

Charter of Rights

for People with Dementia and their Carers in Scotland



Stepping out of the shadows

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The Cross-Party Group in the Scottish Parliament on Alzheimer's brings together Members of the Scottish Parliament with organisations representing the interests of people with dementia. The group works towards ensuring high quality support, services and treatment are in place to assist people with dementia and their carers throughout Scotland. As part of this work the group has considered how to ensure that the rights of people with dementia and their carers are fully recognised at all levels of government and by individuals and non-governmental organisations, regardless of where they are and in every part of their daily lives.

Your support will help us to raise awareness and campaign for the rights of people with dementia and their carers to be recognised.

Please register your support for the Charter by going to the Alzheimer Scotland website: www.dementiarights.org
Thank you.

A handwritten signature in blue ink that reads "Irene Oldfather".

Irene Oldfather, MSP
Convenor, Cross-Party Group on Alzheimer's
October 2009

Why a **charter** is needed

People 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 the illness, they face cultural, social and economic barriers to fulfilling these rights. This charter aims to empower people 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 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 with dementia and their carers do not receive, for the most part, the proper support, care and treatment they need to continue to live fulfilling lives. Services for people with dementia across Scotland 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 in Scotland 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 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 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 with dementia, there is a growing body of evidence to support the view that the rights of people 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.

The Cross-Party Group in the Scottish Parliament on Alzheimer's therefore believes that a Charter of rights is needed to:

- empower people 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 with dementia and their carers; and
- ensure the highest quality of service provision to people with dementia and their carers.

The Charter reflects the views of over 500 people (including people with dementia, their carers, and professionals) who took part in the widespread consultation carried out on behalf of the Cross-Party Group by Alzheimer Scotland between May - July 2009.

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

Preamble

In pursuance of the Human Rights Act 1998 and The Scotland Act 1998 the rights contained within this charter are based on internationally agreed human rights and are intended to promote the respect, protection and fulfilment of all human rights of people with dementia and their carers, as guaranteed in the European Convention of Human Rights, the Universal Declaration of Human Rights, the International Covenants on Economic, Social and Cultural Rights and Civil and Political Rights, and the Convention on the Rights of Persons with Disabilities, the key principles of which are:

- respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- non-discrimination;
- full and effective participation and inclusion in society;
- respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- equality of opportunity;
- accessibility;
- equality between men and women.

The Charter also reflects other legal provisions and in particular the principles of the Adults with Incapacity (Scotland) Act 2000; the Mental Health (Care and Treatment) (Scotland) Act 2003, and the Adult Support and Protection (Scotland) Act 2007.



The charter is guided by a human rights-based approach (known as the "**PANEL**" approach, endorsed by the United Nations).

It emphasises the rights of everyone to:

Participate in decisions which affect their human rights.

Accountability of those responsible for the respect, protection and fulfilment of human rights.

Non-discrimination and equality.

Empowerment to know their rights and how to claim them.

Legality in all decisions through an explicit link with human rights legal standards in all processes and outcome measurements.

Photo from Dundee Consultation Event

People with dementia and their carers, at every stage of the illness and wherever they are, have the following rights.

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.
- 5 People with dementia and their carers have the right to be able to enjoy human rights and fundamental freedoms in
- 10 People with dementia and their carers have the right to access 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

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 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

- 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 access 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.

- an adequate standard of living including social protection; and
 - 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. 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; and
 - encourage the person to use their existing abilities and to develop new skills.