

Sheffcare Charter of Rights for People living with Dementia

Why a Charter is needed

People living with Dementia and their carers (family members and friends) have the same human rights as every other citizen. However, it is widely recognised that, in addition to the impact of living with dementia, they face cultural, social and economic barriers to fulfilling these rights. This charter aims to empower People living with Dementia, those who support them and the community as a whole, to ensure their rights are recognised and respected.

Nature of the illness

Dementia is an illness that over time affects the capacity of individuals to make some or all decisions about their everyday lives, including their money, health and welfare. It gradually affects their ability to communicate reason and act in their own interests. The illness severely compromises their ability to protect their own rights; because of this People living with Dementia are often at greater risk of violence, injury or mental abuse, neglect or negligent treatment, maltreatment or financial exploitation.

Inadequate and inappropriate services

There is evidence from research, inspections by scrutiny bodies and consultations that People living with Dementia and their carers do not receive, for the most part, the right support, care and treatment they need to continue to live fulfilling lives. Services for People living with Dementia are generally poorly resourced, patchy and often inappropriate, sometimes commissioned and provided by staff with very little knowledge of the illness. This is not due to any lack of models of good practice and high quality services but to a systemic failure to mainstream Dementia care and ensure that a comprehensive service is available to all from early diagnosis to end of life care.

Attitudes in society

People living with Dementia still face stigma and discrimination in society as well as a lack of equity of access to high quality Dementia care services. Awareness raising campaigns to increase public understanding are beginning to change attitudes to Dementia. However, changing attitudes and practices to ensure that the rights of People living with Dementia are fully recognised continues to be a major challenge for bodies responsible for the provision of health and social care. In addition to distressing accounts from carers and People living with Dementia, there is a growing body of evidence to support the view that the rights of People living with Dementia are being overlooked, neglected or in a few individual cases, deliberately breached.

Unmet needs of carers

Caring for someone with Dementia can be stressful because of the complex, unpredictable and progressive nature of the illness and may have a profound social, emotional, physical and financial impact on carers, including increased risk of stress related illness such as depression. Many carers feel that their views and needs are overlooked by health and social care professionals and that their right to support as partners in the provision of care is not well recognised.

Charter of rights is needed to:

- Empower People living with Dementia and their carers to assert their rights in every part of their daily lives and wherever they are.
- Ensure that those who provide health, social care and other services understand and respect the rights of People living with Dementia and their carers.
- Ensure the highest quality of service provision to People living with dementia and their carers.

People living with Dementia and their carers, at every stage of the illness and wherever they are, have the following rights:

Participation

People living 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.

People living 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.

People living 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.

People living 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

People living 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.

Public and private bodies, voluntary organisations and individuals responsible for the care and treatment of People living 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 living 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

People living with Dementia have the right to access appropriate levels of care providing protection, rehabilitation and encouragement.

People living 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 living with Dementia and their carers have the right to access opportunities for community education and lifelong learning.

People living with Dementia have the right to access to social and legal services to enhance their autonomy, protection and care.

People living 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 living 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.

People living 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.

People living 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.

In summary, any intervention on behalf of the Person living 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.