

Human Rights Based Approaches in Dementia - A Potential Tool for Policy Advocacy in Northern Ireland?

1. PURPOSE

This short paper prepared on behalf of the Social Change Initiative explores the recent adoption of Human Rights Based Approaches (HRBA), and specifically Charters of Rights, by those seeking positive change in dementia attitudes, policies and services. Drawing on experiences from dementia and disability rights advocates, it reflects practitioners' views on the value of a rights based approach and the lessons they have learned about implementation. It concludes with suggestions on the steps that might be taken to develop rights based approaches in dementia advocacy in Northern Ireland.

2. AN INTRODUCTION TO HUMAN RIGHTS AND HUMAN RIGHTS BASED APPROACHES

Every human being has basic rights and freedoms, based on principles of respect, equality, fairness and dignity. These fundamental rights were first articulated after the second world war in the United Nations Declaration of Human Rights, and subsequently brought into law in all Council of Europe member states in 1951 via the European Convention on Human Rights (ECHR). The Human Rights Act (HRA, 1998) introduced these rights into domestic law in the UK, meaning that all other UK laws must be compatible with the HRA and people can take human rights complaints to UK courts. Figure 1 shows the British Institute of Human Rights' illustration of the 16 rights protected under the HRA¹.

Figure 1



¹ www.bihr.org.uk

In addition to the universal rights set out in the ECHR, there are 9 additional international rights treaties. These enshrine the social, economic, cultural, civic and political rights we can all expect to enjoy; the rights and protections that should be afforded to particular groups in society including those with disabilities, children and women; and the obligations of states to protect people from maltreatment.

Together, these international rights instruments and associated domestic laws provide the rules on how people should be treated and a set of minimum standards that states and public authorities must meet if they are to fulfil people's rights.

A HRBA is about making people (rights holders) aware of the rights they have under this framework and empowering them to claim them, whilst also increasing the ability and accountability of individuals and institutions who are responsible for respecting, protecting and fulfilling rights (the duty bearers)². Importantly a HRBA is a way of working that is concerned with process not just outcomes - the way in which constituents are involved and empowered through the process is as important as the outcomes it seeks to achieve.

A HRBA is underpinned by a set of principles referred to as PANEL:

- **P**articipation - everyone has the right to participate in decisions that affect their human rights;
- **A**ccountability - there should be effective means to monitor human rights standards and remedy any breaches;
- **N**on-discrimination and equality - all forms of discrimination should be prohibited, prevented and eliminated, with particular priority on those facing the greatest barriers to realising their rights;
- **E**mpowerment - rights holders should know what their rights are and how to claim them; and
- **L**egality - rights are legally enforceable entitlements linked to domestic and international legal standards.

The PANEL approach can also be described as follows:

“Human rights are internationally agreed entitlements, not gifts (reference to international standards). Those who are entitled are best placed to describe and argue for those entitlements, (participation) though they may need capacity-building/training/education to help them to undertake that work (empowerment). In the process, they will need to identify those whose responsibility it is to ensure that they get what they are legally entitled to – in the jargon, the duty-bearers – and hold them to account (accountability). Priority should be given to securing the rights of those most disempowered, without discrimination (non-discrimination/equality)³”.

A HRBA offers a means for people to effect meaningful changes in their own lives and future. This may involve using legal tools to challenge responsible authorities, but is often more about encouraging a change in culture and shifting the power between states and the people they serve. Central to this is a move away from paternalistic, or charitable relationships to partnerships based on respect and empowerment.

² A human rights based approach: An introduction - Scottish Human Rights Commission (http://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf)

³ Burkeman S and Cooke S (2010) Human Rights Language and Human Rights Based Approaches. Unpublished report for The Atlantic Philanthropies

In their think piece on HRBA⁴, Cooke and Parker describe the spectrum of approaches that organisations engaged in rights-based work might take:

- A consultative approach - this involves identifying ways in which adopting the principles and values of human rights (dignity, autonomy, non-discrimination, respect etc) will help fulfil existing policies or objectives of the duty bearer, providing them with tools to do their job better. For example in health and social care there is a clear relationship between human rights and the aims of personalisation of care and service user involvement. The aim of this consultative approach is to improve practice and have a significant impact on the day to day operations of the public authority for the benefit of the lives of those it serves. The consultative approach typically requires endorsement from senior strategic level within the duty bearer organisations.
- A campaigning approach - this involves highlighting failures by public authorities to comply with their legal duties under human rights standards. This means putting pressure on the public authorities to respond to alleged failures to uphold and protect human rights, including via legal action. The aim is to hold public authorities to account.

A HRBA can be used to improve the treatment of individuals by public bodies even where their practice already complies with the minimum standards the law requires. An approach that encourages development of a human rights based culture emphasises the responsibilities of public authorities to protect rights and, via the empowerment and participation elements of HRBA, aims to create a more participative and less 'benevolent' attitude towards the people that use their services. This can be seen by public bodies as resonating with public service improvement values and initiatives.

3. WHY MIGHT A HUMAN RIGHTS BASED APPROACH BE OF INTEREST TO DEMENTIA ADVOCACY?

People with dementia have the same rights as every other citizen but can face particular barriers in having their rights respected and fulfilled. As well as the impact of the illness itself on capacity, reasoning and ability to communicate and protect one's own rights, barriers can exist due to societal stigma and discrimination, inadequacy of services to support, care for and treat people with dementia, lack of knowledge among professionals, and paternalistic attitudes.

In their paper on dementia, rights and the social model of disability McGettrick and Williamson⁵ identify a recent shift in dementia discourse towards promoting and protecting the rights of people with dementia through adoption of the models and legal frameworks developed by the disability rights movement. Applying disability rights models to dementia is relatively new - dementia has typically not been considered as a disability - and not without controversy. However, the impairments it causes means that people with dementia fall within the UN Convention on the Rights of People with Disabilities (CRPD) definition as being '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'.

As the main international instrument promoting and protecting the rights of people with disability, the CRPD provides a strong and influential legal framework, which the UK has agreed to implement and abide by. It does not provide new, additional protections but rather clarifies how generic human rights should be applied in the specific circumstances

⁴ Sarah Cooke and Camilla Parker (2008) Human Rights Based Approaches and Duty Bearers. Unpublished report for The Atlantic Philanthropies

⁵ McGettrick, G. and Williamson, T., 2015. Dementia, rights, and the social model of disability. Mental Health Foundation 47.

of people with disability. CRPD rights with particular relevance to people with dementia include the rights to health, habilitation and rehabilitation, independent living and community inclusion, personal mobility, participation in cultural life, equal recognition before the law, and family and home life.

Being underpinned by the social model of disability, the CRPD also demands a fundamental shift in how society understands and responds to disability. The social model of disability is the view that people are not disabled by their impairment (which can usually not be changed), but by a broad range of social, economic, attitudinal, physical, architectural and environmental factors (that often can be changed to address disability). This model is in contrast to the medical model of disability that assumes the impairment is the chief problem, only addressable by medical professionals, with the person with a disability being passive and dependent. McGettrick and Williamson present the following comparison of how these two models of disability might relate to dementia (Figure 2).

Figure 2 - The Medical and Social Models of Disability Applied to Dementia

Medical model	Social model
The problem is contained within the individual; dementia is about deficits – what’s the cure?	Social, attitudinal and architectural environments are the barriers to an individual’s participation
A person with dementia is not involved in decisions: decisions are made for them	A person with dementia is at the centre of the decision-making process (and is supported in this way)
A person with dementia has no responsibilities, no control and is disempowered	A person with dementia is responsible, has control and is empowered and self-determining (facilitated by the appropriate support)
People with dementia are charity cases in need of sympathy; they are victims and are objectified	People with dementia have human rights, are deserving of dignity and respect, and are active subjects
People with dementia are passive dependents	People with dementia are active citizens
Policy and services responses largely paternalistic and oppressive	Policy and services responses as tools of inclusion and active engagement
Power and control is outside the hands of people with dementia: it is with other stakeholders	Power and control in the hands of the individual with dementia

Disability rights are potentially powerful levers for change for dementia and, via the process of shadow reporting, the CRPD provides civil society and disabled persons’ organisations with mechanisms to engage in policy development and hold public authorities to account. Although compliance of policy and practice with the CRPD remains largely untested in court, the use of rights based approaches to encourage better dementia policy and practice is growing.

4. HOW ARE RIGHTS BASED APPROACHES BEING USED IN DEMENTIA ADVOCACY?

Rights based approaches in dementia are taking several forms, encompassing a mix of consultative and more campaigning approaches:

- individual rights-based challenges - using human rights standards to challenge the decisions of service providers as regards individuals;

- establishment of dementia ‘working groups’ - people with dementia working together locally and internationally to advocate for their rights;
- the development of charters of rights and rights based dementia campaigning — defining how people with dementia expect their rights to be promoted and protected by public authorities and encouraging the adoption of rights based approaches in dementia policy and practice.

a. Individual Rights Challenges

This approach involves using legal advocacy, and sometimes court cases, to address decisions made by public authorities which appear not to respect and promote an individual’s human rights. The individuals concerned are typically supported by social justice organisations, who help put forward an argument illustrating the impact on human rights grounds of a decision or action taken by a public body.

For example, the British Institute of Human Rights has supported people with dementia and their carers in England to address decisions made by health and social care providers on such issues as⁶:

- location of care home placement - where it was successfully argued that the placement of a woman in a distant care home, inaccessible to her husband, failed to uphold her right to family;
- improper placement in a care home - where a failure to secure the appropriate authorisation to move a woman with dementia into a care home against her family’s wishes was judged in court to have breached her right to liberty as well as her right to family and private life;
- use of restraint - where the practice of strapping a hospital patient, who was at risk of falling, into her wheelchair for long periods was challenged on the grounds of her right to be free from cruel and inhuman treatment;
- person-centred decisions - where the source of the distressed behaviour of a woman with dementia living in a care home was found to be the late getting-up time applied to all residents across the home. Taking account of her right to private life, the home introduced a personalised schedule that resolved her distress.

Although this approach is centred on decisions affecting individual service users, public bodies are encouraged to apply the principles being argued to their broader policy and practice for the benefit of others.

b. Dementia Working Groups

The voice of people with dementia is increasingly being heard, with dementia member groups and individuals with dementia becoming a stronger element of the dementia discourse at a national, European and international level.

- Working groups of people with dementia now exist across the **UK and Ireland**, for example: Dementia NI, the Irish Dementia Working Group, the Scottish Dementia Working Group, and the many Dementia Empowerment and Engagement Programme (DEEP) members across the UK. The Scottish Dementia Working Group (established in 2002) has a formal reporting structure into government, providing feedback to ministers on the implementation of Scotland’s dementia strategies and its duties under the CRPD.
- At a **European** level, the European Working Group of People with Dementia represents people from 10-15 EU countries and has voting rights on the board of Alzheimer

⁶ <https://www.bih.org.uk/Pages/FAQs/>

Europe. In many cases European dementia working groups work in partnership with (and may be facilitated by) national dementia organisations.

- Working groups exist in Japan, Canada and Australia, and Dementia Action International (DAI) is a **global** self-advocacy organisation of people with dementia, describing itself as ‘the global voice of people with dementia’. DAI works in collaboration with Alzheimer’s Disease International (ADI), which it describes as ‘the global voice for people with dementia’, and aims to engage with national Alzheimer’s organisations.

Working groups are active in shaping the dementia policy agenda, tackling stigma and promoting the rights and entitlements of people with dementia. The self advocacy model in dementia replicates the disability rights movement’s approach to promoting the social model of disability via the development of collective activism from within the disability community itself. McGettrick and Williamson described the dementia working group model as: “*the social model of disability and the human rights-based approach in action*”⁷.

c. Charters of Rights for Dementia and Rights-based Policy Advocacy

Charters of rights have been developed in several countries to help convey how human rights standards should be interpreted as regards people with dementia and express how people with dementia expect their rights to be fulfilled and protected. Their intention is to:

- communicate a clear advocacy message - how do we want things to be?
- empower people to exercise their rights in daily life and hold public authorities to account - what standards should I expect?
- provide guidance to policymakers and service providers - how can we do better?

The Charter of Rights for People with Dementia and their Carers in Scotland was published in 2009, and in 2016 a similar dementia charter was published in Ireland. Consistent with the social model of disability, they both express the rights of people with dementia (and carers in Scotland) across all areas of life, they are not restricted to health and social care concerns.

In England a National Dementia Declaration conveyed a similar message about how people with dementia expect to be treated but without reference to the human rights framework. Alzheimer’s Society’s newly launched strategy sees a much greater emphasis on promoting and upholding the rights of people with dementia in England, Scotland and Northern Ireland. This is consistent with the direction at an international level towards dementia policy that is much more explicitly tied to human rights standards, and in particular the CRPD.

At an international level, Dementia Alliance International (the global advocacy group for people with dementia) published ‘The Human Rights of People with Dementia: From Rhetoric to Reality’ in 2016, calling for dementia advocacy to be more firmly based on human rights principles, and for greater application internationally of the CRPD to promote and protect rights of people with dementia. The DAI document celebrates the adoption by Alzheimer’s Disease International of an explicit human-rights based policy.

The protection and promotion of the human rights of people with dementia is also a central principle of the recently launched World Health Organisation Global Action Plan on Dementia (December 2016). A guiding principle of the action plan is that:

⁷ McGettrick,G. and Williamson,T., 2015. Dementia, rights, and the social model of disability. Mental Health Foundation 47.

“Policies, plans, legislation, programmes, interventions and actions should be sensitive to the needs, expectations and human rights of people with dementia, consistent with the Convention on the Rights of Persons with Disabilities and other international and regional human rights instruments”.

Further details on the Scottish, Irish and English dementia charters are provided in Appendix 1.

5. APPLYING A HUMAN RIGHTS BASED APPROACH - LESSONS LEARNED

Several practitioners involved in disability and dementia advocacy were interviewed about their experiences of applying a HRBA to their work⁸. Their views on the potential value of a HRBA for dementia advocacy in Northern Ireland and the lessons they have learned about implementation are summarised below.

The value and potential of a human rights based approach:

- Practitioners highlighted that as a HRBA has the force of law behind it, it can provide powerful leverage for advocacy. This legal force means that rights based arguments can be convincing, even when they do not involve court action.
- A collaborative approach that seeks to embed the principles of human rights (dignity, autonomy, non-discrimination, respect etc) in public services can be effective. These principles align with many public servants’ personal and professional values. An advocacy organisation working in the health sector has found that services can be improved if frontline staff are enabled to embed their values into their own practice, and to become more confident about challenging practice and decisions that are not aligned with human rights principles.
- It was argued that human rights should be part of the armoury of any advocacy organisation. Each must determine how best to apply a HRBA to its work, but at minimum, advocacy organisations should become comfortable with expressing the outcomes their constituents seek in human rights terms.
- It was further suggested that within an issue such as dementia, advocacy organisations might consider whether they are collectively covering a range of rights based approaches. In practice, an organisation that holds public bodies to account for failures to uphold rights can create space for other organisations to take a more consultative approach.
- According to practitioners, the chief barrier to applying a HRBA relates to the view that it is complex and belongs to specialist (legal) organisations. Complexity can be a ‘turn off’ for advocacy organisations, the people they serve and public bodies and in some cases a political ‘chill factor’ can exist around human rights. It was recommended that dementia organisations collaborate with those already applying HRBA (e.g. in the disability rights sector) so they can develop their understanding and explore what practical approaches can be used.

Applying the principles of participation and empowerment:

- The perception that human rights work exists in a legal space can focus attention on the principles of legality, non-discrimination and accountability. However, several practitioners argued that putting the principles of participation and empowerment into practice offers the best means to transform attitudes and improve public services.

⁸ We are grateful for the advice provided by Alzheimer’s Society Ireland, Disability Action, Alzheimer’s Scotland, British Institute of Human Rights and the NI Human Rights Commission.

- It was noted that negative stereotypes and prejudice is often identified by people with disabilities, including dementia, as the biggest barrier faced. In its recent examination of the UK's implementation of the CRPD, the UN's Committee on the Rights of Persons with Disabilities raised concern at the persistence of prejudice against persons with disabilities, making particular mention of the issue in relation to people with neurological and cognitive conditions such as dementia.
- In this regard, the recent growth of working groups led by people with dementia was welcomed and examples of participatory policy initiatives were noted (e.g. the co-chairing of the implementation of the Physical and Sensory Disability Strategy in Northern Ireland by statutory and disabled persons organisations).
- However, it was also noted that most public bodies and indeed many advocacy organisations have not put in place the mechanisms required for genuine participation and empowerment of people with disabilities, including dementia. At worst participation can be short-term, tokenistic or completely absent. Scope therefore exists to develop participatory means through which people with dementia can have sustained involvement in service development and policy making activity.
- It was suggested that advocacy organisations who wish to see a HRBA in public policy making and service improvement, should also be comfortable that their own organisations reflect the principles of participation and empowerment. For example, dementia organisations might consider to what degree people with dementia can participate in organisational decision making, and if they are represented on their board and committees, and among staff.

Charters of rights:

- Practitioners identified positive impacts that dementia charters of rights have had while also noting several challenges to be considered if adopting this approach in Northern Ireland.
- It was noted that dementia charters have made a powerful statement about how people with dementia expect to be treated and have helped to clarify how human rights apply specifically to people with dementia. A charter can provide a common language that people affected by dementia, government and service providers can use to describe how to 'get it right' for people with dementia across a broad range of areas.
- Charters have also acted as a strong advocacy tool, particularly around participation and empowerment. In Scotland, the dementia charter has provided a framework for both the development process and content of national strategies and dementia initiatives. The charter has enabled people with dementia and advocates to hold public bodies to account for decision-making done without appropriate input from those affected, and to promote good, ongoing participation practice.
- Some questioned the role of charters of rights in the context of an existing rights framework, in particular the CPRD which already sets out how human rights apply to persons with disability. The risk was highlighted of adding further confusion to a human rights picture that is already poorly understood. This risk was deemed greater if charters include 'rights' that are not actually enforceable under law. However, others saw the value of a dementia-specific charter of rights to address the particular challenges faced by those affected by dementia, not least those associated with stigma, ageism and the progressive nature of the condition.
- Lessons learned by practitioners suggest that if a dementia charter was pursued in Northern Ireland, it should take account of the following recommendations:

- the process of creating a dementia charter should itself be rights based, with leadership and participation of people with dementia;
- it must have the involvement of all relevant parties (at minimum people affected by dementia, politicians, government officials, health and social care professionals and a range of other public service providers) from the outset, their consensus on the text to be used, and their commitment to adopting it once complete. Without this it risks becoming a 'feel-good' action with little sustained change in the empowerment and involvement of people with dementia; and
- creating a charter is not an end in itself, it should become a tool in a broader advocacy campaign with clear aims - before starting development, there should be agreement as to the purpose of the charter, and how it will be used to pursue the advocacy outcomes sought.

6. DEVELOPING HRBA IN DEMENTIA ADVOCACY IN NORTHERN IRELAND - POSSIBLE NEXT STEPS

Should dementia advocacy organisations in Northern Ireland seek to develop a HRBA to their work, they may consider the following next steps.

- Dementia advocacy organisations might begin by considering (in collaboration with their constituents) to what degree they are embedding rights based principles into their own ways of working. Are there means through which people with dementia are empowered and involved in organisational decision making and development of policies and practices? What more might be done?
- Dementia advocacy organisations and those they represent might come together to learn more about HRBAs and discuss what taking a rights based approach would mean for them collectively and individually. This might involve bringing in experience, for example via collaboration with local human rights and disability organisations or with other dementia organisations embedding a HRBA into their work.
- Organisations might also confirm their target outcomes in terms of the changes they want to see for people with dementia and how they will use a HRBA to try to achieve them. This might involve both individual and joint working, with organisations applying more consultative or campaigning rights based approaches as appropriate.
- Some such rights based approaches could include:
 - adopting human rights principles into the internal ways of working, priorities and discourse of dementia advocacy bodies;
 - raising awareness about the rights of people with dementia and promoting the social model of disability;
 - recording and challenging breaches of human rights, including taking legal action where appropriate;
 - scrutinising policy and practice in terms of human rights principles; and
 - encouraging and facilitating the adoption of a rights based approach to the development of dementia policy and practice, via mechanisms that empower and genuinely involve people with dementia in creating change. Opportunities that might be explored include the development of national dementia policy, local commissioning and service development activities, workforce development and education, and the development of dementia care pathways.

Appendix 1 - Further Details on Dementia Charters of Rights

Scotland

The Charter of Rights for People with Dementia and their Carers (2009) was developed by the Cross-Party Group on Alzheimer's Disease in the Scottish Parliament in 2009, in collaboration with people living with and affected by dementia and guided by PANEL principles. The aim of the Charter is to empower people with dementia and carers to assert their rights in every area of life, ensure that those providing them with services and support are aware of the rights of people with dementia, and to support the highest quality of service provision. The rights stated in the Charter are shown in full below.

Charter of Rights for People with Dementia and their Carers in Scotland (2009)

Participation

1. People with dementia and their carers have the right to be provided with accessible information and the support they require in order to enable them to exercise their right to participate in decisions which affect them.
2. People with dementia and their carers have the right to live as independently as possible with access to recreational, leisure and cultural life in their community.
3. People with dementia and their carers have the right to full participation in care needs assessment, planning, deciding and arranging care, support and treatment, including advanced decision making.
4. People with dementia and their carers have the right to be assisted to participate in the formulation and implementation of policies that affect their well-being and the exercise of their human rights.

Accountability

5. People with dementia and their carers have the right to be able to enjoy human rights and fundamental freedoms in every part of their daily lives and wherever they are, including full respect for their dignity, beliefs, individual circumstances and privacy.
6. Public and private bodies, voluntary organisations and individuals responsible for the care and treatment of persons with dementia should be held accountable for the respect, protection and fulfilment of their human rights and adequate steps should be adopted to ensure this is the case.

Non-discrimination and equality

7. People with dementia and their carers have the right to be free from discrimination based on any grounds such as age, disability, gender, race, sexual orientation, religious beliefs, social or other status.

Empowerment

8. People with dementia have the right to have access to appropriate levels of care providing protection, rehabilitation and encouragement.
9. People with dementia have the right to help to attain and maintain maximum independence, physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.
10. People with dementia and their carers have the right to access to opportunities for community education and lifelong learning.
11. People with dementia have the right to access to social and legal services to enhance their autonomy, protection and care.

12. People with dementia have the right to health and social care services provided by professionals and staff who have had appropriate training on dementia and human rights to ensure the highest quality of service.

Legality

13. People with dementia and their carers have the right to have the full range of human rights respected, protected and fulfilled. In addition to those explicitly contained in the Human Rights Act 1998, these include;

- the right to live in dignity and security and be free of exploitation, violence and physical, mental or sexual abuse
- economic, social and cultural rights including the right to an adequate standard of living including, social protection
- the right to the highest attainable standard of physical and mental health.

14. People with dementia and their carers have the right to information, to participation in decision making and, where rights are not observed, the right to seek remedy through effective complaint and appeal procedures.

15. People with dementia have the right, regardless of diagnosis, to the same civil and legal rights as everyone else. Where someone lacks capacity to take a specific action or decision due to their mental disorder, anyone acting for them must have regard for the principles and provisions of the Adults with Incapacity (Scotland) Act 2000 Act. These principles are enshrined in Article 12 of the Convention on the Rights of Persons with Disabilities which sets out international standards in relation to legal capacity. In summary, any intervention on behalf of the person with dementia who lacks capacity must:

- benefit the person
- restrict the person's freedom as little as possible whilst still achieving the desired benefit
- take account of the person's past and present wishes (with appropriate support to assist communication)
- take account of the views of relevant others
- encourage the person to use their existing abilities and to develop new skills.

The Standards of Care for Dementia in Scotland set out how health and social care services should look if they are to fulfil the rights and stated desires of people with dementia as regards care, treatment and support. The Standards document aligns the rights included in the Charter of Rights to the series of health care standards below (also expressed as 'rights') then describes what good care looks like against each standard. In effect, this sets out the care pathway for dementia in Scotland, services that should be provided and quality dimensions for those services. People with dementia and families are encouraged to use the Standards of Care for Dementia to demand the care, treatment and support they need, and service providers are encouraged to use them as a benchmark to assess and improve the quality of their services (measures and reporting mechanisms are specified).

The third element of Scotland's dementia strategy - the Promoting Excellence Framework (2011) - defines the workforce competencies needed to deliver on the Standards of Care and Charter of Rights.

Standards of Care for Dementia in Scotland (2011)

I have the right to...

- be regarded as a unique individual and to be treated with dignity and respect
- access a range of treatment, care and supports
- be as independent as possible and be included in my community
- have carers who are well supported and educated about dementia
- end of life care that respects my wishes

Ireland

Alzheimer's Society of Ireland & the Irish Dementia Working Group published A Charter of Rights for People with Dementia in 2016. The Charter is based on the Scottish Charter of Rights for People with Dementia and their Carers, although it doesn't have its dual framing around people with dementia and carers, and omits or slightly amends several of its statements. As per the Scottish charter, the Irish Charter aims to be a resource and support for people with dementia, empowering them to exercise their rights in daily life, as well as being a tool for the people who support them, policy makers and service providers.

A Charter of Rights for People with Dementia - The Alzheimer's Society of Ireland

Participation

- People with dementia have the right to be provided with accessible information and necessary supports to enable them to exercise their right to participate in decisions and policies which affect them.
- People with dementia have the right to live as independently as possible with access to recreational, leisure and cultural life in their community.
- People with dementia have the right to full participation in care needs assessment, planning, deciding and arranging their care, support and treatment.

Accountability

- Public and private bodies, voluntary organisations and individuals responsible for the care and treatment of people with dementia should be held accountable for the respect, protection and fulfilment of their human rights and adequate steps should be adopted to ensure this is the case.

Non-discrimination and equality

- People with dementia have the right to be free from discrimination based on any grounds such as age, disability, gender, ethnicity, sexual orientation, religious beliefs, membership of the travelling community, civil and family status.

Empowerment

- People with dementia have the right to access appropriate levels of care providing protection, rehabilitation and support. People with dementia have the right to help to attain and maintain maximum independence, physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life.

- People with dementia have the right to access opportunities for community education and lifelong learning.
- People with dementia have the right to health and social care services provided by professionals and staff who have had appropriate training on dementia and human rights to ensure the highest quality of service.

Legality

- People with dementia have the right, regardless of diagnosis, to the same civil and legal rights as everyone else. Where someone lacks capacity to take a specific action or decision due to their cognitive condition, anyone acting for them must have regard for assisted decision making (capacity) legislation in Ireland.
- Where rights are not observed, the right to seek remedy through effective complaint and appeal procedures.

England

A dementia charter of rights has not been developed in England. The National Dementia Declaration for England published in 2010 shares some of the elements of a rights charter. It was produced by an alliance of organisations with an interest in dementia (including charities, hospitals, social care providers, Government bodies, pharmaceutical companies, royal colleges and businesses) with input from people with dementia and their families and carers. It sets out 7 'I Statements' that describe the aspirations of people with dementia for the outcomes they would like to see in their lives.

1. I have personal choice and control or influence over decisions about me.
2. I know that services are designed around me and my needs.
3. I have support that helps me live my life.
4. I have the knowledge and know-how to get what I need.
5. I live in an enabling and supportive environment where I feel valued and understood.
6. I have a sense of belonging and of being a valued part of family, community and civic life.
7. I know there is research going on which delivers a better life for me now and hope for the future.

The Declaration is not linked to the human rights framework, but there is some common content between the 'I Statements' and the other dementia rights charters, for example both refer to the ability of people with dementia to access information, participate in decisions that affect them, be free from discrimination and to participate fully in their communities.

England, Wales & Northern Ireland - Alzheimer's Society

Alzheimer's Society strategy for 2017-22 'A New Deal on Dementia' sets out its aims for change in terms of dementia support, dementia in society and dementia research. Its commitments to a 'new deal on society' include a pledge to bring dementia rights into the mainstream and make sure that people with dementia are treated as equal members of society.

A new campaign for Northern Ireland - 'It's all about rights' - further supports the emphasis on rights. Through this campaign Alzheimer's Society aims to advocate on the rights of people affected by dementia, which are expressed as:

- a right to know about dementia and how it will affect you;
- a right to support that helps you live well for longer and that maintains quality of life as dementia develops;
- a right to make decisions about health, welfare and finance while you have capacity to do so;
- a right to be part of your community and to be as active and involved as you choose, along with family carers who often feel isolated in their caring role;
- a right to quality dementia care in all care settings including your own home; and
- a right to information about reducing our risk of developing dementia and recognising symptoms so we seek medical help early.