupation with loss and deficit.

Suzanne Cahill explains the limitations of this model (Cahill, 2019)²:

“All too often we hear dementia referred to as the thief that steals the individual; the person is the “patient” or “sufferer”, a “shell of her former self”; the family caregiver is the “hidden victim” and the increase in the number of people with Alzheimer’s disease is a “rising tide/ tsunami”... These words do nothing to promote the agency, dignity and humanity of the individual...”

The bio-psycho-social model

A one-sided focus on the medical symptoms of dementia can divert our attention from the many ways in which society itself can disable – or enable – people who are living with it. And from the ability of people to rebuild and continue enjoying their lives, as well as contributing to society. So, as Williamson highlights (Williamson 2019), *‘while understanding dementia as a disease is necessary, it is insufficient as a way of shaping how society reacts to the condition, and it can at times also lead to very unhelpful responses.’*³

While the medical model is still very powerful in the UK and the wider world, there are other models which we believe offer a more nuanced, accurate and helpful framing. The bio-psycho-social model (first introduced by George Engel⁴ in 1977) sees dementia as a manageable long-term health condition, with lived experience reflecting biological, psychological and individual social factors.

Proponents of the bio-psycho-social model emphasise that the impact of dementia itself on functioning does not have a linear progression. It seems to be influenced by social context and the behaviours of others,

2 Cahill, S. (2019) **Reframing dementia as a disability and a human rights concern**. In Irish Times 31/12/2019. Accessed on 22 October 2022.

3 Williamson, T. (2019) ‘The Dementia Manifesto: A revolution in how dementia is understood?’ blog at <https://bit.ly/3ivAWzW> . Accessed on 22 October 2022

4 Engel GL (1977) The need for a new medical model: a challenge for biomedicine. Science 196, 129–136

and how far each reaffirms, upholds, disrespects or denies personhood. Tom Kitwood's development of a person-centred approach in dementia in the 1990's⁵ (Kitwood, 1993) focuses on the factors that nourish or undermine personhood. As Claire Surr⁶ (2019) explains:

“How a person experiences living with [dementia] is determined by the full range of biological, physical, social, psychological, spiritual and environmental factors, in conjunction with how inclusive and supportive communities and wider society are.”

The social model

Kitwood's person-centred approach easily leads us to thinking about things that it has in common with the social model of disability (and other strands of thinking, such as the right to independent living). The social model views disability as a social construct and locates the problem of disability outside the individual and in discrimination policies. In this model, the term 'impairment' is used to talk about a person's medical condition or diagnosis, or to describe their functioning; and the word 'disability' is used to describe the social effects of their impairment.

The social model does not deny the existence of impairments that may affect disabled people's daily lives, but it shifts the emphasis onto the real barriers which affect participation. The social model of disability demonstrates that removing barriers for disabled people benefits everyone – for example, providing more accessible information (such as plain, jargon-free language, clear typefaces and layouts or other methods of communicating) assists a wide variety of people.

The social model locates the “problem” outside the disabled person and therefore offers a more positive approach because:

- it doesn't “blame” the individual or turn them into the problem
- it involves everyone in identifying solutions
- it encourages co-operative problem solving
- it removes barriers for others as well as disabled people, that is, it is an equal opportunities model
- it acknowledges disabled people's rights to full participation as citizens.⁷

⁵ Kitwood, T. (1993). Towards a theory of dementia care: the interpersonal process. *Ageing and Society*, 13, 51-67.

⁶ Surr, C. in 'Dementia Reconsidered Revisited: The Person Still Comes First' Kitwood, T and Brooker, D (2019)

⁷ <http://ddsg.org.uk/taxi/social-model.html> accessed 3 November 2022

The challenge here - as for the disability rights movement as a whole - is that we can't expect to easily change the common understanding of the word 'disability' just because we've decided it should mean something different. So it is perhaps more helpful to talk explicitly about the barriers, discrimination and inequality experienced by people living with dementia - which immediately directs people towards socially constructed things.

The implication of the model is that, in common with many other people who have an impairment or long-term health condition, people with dementia experience barriers, discrimination and inequality (what it calls disability) when trying to go about their lives. So dementia is a predicament that causes impairments which become disabling unless social barriers (attitudinal, social, environmental) are removed. This is because the way the world is designed – combined with our own attitudes - fails to support their inclusion and participation.

The UN Convention on the Rights of Persons with Disabilities (UNCRPD)⁸ offers a helpful framework for thinking this through and choosing priorities for action. It is based on the social model but sees disability as 'an evolving concept', emphasising the full and equal participation of people with disabilities, including people with dementia. Although this is not UK law, the UK became a signatory in 2007 and ratified the convention in 2009.

Although people with dementia have many distinct and perhaps unique impairments, they also have a shared experience of disability or disablism. However, as a group they have usually been excluded from the larger disability organisations, from the disability activism movement as a whole, and from disability policy and services. One example is the lack of any reference to dementia in the National Disability Strategy (July 2021) – or any collaboration or input into its drafting. This exclusion continues to disadvantage people with dementia because they don't get to be heard, to be consulted or to influence these networks; and they don't get funding through them. Their needs are not viewed through the lens of disability legislation and provision. They don't have access to what the disability movement has learned and achieved over more than 60 years, nor can they share *their* learning with people with other disabilities either – or help the social model of disability to evolve and take account of their lived experience.

⁸ United Nations. 2006. "Convention on the Rights of Persons with Disabilities." Treaty Series 2515 (December): 3.

The human rights model

Within disability studies, the social model of disability has been almost as strongly criticised as the medical model of disability. For one thing, the model focuses only on how participation in society and the capacity to exert control over one's life are mediated by external barriers. It has nothing really to say about the impact of these on an impairment or health condition itself.

On a practical level, people with dementia are often unaware of their entitlement to health and social care services, rehabilitation, employment support, housing, and disability benefits (including the need for advocacy to obtain these) - let alone their more fundamental human rights, for example to a family and private life, and to independent living as part of the community. Their needs are not properly understood or assessed with regard to disability benefits and services. And accessibility projects and environmental adjustments tend to focus still on physical access to services, and ignore their equivalent for people with cognitive impairments - 'cognitive ramps' to assist understanding, just as wheelchair ramps assist access.

Gerard Quinn (presently the UN special rapporteur on the rights of persons with disabilities) wrote in 2012⁹, in alignment with Kitwood and others, that the UNCRPD is about 'nourishing personhood and creating the conditions for human flourishing'. The focus here is on things like supported decision making, social inclusion, practical and financial support, adjustments and addressing things like stigma and social attitudes.

Theresa Degener¹⁰ (a member of the CRPD Committee) also questions whether the social model of disability is sufficient alone to honour the human rights of disabled people (Degener 2014) . Her intention is not to abandon the social model of disability, but to develop it further. She argues the UNCRPD goes beyond and creates the human rights model of disability. She tells us that the difference between the social and the human rights model is that, in the latter:

- Impairment does not hinder human rights capacity

⁹ Quinn, G (2012) 'Getting a Life – Living Independently and Being Included in the Community'. Accessed on 26 October 2022 at https://europe.ohchr.org/Documents/Publications/Getting_a_Life.pdf

¹⁰ Degener, T (2014). 'A human rights model of disability' Accessed on 26 October 2022 at https://www.researchgate.net/publication/283713863_A_human_rights_model_of_disability

- Economic, social and cultural rights, as well as civil and political rights, are encompassed
- Impairment is valued as part of human diversity
- Identity issues are acknowledged
- Assessment of prevention policy are allowed for
- It strives for social justice

Which model?

The more we think about it, the clearer it is that the situation is not binary. We don't have to say that one model is completely wrong and another completely right. Neil Crowther argues¹¹ that:

“acknowledging how these external factors shape a person’s experience of living with dementia is not a call for a wholesale shift from a so-called ‘medical model’ to a ‘social model’ of dementia. Addressing them would not mean that the disease would not progress, have harmful and distressing effects on people, and eventually cause death. Just like other progressive or terminal diseases or conditions, such as HIV/AIDS, cancer or multiple sclerosis, the pursuit of new treatments and therapies that slow the progress or ameliorate the impact of underlying diseases, are all crucial contributors to more people being able to live a good life, while living with dementia. Indeed, challenging stigma and transforming society’s expectations of the potential to live with the condition have proved important in securing investment in research and rehabilitation, because they help cultivate hope and possibility. Ultimately, were medical research able to absolutely prevent or cure the degenerative diseases leading to dementia, there is little doubt a majority of people would avail themselves of such opportunities.

While medical science has yet to offer more than ameliorative treatments, there is increasing evidence about the potential to improve the wellbeing of people as they live with dementia by also addressing the external, socially-constructed factors that shape their experience.

¹¹ Crowther, N (2022) “Place, people, purpose and power – promoting the wellbeing of people living with dementia through personalised care and support”. Accessed on 22 October 2022 at <https://drive.google.com/file/d/1ksKMBle-g8G51BQdtrkzn-2E8PRo56M8/view>

As a result, it seems to me morally – and based on existing international and domestic law, legally - necessary to pursue social change aimed at supporting people to maintain their personhood and through doing so, the means to continue to live as good a life as possible.”

So it's not about shoehorning people with dementia into models and frameworks that were not actually developed with their involvement (or even with them in mind). It's about drawing on and enriching them. We believe that our focus should be less on a theoretical model and more on broadening the default preoccupation with 'cure or care' to living our best life with dementia - and addressing all the factors that shape this.

It is for all these reasons that we are committed to changing this situation, by ensuring that we accept, understand, talk about, advocate for and act on the disabilities which people with dementia experience. Things can be changed, and people's lives can be improved – even before a cure is found. There is hope.

And we want to encourage others to follow suit.

In the next section we explain the many benefits of this approach.

“

It took me the whole of lockdown to let me email the GP [instead of phoning] when I needed help. If that had just been the adjustment at the beginning..! It makes you feel as though you are a nuisance, when you're actually just trying to lead your life.

”

Wendy Mitchell (*living with dementia*)

Personal story: Raj and Fatima

Raj, a retired chef, lives at home with his wife Fatima – they have just celebrated their 55th wedding anniversary. Raj recently had a stroke that has led to a diagnosis of vascular dementia, and his mobility has been affected. He is now struggling with getting up and down the stairs in his home, and so they have asked the local authority to provide him with a stair lift.

The local authority inform them they don't provide stair lifts for people with dementia. Instead they suggest that they turn part of their open plan living/dining room into a bedroom for him, and they will provide him with a commode.

Raj and Fatima are not happy about this, as they feel it doesn't take into account Raj's needs and him as an individual. He is also concerned about his privacy and dignity.

They choose to challenge the decision by writing to the local authority, within which they mention the following laws and how they apply to their situation:

- The Equality Act 2010 – the fact that they were turned down solely on the basis of Raj's diagnosis is discriminatory and not allowed under the Equality Act. Raj should have had an individual assessment based on his needs and his condition and abilities – not an assumption made on a diagnosis.
- Human Rights Act 1998 Article 8 – Raj has a right to respect for his private and family life, which includes dignity. It is not very dignified to expect someone to sleep, eat, toilet etc in the same room that is used for visitors as well as the rest of the family. The expectation that they would turn part of their downstairs into a bedroom, bathroom and toilet area for Raj is against his Article 8 rights as it offers no privacy and is against his dignity.
- Human Rights Act 1998 Article 14 – this is the right to have all the rights under the Human Rights Act protected without discrimination. Raj's Article 8 right was only breached as the local authority were acting discriminatorily, as the basis for why they refused support was due to his dementia and not any individual assessment.

Following their challenge the local authority agreed to do an individual assessment. An occupational therapist visited their home and assessed Raj's individual need for a stairlift.

Section 3

Focusing on the barriers which disable people with dementia



People's experience of dementia as a health condition is as much about the nature of the world they inhabit as it is about the impact of the underlying condition... People's health can decline or improve as a result of extrinsic factors that either do, or fail to, anchor people in the world and their own selves.



Neil Crowther (*independent consultant, former carer*)

3. Focusing on the barriers which disable people with dementia

As already explained, the bio-psycho-social and social models of disability provide a way of focusing on how the loss of functioning, agency and participation in society connect with attitudinal and environmental factors; with the strengths, resilience and abilities of people with dementia themselves; and with the principles of solidarity and inclusion.

We must address these societal and environmental barriers proactively, thinking more about rights, citizenship, inclusion and equality. To achieve this, we must be ready to make adjustments both to the physical environment, and to our attitudes and behaviours, and to adopt a rights-based approach, including with respect to care and support.

In this chapter we set out what we see as some of the benefits of this approach.

Three key benefits

- 1. Hope and empowerment:** Recognising dementia in terms of disability rights can empower, and give hope to, those who are diagnosed, and their families. Greater awareness of their human rights means that people with dementia can push for support and rehabilitation to enable 'recovery' (in the sense of being more in control, not of being cured) – rather than just medication and monitoring. And they and their families may be better understood, and less ashamed of, and stigmatised by, the condition.
- 2. Equity and inclusion:** The bio-psycho-social and social models of disability provide a way of focusing on how the loss of functioning, agency and participation in society connect with social, attitudinal and environmental factors; with the strengths, resilience and abilities of people with dementia themselves; and with the principles of solidarity and inclusion.

By looking at dementia through this lens, those who support people with dementia can review the impact that they have; can reconsider the value of hearing and responding to personal experiences; can reframe their focus to consider strengths instead of deficits; and can better understand the impact of public policy¹². People with dementia are centre stage, and are recognised as equal citizens with equal rights.

- 3. Legal ‘clout’:** The cognitive impairments caused by dementia, and the discrimination and barriers which people with dementia experience, undoubtedly make it a disability in law. And recognising this should help people with dementia to access everything that others, with or without disabilities, access. So reframing dementia in terms of disability is not about imposing another label on individuals – it is about using legal definitions as a means to an end, as a tool. It should be noted that there has not yet in the UK, to our knowledge, been any legal challenge about reasonable adjustments for people with dementia. But we should note that other ‘groups’ e.g. people with mental health difficulties, and the deaf community, although they often don’t consider themselves as disabled, have nevertheless made very good use of disability legislation to claim their rights. One example is the successful campaign to get British Sign Language recognised as an official language.

And more benefits...

- 4. Access and adjustment:** People who live with dementia tell us that they are constantly having to adjust to the new challenges that are thrown at them, both by the impairments of dementia itself and by the barriers that further disable them. But they can often find their own ‘work-arounds’ to ‘outmanoeuvre’ them. If we understand this, we can support them in their efforts to adapt as much as they can, and to share their strategies with others in the same boat. Society can also learn from them what the barriers are and redouble its efforts to minimise them through what the law calls reasonable adjustments / accommodations (see next page).

¹² Ref: Gilliard J (2005) Dementia care in England and the social model of disability.
<https://bit.ly/3BpCGC7> Accessed on 22 October 2022

- 5. Research ‘clout’:** People with dementia have much to gain from a research perspective that acknowledges the more progressive models of disability and is co-produced; research that is accountable to, and benefits, disabled people and is about social change. For example, research led by mental health survivors (people who have often found mental health services unhelpful) did much to change the nature of evidence – shifting what was considered to be knowledge and evidence away from traditional, biomedical psychiatric framing. People with dementia are also now starting to demand to ‘be in the driving seat’ of research which concerns their lives¹³.
- 6. Policy ‘clout’:** Recognising the disabling barriers and discrimination associated with dementia will give access to many other policy levers – whether directly, or through disability organisations and/or long-term conditions networks. For example, it gives strength to the movement to phase out multi-bed institutional ‘warehousing’ in poor quality care homes (these, while still deemed acceptable for people with dementia, are now less common for those with other disabilities). Access to these networks could shift the focus from one defined by funding constraints and risk aversion to one based on recognition of people’s human rights.
- 7. Co-morbidities:** People with dementia more often than not have other impairments and conditions to cope with as well (‘co-morbidities’). The cumulative impact of these co-morbidities is often ignored because of ‘diagnostic overshadowing’ – i.e. the person is seen only in terms of their dementia. Co-morbidities are more likely to be recognised and treated if dementia itself is framed in terms of the barriers which disable.
- 8. Sharing and learning:** People with dementia, and their organisations, can gain from linking with the wider disability movement because they share so much in common with people with other disabilities. Whereas people with dementia might not readily identify with the term disability, it is the case that their

¹³ See **Dementia Enquirers** programme Accessed on 22 October 2022

condition is one of the major causes of disability and dependency among older people worldwide. Though being part of the disability movement is the means to an end, not the end itself, discussion between people with a range of disabilities can be very fruitful, and can help us to look at things in different ways. Inclusion in the disability world can help people with dementia and their advocates to challenge together the things they have in common, such as:

- The stigma, powerlessness and frustration associated with their condition. (This is often internalised i.e. the individual has their own sense of devaluation and discrimination)
- Demeaning language and prejudicial attitudes
- Poorly adapted environments
- Lack of training, knowledge and good leadership among professionals, staff and other people they have contact with
- Services cutting corners to save money
- Paternalistic attitudes and services
- Indirect and direct discrimination—as well as double (or multiple) discrimination linked to age, gender, race, sexual orientation etc
- Being excluded from opportunities, services and activities that people with other disabilities and people without disabilities participate in

Moreover, the disability movement has much to learn from people with dementia – and should be open to the challenge of including their lived experience. Though the movement may well need to review and adapt the model which underpins it, it has the potential to be much stronger and more inclusive because of this.

- 9. One voice:** Finally, greater focus on the disabilities associated with dementia will bring key dementia organisations into line with each other and offer a more coherent message to all. Most, if not all, of the relevant major dementia organisations, both in the UK and world-wide, now find the case for framing in this way compelling and necessary. Although changing public attitudes without the engagement of players from all sort of organisations – including much more generic ones – is hard, a unified approach from all dementia organisations will be very helpful.

Personal story: Mary

Mary is 72 and has lived on her own for the last few years since her partner died. She received a diagnosis of Alzheimer's disease over a year ago but has been coping well with additional support from family and friends. Mary decides that she would like to move to sheltered accommodation so that she can be nearer to her friends, for additional company of closer neighbours and also the reassurance of knowing there is a warden in case she needs help.

Mary contacts a local sheltered accommodation where a number of her friends live, but they inform her that she is not eligible for a place there. When she asks why, she is simply told it is because they don't accept people with dementia.

Mary speaks to friends who urge her to get advice. She decides to put in a complaint about the way her request was treated. Within her complaint she mentions the Equality Act, and the fact that she was turned away solely on the basis of her diagnosis of Alzheimer's disease, which amounted to discrimination. She received a reply from the manager who looked into the complaint and apologised and offered Mary an individual assessment to see if she was eligible for a place. Mary turned this down as she found another lovely sheltered accommodation that was only too happy to have her move in. However, she was glad that she put in the complaint as she felt that they would learn not to treat others like they treated her.

Section 4

Frequently Asked Questions (FAQs)



By using the right language, saying the right key words and key phrases... it suddenly opens a lot of doors and make a lot of changes. And I always say to people not to be afraid of the language... just to go with it and just to push for the rights that we have.



Sam Cox (*Alzheimer's Society*)

4. Frequently Asked Questions (FAQs)

Q Is it actually *helpful* to focus on dementia through a disability lens?

A **Yes.** Under the social model, the term ‘impairment’ is used to talk about a person’s medical condition or diagnosis, or to describe their functioning; and the word ‘disability’ is used to describe the social effects of their impairment.

Barriers in society, in our local communities (including stigma) and within ourselves (including shame and embarrassment), can prevent those of us with cognitive impairments from living the lives we want to. Yet because dementia is not seen as a ‘disability’ by society, help and support fall short of that assumed to be the right of those with other impairments or health conditions. The barriers are often arbitrary and emerge from designing society to make life and work easier for the fit and healthy, while ignoring those living with an impairment.

Those with hidden impairments, such as dementia, have the same rights and entitlement to dignity and respect. Cognitive impairment caused by progressive neurological disorders including dementia can be very frustrating and limiting, but people often find ways to continue doing what they need or want to. It is the barriers in everyday life that are disabling, because they prevent people who find some things difficult from continuing to live as they choose. For example, a noisy environment may prevent someone from continuing to go out – this noise may seem inevitable, but there are often ways to reduce its impact. Or an unsympathetic employer may mean that a person diagnosed with dementia effectively has to stop work – with all that that entails. Yet with imagination and collaboration, many of the barriers to continuing work can be overcome.

So, by focusing on dementia through a disability lens, we open up awareness of, and access to, inclusion, respect, cognitive aids, rehabilitation, *reasonable adjustments/accommodations* of all kinds¹⁴ ... and equal participation in society. The recognition of the disabled status of people living with dementia gives rise to eligibility for anti-discriminatory disability rights, together with related human rights and legal protections – for both people with dementia and their supporters and families. There is even the potential for anti-discriminatory legislation to be tested in dementia-related cases.

We also highlight the core mantra of the disability movement i.e. ‘nothing about us without us’ – something which still needs to be fully adopted by the dementia world. So this framing offers hope, and shifts the focus to empowerment. It can be liberating – even a revelation – to realise that so many of the problems associated with having dementia are not ‘their fault’, but about how society responds – and that they can therefore be addressed.

The social model approach makes it possible to talk clearly about a named individual (the person), their impairment (medical condition or functioning) and the disability (society’s barriers).

For example: *Norma (the person) is a woman who has vascular dementia (the impairment). When the barriers and discrimination (the disabilities) that restrict Norma have been removed from society, Norma will still have dementia and be called Norma... but she will no longer be disabled.*

Q Are people with dementia legally people with disabilities?

A Yes, although disability law is not about diagnosis or specific health conditions. The effects of dementia can be a disability, because they cause “*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). The Statutory Code of Practice makes it even clearer that dementia is a disability for the purposes of this Act.

¹⁴ If an organisation providing goods, facilities or services to the public or a section of the public, or carrying out public functions, or running an association finds there are barriers to disabled people in the way it does things, then it must consider making adjustments (in other words, changes). If those adjustments are reasonable for that organisation to make, then it must make them.

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 UK is a signatory to the UNCRPD which means that UK law and policy should be compliant with the Convention.

Both our domestic law and the UNCRPD are really powerful tools that highlight the human rights of people with dementia. They could and should be much more commonly used – particularly given that dementia is one of the UK’s most common disabilities, and one that is growing very fast. Please see the case studies within this booklet.

Q Do we really need to impose another label on people?

A No. Of course people with dementia can choose how they individually describe their own situation – and what labels, if any, they do or do not identify with. Some people actually say they find the disability label liberating, because they realise how many of their problems are external to them – and they want the disabilities associated with dementia to be recognised (see Section 9).

Nevertheless, only around a half of all people with disability-related rights under the Equality Act self-identify as ‘disabled’ . It seems that people with a whole range of diagnoses like to insist they are not disabled, as that is in some way a label which lacks hope.

In the same way, although ‘disability’ should not be considered as a negative label, many people struggle to think of their experience of dementia in terms of disability. They are understandably reluctant to accept another ‘label’ on top of ‘dementia’ - itself not much-loved – and may prefer to describe it in terms of a long-term condition or chronic illness. Organisations may choose to do the same – talking for example about disabling barriers.

To be fair, we can’t expect to easily change the common understanding of the word ‘disability’ just because the social model decided it should mean something different. So it is perhaps more helpful to talk explicitly about the barriers, discrimination and inequality experienced by people living with dementia - which immediately directs people towards socially constructed things.

This is all fine, as long as everyone understands the benefits that the disability framing and tools can bring. This document is not about the label, but about how the disabling aspects of dementia can be overcome. In other words, how people think about themselves and about labels might be quite different to what is helpful when thinking about a group of people. For even if some (or many) people with dementia reject the ‘disability’ identity, they are still entitled to the social adjustments that enable them to continue to participate in their communities, and ensure inclusion and change.

So it’s not so much about labelling, or about marching under a particular banner, as about taking *strategic advantage* of the rights that people have. Advocates, organisations, policy makers, educators, researchers and practitioners all have a responsibility to use whatever tools are available to change and improve things.

Q But don’t we need to focus on a cure or more effective care/treatment over and above anything else?

A No, it’s not a case of either-or. Of course we need to search for cures and treatments as well as tackling social barriers – but one doesn’t exclude the other. In terms of care, the pure ‘medical model’ simply doesn’t deliver – there are very few medical interventions even for the common symptoms of dementia such as insomnia and depression. And with regard to cure, soon there will be a million people living with dementia in the UK – it’s almost certainly too late for a cure for them, but not too late to tackle social barriers. We believe there is a moral obligation to help people overcome the barriers they face in shaping their lives and well-being. A focus on ‘fixing the person’ obscures the potential for making their lives better by improving attitudes and the environment *in the present*.

Q Surely the medical symptoms of dementia are an important part of the experience?

A Yes of course. The causes of dementia are diseases in different parts of the brain, and the symptoms that accompany the condition result in impairments which can be very challenging, and probably life-changing. Establishing that there is a medical cause is important in clarifying expectations, and in accessing available symptomatic treatments, therapeutic programmes and services. But by framing

the condition in terms of its *outcomes* – i.e. disability – we also acknowledge the impact of social aspects, both environmental and attitudinal. And these can of course interact with the symptoms, and affect the lived experience of dementia, either negatively or positively.

Q Aren't you brushing over the fact that a diagnosis of dementia is inevitably a tragedy?

A No. This approach is about reframing dementia from *inevitable* tragedy to *predicament*, as Tom Shakespeare has explained (see Film 3, link on page 60). A *predicament* is a situation that is difficult to manage or get out of, and that is something none of us wants to have. But a predicament doesn't have to be understood as a 'tragedy'. And the more we work together to dismantle the social barriers, the less disabling it is. The tragedy model undermines the work towards positive adjustments and the idea that people with dementia still have as much worth as any other human being (rather than being considered as nothing more than helpless victims). And every person with dementia brings to it the strengths and stories of their whole lives.

Q But social care is in such a bad way that the law is routinely ignored and people with other disabilities also frequently get a bad deal, don't they?

A Yes, but... knowledge of our rights can at least give us the confidence, the courage and the tools to challenge wrong decisions. And we know that many appeals are upheld - the more the system is challenged, the more likely it is to be changed.

Presently, social care as it relates to people living with dementia is too often imagined only as a 'storage solution', not as essential support to live life and maintain wellbeing.

Additionally, some people might think it's wrong to ask for 'special treatment' for people with dementia – especially in these hard times. But requesting 'accommodations' or 'reasonable adjustments' is simply about seeking equity or parity with people with other disabilities (or none). That is the opposite of special treatment, entitlement, complaining, demanding or whining.

Q Is this really relevant at all to people at a very advanced stage of dementia?

A Yes. And maybe more than ever! People with dementia have the same inviolable legal rights as others no matter how advanced their condition. Making sure that people are safe and free from pain (i.e. meeting their basic *needs*) is vital – but that is not enough to meet their *rights* around social contact, inclusion and relationship. Even at the end of life, there is still so much that can be done to make lives worthwhile and meaningful. Social care and human rights must always go hand in hand – in every aspect of caring, we have to adapt all the more the accommodation and adjustments we are making. Choice even in the smallest things – such as in who washes you or provides your intimate care – are as much an expression of human rights as are ‘higher level’ choices about work or leisure. Ensuring that the rights of people with very severe impairments are recognised and upheld is crucial, not least because those impairments may prevent them from fully understanding their rights or communicating their needs and wishes.

Q Is there anything in this for unpaid carers/family members?

A Yes. Social barriers can also cause huge distress to family carers. If this approach can be used to help the person they are caring for, that will of course help them too. One example is the successful campaign around the Blue Badge parking permit for people with dementia¹⁵ – which has helped carers enormously.

Another benefit is that this approach highlights the right of family carers to visit and support their person with dementia in any health or care setting. This is essential because this person may rely on them for practical help such as eating, drinking and mobility; for psychological support such as maintaining wellbeing and remaining connected to the world; for conveying medical and other information; and for assisting with decision-making and discharge-planning.

¹⁵ This campaign, which took place in 2018, brought together people with dementia and people with autism (so-called ‘hidden’ or ‘invisible’ disabilities) to demand equal access to the disabled Blue Badge parking scheme. The scheme is administered by local authorities and some refused to include people with dementia or autism. The campaign was successful because the government issued statutory guidance that required local authorities to include people with dementia or autism as being potentially eligible for the scheme.

With an understanding of the rights and entitlements that accompany dementia being accepted as a disability, family carers can become stronger advocates for those they care for, especially if they have more advanced dementia and are less able to speak for themselves. Thinking about dementia and disability can help unpaid carers to realise how many of their problems are external to the condition and the person they are supporting... and can therefore be very liberating. In addition, carers are themselves often discriminated against – and the Equality Act makes it clear that this is unlawful.

Susan Bruce, a former carer, testifies that our vision:

“... allows me to see dementia and its problems in a much wider scale. With my mother I was very focused on what mum and I went through – but now I can see a much bigger picture. My mum was refused a stairlift because she had dementia – I did not know! To know that all of this work is going on is just really incredible, because something has to be done. It would have really helped me to have known that I did have rights (even though I worked with DWP for 30 years, so I was very clued up anyway). It would have helped tremendously.”

Personal story: John

Since retiring, John has been actively involved in his grandchildren's lives, picking them up from school most days, taking them to the park and their other activities. John is known as someone who likes to be active and engage fully in what everyone is doing, so has been known to get the pool with the grandkids for their swimming lessons, going on zip wires as well as trying out climbing walls and abseiling.

When John was diagnosed with Alzheimer's disease he didn't want it to get in the way of his family life and the things that he did. If anything, the grandkids said it made him more fun as he was determined to carry on having fun with them. One day after school John took his grandchildren to the park, and it was whilst on a skateboard he had an accident and was taken to hospital.

He was patched up and later discharged but was told that he would be best to be placed on the waiting list to have a hip replacement as this would hopefully get him back more mobility. Since being discharged he has found that he is limited in what he can do and can't run around with the grandkids anymore. He follows up with the GP about his hip operation, but the GP warns him that due to his dementia it is highly likely that he won't receive the hip replacement surgery – as other people that don't have dementia will be prioritised above him.

After seeking advice, John and his family complain about the delay. Within their complaint they mention the fact that as this has only happened to John due to his dementia, and if he was someone else that didn't have dementia they would not be experiencing this delay or refusal of the surgery that it is discrimination. This is not allowed as John is protected by the Equality Act.

It was agreed that his complaint would be looked into, and it didn't take long for John to be outlined of the waiting times and for him to have a referral to see a specialist with the view of him having the surgery sooner.

In the months that passed, John did receive the surgery and physiotherapy and is looking forward to getting back to the park with the grandkids.

Section 5

How to embed 'Dementia and Hope' into your organisation

“

The disability rights movement – our organisations, our articles and our campaigns – has to include people with dementia. If it fails to do so, it has failed.

”

Tom Shakespeare (*disability academic*)

5. How to embed 'Dementia and Hope' into your organisation

Every organisation has to make its own decisions about how it frames dementia. We all have unique missions, histories, funding situations, staffing, strategic priorities and much more. Moreover, our different audiences and stakeholders will respond to different language and 'framings'. But we hope we have persuaded you of the many benefits of re-framing dementia as a long-term condition which results in both *impairment* and *disability*. And we also hope we have shown you the importance of demonstrating adherence to, or going beyond, the requirements of the UNCRPD and the Equality Act.

Key messages

If so, here are some of the key messages we will all want to send out to people with dementia and their families:

- Whether or not we have dementia, we all have the same status as human beings with the same human rights. We are all citizens.
- Thinking about dementia in terms of human rights and disability rights brings empowerment and hope.
- All disabilities and long-term conditions – including dementia – arise from impairments caused by the health condition itself. But these are made worse by disabling social barriers such as lack of understanding, prejudice and stigma, and the environment.
- It doesn't matter whether or not you identify as disabled. You can still use disability law to help you get what you need to live well.
- You have a right to support and rehabilitation – and to live independently (though that doesn't mean without support, meaningful relationships or activities).
- You shouldn't be denied a service (such as counselling or physiotherapy) or an adaptation (such as a stair lift) simply because you have dementia – or because you are the 'wrong' age. You have the right to be assessed as an individual.

- Accessibility is not just about physical ramps and wider doorways. For people with dementia it can be about quieter spaces, reminders, being given a chance to speak, better lighting, matt floor surfaces, simple summaries, less complicated forms, a choice of how to be communicated with. These can be thought of as ‘cognitive ramps’.
- If you have dementia and you find that things are not accessible to you (too fast, too complicated, too difficult to understand, too exhausting) you can and should ask for a ‘reasonable adjustment’. This is not about complaining or whining or asking for special treatment – it’s about equity.
- We all face predicaments in our lives. Dementia is a predicament – it may be difficult, but it’s not by definition a tragedy. Dementia is something none of us wants to have, but it’s also something that doesn’t have to ruin our life.
- We don’t want to give false hope. But – with help from others – you can continue to live your life hopefully and positively.
- You may well have other impairments that may or may not be related to your dementia. You have a right to have these recognised and addressed, regardless of your dementia.
- Other people’s attitudes and lack of understanding – or even prejudice – can disable you. They need to be educated and challenged.
- Just because you have dementia, it doesn’t mean you can’t continue doing what you love doing – or even learning something new. You still have a lot to give – you have skills, life experience, wisdom and vital roles (as an employee, a volunteer, a parent, a partner and/or a grand-parent).
- Dementia is caused by neurological, ‘organic’ diseases of the brain, so it is different from psychiatric/mental health conditions. Nor is it an inevitable part of growing old. Not that either of these are anyone’s fault, and they should not be stigmatised. But dementia is a disabling long-term condition that is caused by disease in your brain.
- Families, networks, relationships and interdependence are as important as individual rights and independence – we all need both.
- Even at the end of life, there is still so much that can be done, that *we can all do*, to make lives worthwhile and meaningful.

We should think about embedding these messages in our publicity, marketing and fund-raising, in our advice services, in our staff and volunteer training, in our relevant policies and procedures, and in all our dealings with other organisations. We could draw up an organisational plan based on our honest answers to these questions:

Our language and imagery

How is dementia described on our websites, social media channels, leaflets, and other materials? Is our messaging, imagery and language positive and consistent? What terminology will we use – could we talk more about disability; disabling long-term condition; human rights; barriers; reasonable adjustments/ accommodations; entitlements; citizenship; fairness; inclusion; dementia-accessible instead of dementia-friendly? And less – or not at all - about loss; tragedy; sufferers; burdens; and hopelessness? (see ‘Dementia Words Matter’ DEEP guide)¹⁶.

People with lived experience

Do we ensure that their voice is constantly there, at every level of our work, to help us learn from them? In what ways can they be active participants and partners in our organisation, as service users, advisors, volunteers, current or even future employees. How can they influence the decisions being made in our organisation?

Our staff and volunteers

How do staff and volunteers talk and think about dementia? What conversations and /or training do they need to understand this reframing of dementia? Can you supply them with this booklet?

“ It might have helped to be told about the back-up, the law and the support I could have had. ”

Sue (carer)

¹⁶ DEEP (2014) ‘Dementia words matter: Guidelines on language about dementia’ <https://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf> Accessed on 22 October 2022

Our campaigns

How can we ensure that our campaigns – including fundraising campaigns – are compatible with this re-framing? And avoid promoting dementia as an inevitable tragedy?

Our spheres of influence

What channels do we have to publicise and explain what we are doing? Can we use our newsletter; media contacts; research partners; policy connections or social media to communicate and promote how we are reframing dementia?

Our networks

How can we strengthen our connections with:

- disability organisations, networks and alliances?
- disability researchers and research funders?
- policymakers who have a disability brief, including the Minister for Disabled People, Health and Work Opportunities? Can we get access to and involvement in the All-Party Parliamentary Group for Disability, to the Disability Unit (part of the Cabinet Office), to the Disability Confident campaign, and to the National Disability Strategy?

And how can we then persuade them to include people with dementia, and dementia ‘issues’, as mainstream within their work? And to introduce proper structural reform and change, for example with regard to transitions ‘in and out’ of care, and to congregate care settings.

The PANEL principles

This guidance has focused on the importance of the human rights of people with dementia. Putting this focus into practice is called a ‘human rights based approach (HRBA).

The PANEL principles¹⁷ are one way of breaking down what a human rights based approach means in practice. PANEL stands for **P**articipation, **A**ccountability, **N**on-Discrimination and **E**quality, **E**mpowerment and **L**egality. The **PANEL principles** were adopted in Scotland’s National Dementia Strategy. They could be a useful tool

¹⁷ A human rights based approach: an introduction’ (2019) Scottish Human Rights Commission <https://bit.ly/338HrnK>

for you in reviewing your compliance with the law, help you to make abstract legal and philosophical principles completely tangible and understanding how the law can help your organisation as well as people with dementia.

Examples of organisational responses to DDH

Young Dementia Network (YDN) has produced a new section on its website, with bespoke resources for different audiences , which has been promoted on social media. YDN also organised a webinar to promote these resources in March 2021, led by Nigel Hullah and Wendy Mitchell, in conversation with Philly Hare.

Rare Dementia Support (RDS) has worked with their Voice of Independence and Positivity group (VIPs) on more inclusive and accessible language as a basic ‘reasonable adjustment’. The VIPs have discussed how different words make them feel – whether they feel they uphold their rights, or are stigmatising or disempowering – and these reflections have been shared with the staff at the Dementia Research Centre. They are now planning an output that can be shared within RDS and the Dementia Research Centre and used with volunteers.

Alzheimer’s Society has carried out a targeted literature review and a discussion with key informants, with a particular focus on dementia and the social model of disability. This work has helped support their ongoing thinking around how the Society frames dementia and the importance of continuing to involve people affected by dementia in the discussion.

John’s Campaign is increasingly focusing on a language of rights and equality (as opposed to persuading society to ‘be kind’). They are now working constantly with lawyers and parliamentarians on their visits campaign, which has brought them into more contact with other people with disabilities. Nicci Gerrard, co-founder, testifies: “When we talk to care homes and hospitals etc. who are still resisting access, we use that language of disability and rights. I think it’s crucial to our campaign - and at the heart of it really.”

Dementia UK's radical ten-year policy change and influencing strategy (2025-35) has incorporated themes from this approach. They are calling for dementia to be taken out of 'mental health' systems, with its own national dementia pathway in its own right. They are doing lots of reframing around disability in the social model, rights, activism and citizenship to change societal perceptions.

Innovations in Dementia (iD) has been focusing on 'making rights real'. People with dementia embrace rights when they see it can make practical changes. For example, its project 'The Right to a Grand Day Out' resulted in a direct change to legislation on Blue Badges. The regular DEEPer Conversations podcasts often focus on people's rights to stay in the mainstream. In addition, iD is re-writing all DEEP guides to use the language of rights. As well as building leadership in the DEEP network to shift power and control, iD has also been reaching out to disability organisations, such as Disability Rights UK, and policy structures, including the Disability APPG and Minister.

Alzheimer's Research UK (ARUK) has incorporated this approach in their new Equality, Diversity and Inclusion (EDI) strategy, and into their ongoing review of all their information materials and helpline advice. This approach is also be one of the themes to be discussed with their internal communications team in the coming year.

tide (together in dementia every day) has also shifted its focus slightly. In their large-scale campaign with Roche 'Front of Mind' , they have been comparing dementia to how people with other diseases and disabilities are treated. They are becoming more involved in peer support and connecting carers to each other, as well as rebranding their coffee mornings to 'Chat and Change' meetings, and their monthly focus groups to 'Inform and Influence'. And they have been trying to get a better balance in their communications between the joys and distresses of caring, bringing a more hopeful outlook on dementia.

Lewy Body Society has shared this approach with their special advisory committee, Admiral Nurses, trustees and even contractors – and have had 100% positive feedback. They want it to play a major role in their decision making. The approach has helped them a lot in giving advice and information.

Personal story: Mandeep

Mandeep has always loved going out with friends to the theatre, to watch the latest romance and drama films at the cinema, and for afternoon teas. After being diagnosed with vascular dementia, she was determined to still do these, and her friends supported her. However, on one trip to the cinema, Mandeep got a little confused when trying to find the toilet and almost set off the fire alarm by using an emergency exit. A member of staff told her that she could not attend the cinema anymore due to her dementia.

Horried, her friends rallied round, and asked to speak with the manager. They explained what had happened, and that any ban on Mandeep would be discrimination under the Equality Act. The manager quickly apologised and offered some freebies as compensation, but Mandeep and her friends wanted assurances that this wouldn't happen again. The manager assured her that he would have words with the staff member who said this and also the wider team to ensure that everyone knew how they should have reacted in this situation.

Section 6

The story so far...in brief!

“Are we valued as people after a diagnosis? Are we valued as citizens? Are we valued as contributing members of society? My experience is, no, we're not. There's a constant devaluing of us as individuals which affects our rights and responsibilities.”

Nigel Hullah (*living with dementia*)

6. The story so far...in brief!

The Universal Declaration of Human Rights was adopted by the General Assembly of the UN in 1948. This UN Convention was (and still is) meant to protect every single member of civil society in the world—including people diagnosed with any type of dementia, and who have disabilities caused by the impairments from their dementia. The **European Convention on Human Rights (ECHR)** followed, coming into force in 1953 as an international convention to protect human rights and political freedoms in Europe.

The Human Rights Act 1998 came into force in 2000. Its aim was to incorporate into UK law the rights contained in the ECHR. Though the ECHR does not use the social model of disability, the CRPD and the Equality Act (see below) do.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol was adopted in 2006. To date, 194 countries have ratified the CRPD, including the UK. It states that:

“ The CRPD is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorisation of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated, and where protection of rights must be reinforced (UN 2017). ”

The Equality Act 2010 covers England, Scotland and Wales (Northern Ireland does not have a single equality act). It legally protects people from discrimination in the workplace and in wider society, and says there's a duty to make reasonable adjustments if you're placed at a **substantial disadvantage** because of your disability compared with non-disabled people or people who don't share your disability.

It replaced previous anti-discrimination laws with a single Act, making the law easier to understand and strengthening protection in some situations. It sets out the different ways in which it's unlawful to treat someone. Although the Equality Act¹⁸ itself does not refer to diagnoses or specific illnesses, because it is based on the Social Model of Disability, the Government's Guidance does.

In 2016, members of **Alzheimer's Disease International (ADI)** agreed to adopt a rights-based approach to dementia advocacy. They emphasised that, *"although persons with dementia are indisputably included in CRPD Article 1, they have been excluded from its implementation by Member States. By the same token, CRPD is not reflected in the dementia strategies and plans of 26 Member States and two regions. The exclusion of persons with dementia from the Convention could be considered as an example of systemic if unintentional discrimination."*

The World Health Organisation (WHO), in its Global Action Plan for a Public Health Response to Dementia adopted in 2017, also highlighted dementia as a condition causing disabilities, and placed the human rights of people with dementia at the core of the Plan.

Also in 2017, Keith Oliver, supported by his wife Rosemary and Philly Hare from Innovations in Dementia, travelled to Geneva to present a co-produced 'alternative report' to the UNCRPD Committee in Geneva. He did this on behalf of the **Dementia Policy Think Tank**, which had been founded by eight people with dementia in the UK, and which was the first dementia group to be recognised by Disability Rights UK as a Disabled People's User Led Organisation. The resulting UNCRPD Committee report was the first to mention people with dementia specifically.

Dementia Alliance International (DAI) – the global voice of people with dementia–has long been pushing for dementia to be recognised as a major cause of disability and dependence globally. DAI calls for dementia as a disability to be reflected in all regional and national dementia strategies and plans. It says that post-diagnosis 'care' must be more than just an assessment of our activities of daily living, being advised to get our end-of-life affairs in order, and getting acquainted with care. A new pathway of psychosocial and disability

¹⁸ Equality Act 2010 Guidance (May 2011) Office for Disability Issues (<https://bit.ly/3qGajxc> Page 8)

support to live positively and independently with dementia for as long as possible, Community Based Rehabilitation (CBR), must also be considered when implementing WHO's Global Dementia Action Plan into policy. For DAI, this would include:

- Focus on assets, not deficits, and quality of life
- Community-based rehabilitation, which includes exercise and other lifestyle changes in line with other chronic conditions, speech pathology, a neuroplasticity approach¹⁹, occupational therapy and neuro-physiotherapy
- Disability assessment and support, immediately post-diagnosis
- Grief and loss counselling, not just information about dying, aged care and behaviour that challenges ('challenging behaviours')
- Peer-to-peer support groups for people with dementia, care partners and families, and for those with younger onset dementia, older parents and children
- Support to maintain our pre-diagnosis lifestyle, if this is a person's choice
- Support to continue working if a person with younger onset dementia, again if this is a person's choice
- Support to continue usual activities, socialising, sport, recreation, community engagement, volunteering
- Inclusive and accessible communities – not just dementia-friendly, as too often the awareness-raising initiatives are still based on a person's deficits
- Palliative care

¹⁹ Neuroplasticity is the ability of neural networks in the brain to change through growth and reorganisation.

Here is an explanation of the power of the CRPD from Dementia Alliance International (DAI)²⁰:

“ Enforced segregation and institutionalisation continues, and many other breaches of human rights have been under the spotlight as never before. Non-disabled people don’t talk about their ‘right to live independently and to be included in the community’, because their rights are not being denied, and the CRPD is meant to be an instrument to ensure the rights of people with disabilities. Living independently and being included in the community are essential to quality of life and well-being of all, including of persons with disabilities... It is our right to be treated with dignity and respect, and to equal inclusion, including full and equal access to the CRPD, like all others living with disabilities. ”

20 DAI statement for the 2021 ECOSOC High-level Segment of The 2021 Session of the Conference of State Parties Conference (CoSP) on the Convention on the Rights of Persons with Disabilities (CRPD) <https://bit.ly/3kv2l1h>

Personal story: Yan

Yan has never enjoyed what he considers to be 'just sitting' – watching TV or having a long lunch – and he definitely wasn't interested in activities like bingo or singing. After retiring he looked into local groups. He joined a walking group, and his partner encouraged him to join the local Men's Shed project – essentially a giant workshop.

Not long after Yan retired, he was diagnosed with dementia. He knew that his short term memory in particular was affected, and so he would carry a notebook with him to write little notes in as reminders. He still continued with his local groups, and he explained to someone at the Men's Shed that he had Alzheimer's. Nothing more was said about it, but later that day his partner received a phone call to say that, due to insurance, Yan could no longer attend.

Yan was very upset about this, and concerned it would stop him from doing other activities and attending other groups. He reached out for advice and found out that, by treating him in this way, the Men's Shed was acting in a discriminatory way, which was not allowed under the Equality Act. He put in a complaint to the group mentioning the Act, and he later got an apology and was invited back.

Section 7

‘Reasonable adjustments’ for people with dementia

“In essence, it is about viewing the person with disability in terms of their environment, the attitudes, the behaviour... And they’re looking for changes in their environments to allow them to maximise their independence – and be active citizens and participants in their own lives.”

Grainne McGettrick (*rights specialist*)

7. 'Reasonable adjustments' for people with dementia

The Equality Act 2010 covers England, Scotland and Wales. It legally protects people from discrimination in the workplace and in wider society, and says there's a duty to make reasonable adjustments if you're placed at a **substantial disadvantage** because of your disability compared with non-disabled people or people who don't share your disability.

Lack of access to disability services and reasonable adjustments – some examples

- Not being offered – or being denied – rehabilitation, counselling or help to adapt to your condition
- Being pressured into leaving work when diagnosed with dementia, without an assessment – yet been denied exemption from the 'Work Capability Assessment' process
- Being assumed to be lacking capacity to make small or big decisions, without the necessary assessment
- Being denied recognition of your mobility problems, sensory issues and other comorbidities
- Being expected to function in environments which are overwhelming and oppressive for you because of your dementia
- Being denied benefits because the implications of your cognitive issues are ignored
- Being refused mortgages or insurances
- Being medicated or restrained, rather than being given skilled support for your distress responses
- Having your nutritional, hydrational, health and pain needs ignored because you cannot communicate them easily
- Being denied a Blue Badge for parking, because dementia alone is not seen as a disability (though hooray, the guidance has recently changed!)
- Being denied a stair lift or a personal assistant *because you have dementia* (rather than because of your individual assessment of need)

- Being expected, pressured or even forced to move into a care home against your wishes and through lack of any other option (especially when you have been admitted to hospital for other reasons)

How to challenge and achieve change – some examples

- Your GP usually sends reminders to her patients by text. You can't use a phone – but you can read a letter. Explain, and ask for a letter.
- Your hospital waiting room plays continuous music, which makes you feel tired and confused while you prepare for your appointment. Explain, and ask them to turn it off or lower the volume.
- You are still able to work, but you can't cope with rush hour. Explain, and ask your employer to let you to start work earlier or later.
- You want to stay involved with your local parish council, but by the time you have a chance to speak, you've forgotten what you want to say. Explain, and ask to be given priority when you wave your hand or an 'I Want to Speak' yellow card.
- The Department of Work and Pensions (DWP) requires you to travel for an annual review. The journey involves two bus journeys, which makes you very anxious. Explain, and ask for a venue that is nearer, or a home visit.
- Consider wearing a sunflower lanyard, which shows that you have an invisible disability and may require help (for example when navigating an airport or other complicated public space.)

“ To me the medical model of care operates on a deficit agenda. It concentrates on what *can't* be done. ”

Nigel Hullah (*living with dementia*)

Personal story: Tom

Tom is a mechanic in a local garage. After various doctor visits, tests and hospital appointments, Tom is diagnosed with dementia. He informs his employer and his colleagues, as he hopes it will explain some of his recent behaviour and absences, and will get him the support and understanding he wants.

However, over the next 6 months, Tom continuously feels stigmatised and suspects that both his employer and colleagues are trying to push him to leave. It gets to a point where Tom, who has always enjoyed his job, doesn't want to work there anymore. But he is concerned he could not get a job somewhere else. He starts to look for some help into his options and speaks with his Dementia Adviser, who puts him in touch with a trade union. They speak with the employer about their actions, which are not only against the Equality Act, but also effectively leading to constructive dismissal which is not allowed under the law.

The employer apologises and makes changes in the workplace. All the staff attend Dementia Friends sessions and training. Reasonable adjustments are also made to Tom's role so that he can continue to work for as long as he wants and is able.

Section 8

Further reading

“[The social model of disability] just potentially changes the whole narrative about how dementia is understood, while still recognising that it’s a disease.”

Toby Williamson (*independent consultant*)

8. Further reading (in chronological order)

Alzheimer's Disease International (2012) Global Dementia Charter

'I Can Live Well With Dementia'

Available at: <https://bit.ly/3pY8LxE> – Click here to view



The rights-based Charter intends to revolutionise care and to campaign to ensure people living with dementia live well, and that their family and friends are properly supported.

McGettrick, G (2015) Dementia, rights, and the social model of disability. Mental Health Foundation and Joseph Rowntree Foundation

Available at: <http://bit.ly/2LaffUi> – Click here to view



This paper describes the social model of disability in relation to dementia, as well as national and international law that is informed by the social model 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.

Crowther, N (2016) Harnessing the United Nations Convention on the Rights of Persons with Disabilities to improve the lives of persons with dementia

Available at: <https://bit.ly/2UjYRK2> – Click here to view



This paper recommended a course of actions for dementia organisations including:

- engaging with the United Nations Committee on the Rights of Persons with Disabilities, including through its policy making processes
- seeking to develop productive relationships with the global network of National Human Rights Institutions

- preparing and disseminating widely a paper on the UNCRPD and the rights of persons with dementia
- encouraging and supporting national and regional Alzheimer's organisations to participate in the examinations by the United Nations Committee on the Rights of Persons with Disabilities of their own states.

Dementia Alliance International (2016) The Human Rights Of People Living With Dementia: From Rhetoric To Reality

Available at: <https://bit.ly/3dkCWZx> – Click here to view



A publication to coincide with the adoption by Alzheimer's Disease International of a human rights based approach.

The United Nations (2017) Convention on the Rights of Persons With Disabilities (CRPD).

Available at: <https://bit.ly/3romih9> – Click here to view



International agreement on the rights of disabled people: Easy read version.

Innovations in Dementia (2017) Our Lived Experience – Current Evidence on Dementia Rights in the UK: An Alternative Report to the UNCRPD Committee

Available at: <https://bit.ly/3ETBM1S> – Click here to view



This alternative report was co-produced by the Dementia Policy Think Tank, founded in 2016 by eight people with dementia in the UK. The group was the first dementia group to be recognised by Disability Rights UK as a Disabled People's User Led Organisation.

Shakespeare, T et al (2017) Rights in Mind: Thinking Differently About Dementia and Disability. Sage

Available at: <https://bit.ly/2TBhNmR> – Click here to view



This paper explores whether dementia should be considered as a disability, and whether people with dementia might consider themselves as disabled people. It reviews examples of, and

issues raised by, the political activism of people with dementia, and considers how language constructs dementia negatively. It also discusses how the environment influences the experience of dementia. It shows that a relational model of dementia lays the basis for a human rights approach to the condition, based on collaborative partnerships between people with dementia and people from other disability communities.

World Health Organisation (2017) Global Action Plan On The Public Health Response To Dementia 2017-2025. Geneva: World Health Organisation.

Available at: <https://bit.ly/3eXmpLe> – Click here to view



Highlights dementia as a condition causing disabilities, and has placed the human rights of people with dementia at the core. This includes implementation of rights through the CRPD, with empowerment, inclusion and accountability as three of its seven cross-cutting principles.

Alzheimer Europe (2017) Human rights and opportunities. Dementia as a disability? Implications for ethics, policy and practice

Available at: <https://bit.ly/3G1nw8G> – Click here to view



This paper explains how national and international law has relevance to the lives of people with dementia to ensure their rights are upheld. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) is one important piece of international legislation that is relevant to help people with dementia enjoy human rights and quality under the law. Article 12 of the CRPD, recognition before the law, is critical. It states that the person has legal capacity (decision making ability) on an equal basis in all aspects of life. The CRPD is a tool that dementia advocates, Alzheimer and other organisations can use to advocate for change.

Hale, C (2018) Reclaiming 'Chronic Illness' An introduction to the Chronic Illness Inclusion Project: a discussion paper from the Centre for Welfare Reform

Available at: <https://bit.ly/3n42lv9> – Click here to view



This paper explains how the experience of chronic illness can be translated into the social model of disability, beginning with the distinction between impairment and disability. It argues that 'chronic illness' is a self-ascribed identity which implies both a distinctive form of impairment and a shared experience of disability or disablism.

Our Dementia, Our Rights (Innovations in Dementia 2018)

Available at: <https://bit.ly/3ETBM1S> – Click here to view



This booklet explains why it can be helpful to know, and talk about, rights for people with dementia. Rights can help us to uphold shared values in challenging circumstances. The language of rights can help people 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 people to ask for what they need, and to challenge decisions when they seem to ignore their 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.

Cahill, S (2018) Dementia and Human Rights. Policy Press

Available at: <https://bit.ly/3mwHFN5> – Click here to view



Launching the debate into new and exciting territory, the book argues that people living with dementia come within the UN Convention on the Rights of Persons with Disabilities and therefore have full entitlement to all the rights the Convention enshrines.

Hughes, J. and Williamson, T (2019) The Dementia Manifesto (CUP)

Available at: <https://amzn.to/3nmOxMH> – Click here to view



This manifesto sets out important principles about the nature of dementia both as a disease and as a disability and explores how a values-based, person-centred and rights-based approach can be applied to every aspect of the experience of dementia. Using vignettes, the book covers a variety of issues such as diagnosis, treatment, care, social attitudes, research, public policy and funding.

Hidden No More: Dementia and disability (APPG 2019)

Available at: <https://bit.ly/31u29Ob> – Click here to view



This 2019 report from the All Party Parliamentary Group on Dementia shines a spotlight on dementia as a disability. It seeks to enable people with dementia to assert their rights to services and for their rights as citizens to be treated fairly and equally. In a survey for this report with over 2,500 respondents, 81% said that they see dementia as a disability and that it should be identified as such.

Law for Dementia Carers Covid-19 report – Impact of the Coronavirus Act 2020 and Legal Issues on Carers of People with Dementia (2020)

Available at: <https://bit.ly/32U4WB1> – Click here to view



L4DC is a joint project between Together in Dementia Everyday and Making Space. It has a rights based agenda and aims to raise awareness and inform carers of people with dementia of their legal rights, including human rights, which can support them in their role. This report explores the impact of the Care Act Easements on carers.

Equality Act guidance (2021)

Available at: <https://bit.ly/3gOJgKH> – Click here to view



Guidance from the Equality and Human Rights Commission (EHCR) – for employers, workers, service providers, service users, education providers, in England, Scotland and Wales.

Crowther, N. (2021) Reframing dementia

Available at: <https://bit.ly/3aE7Mu2> – Click here to view



An edited version of a talk with Innovations in Dementia October 2021

Crowther, N (2022) Place, people, purpose and power. DCAN

Available at <https://bit.ly/3x7rU3o> – Click here to view



This discussion paper looks at the importance of sustaining personhood and wellbeing through the four interdependent dimensions of place & things, power & agency, people & relationships, and purpose & routine.

Section 9

Films and audio resources

“

I think there should be some focus at the point of diagnosis on sharing knowledge of legal rights.

”

Liz (*carer*)

9. Films and audio resources

Kate Swaffer and Peter Mittler (2016 ADI Conference) on the need for a human rights based approach to dementia (Film: 33 mins)

Available at: <https://bit.ly/3qigyoT> – Click here to view



Dianne Gove (2018 Alzheimer Europe conference): Recognising dementia as a disability (Film: 14 mins)

Available at: <https://bit.ly/3kz7quT> – Click here to view



Kate Swaffer (2021), Dementia Through The Disability Lens (Podcast interview: 40 mins)

Available at: <https://apple.co/3zeUfDQ> – Click here to view



The PANEL Principles: Taking a Human Rights Based Approach (2020) (Film: 2 hrs 38 mins)

Available at: <https://bit.ly/3iw0zA6> – Click here to view



“Leading our own research – what can people with dementia and people from other disability movements learn from each other?”

Dementia Enquirers Podcast 2

Available at: <http://bit.ly/2P3tuh9> – Click here to view



Dementia, Disability... and Hope (2021) – a series of 7 films made by Philly Hare at Innovations in Dementia for One Dementia Voice:

Film 1: People with dementia discuss what this approach means to them (15 mins)

Available at: <https://youtu.be/B6gckn9B4-8> – Click here to view 

Film 2: Carers discuss the relevance of information about rights to support their requests for better support (11 mins)

Available at: https://youtu.be/3J1O-VJ_4qc – Click here to view 

Film 3: Prof. Tom Shakespeare, sociologist, bioethicist and disabled person, sets dementia in the context of the disability rights movement (21 mins)

Available at: <https://youtu.be/BqgGLoAaKzk> – Click here to view 

Film 4: Neil Crowther, independent expert on equality, human rights and social change, and former carer for his father, explains the relevance of the social model to dementia (20 mins)

Available at: <https://youtu.be/0tDr4EGegNQ> – Click here to view 

Film 5: Toby Williamson, social care consultant and rights expert, talks about equality and changing the narrative of dementia (20 mins)

Available at: https://youtu.be/BQSP1AZ9_MA – Click here to view 

Film 6: Sam Cox, Knowledge Officer for Legal and Welfare Rights at Alzheimer's Society, explains why it's important to be aware of and use the law (11 mins)

Available at: <https://youtu.be/lbvKBsYYCdQ> – Click here to view 

Film 7: Grainne McGettrick, Research and Policy Manager at Acquired Brain Injury, Ireland (and previously at the Alzheimer Society of Ireland), reflects on the importance of human rights and capacity law for people with dementia (19 mins)

Available at: <https://youtu.be/mOdroCzPFQk> – Click here to view 

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