

SEE THEIR RIGHTS

See the person as an individual, not the dementia. We all have our own likes and dislikes, our own life story, which tells us more about who we are than a diagnosis does.

KNOW THEIR RIGHTS

Educate yourself and others. Understanding dementia isn't only about diagnosis and being able to identify symptoms. But reducing stigma and knowing how to respect and respond to the needs, will and preferences of people living with dementia.

PROMOTE THEIR RIGHTS

Learn more about Dementia and Human Rights and how you can influence and advocate for them. The PANEL Principles provide a framework to put a human rights-based approach into practice and ensure real change for people living with dementia.

DEMENTIA RIGHT PROJECT

The DEMENTIA RIGHT – DEVELOPING A RIGHTS-BASED APPROACH TO DEMENTIA aims to improve the quality of life, social inclusion and dignity of people living with dementia, their carers and families, by developing effective guidelines for the implementation of a rights-based approach to dementia, including healthcare settings, to better meet the needs, will and preferences of people living with dementia.

ACKNOWLEDGEMENTS

This project was co-funded through the ERASMUS + Programme (2020-I-PT01-KA204-078657) and was co-produced with contributions from all partners of the DEMENTIA RIGHT Consortium and endorsed by organizations representing people living with dementia and their carers. The resulting "CHARTER OF RIGHTS FOR PEOPLE LIVING WITH DEMENTIA" is also based on the Scottish "Charter of Human Rights", developed by the Cross-Party Group in the Scottish Parliament on Alzheimer's, on the Alzheimer Society of Ireland & the Irish Dementia Working Group's "Charter for Rights for People Living with Dementia". The Charter has been informed by the "PANEL" approach to Human Rights-based policy and practice, endorsed by the United Nations, consistent with the Global action plan on the public health response to dementia 2017-2025, the Universal Declaration of Human Rights and the Convention on the Rights of Persons with Disabilities.

CHARTER OF RIGHTS FOR PEOPLE LIVING WITH DEMENTIA

RESPECT PROTECT AND PROMOTE



THIS CHARTER OF RIGHTS has been developed to empower people living with dementia, those who support them and the community as a whole, to ensure their fundamental Human Rights are respected, protected and promoted.

HUMAN RIGHTS focus on equality, dignity, respect, freedom and justice and are inherent to all human beings, regardless of any disability, illness or disease. Human Rights are absolute and universal (equal for all human beings), indivisible (equal in importance) and interdependent (they interact as part of a global framework of Rights).

DEMENTIA can be defined as an umbrella term for a number of neurological conditions that contribute to the progressive decline of brain function, which can cause problems with memory, thinking, problem solving, language, behavior and perception.

There are over 55 million people worldwide living with dementia today with a new case diagnosed every 3 seconds. It is one of the major causes of disability and dependency among older people worldwide.

PEOPLE LIVING WITH DEMENTIA, their carers and families have the same rights as every other citizen. However, in addition to the impact of the disease, they often face cultural, social and economic barriers to fulfilling their rights.

DEMENTIA RIGHT PROJECT believes that all policies, plans, legislation and programmes must be sensitive to the needs and preferences of people living with dementia, and values their Human Rights.

PRINCIPLES TO ENSURE REAL CHANGE

The **PANEL principles** provide a framework to put a human rights-based approach into practice and ensure real change for people living with dementia. PANEL stands for Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality.

The PANEL approach is endorsed by the United Nations and includes all the cross-cutting principles identified by the WHO Global Dementia Action Plan.

PARTICIPATION

People living with dementia, their carers and family members, like any citizen, have the right to participate in all decisions, including health and social care policies that may affect them or their wellbeing. People living with dementia and their carers have the right to accessible, accurate information, and be supported to enable them to participate in an informed decision-making process. They also have the right to full participation in all decisions regarding their care needs; assessment, planning, support, treatment and advanced-decision making.

Additionally, people living with dementia have the right to live their lives as independently as possible, with absolute respect for their will and preference, and to actively participate in their communities.

ACCOUNTABILITY

As rights holders people living with dementia, their carers and family members have the right to exercise their Fundamental Rights in every part of their daily lives. As duty bearers, public and private bodies, voluntary organizations and individuals responsible for the care and treatment of people living with dementia, should be empowered to and held accountable for enabling people living with dementia to exercise their Human Rights.

NON-DISCRIMINATION AND EQUALITY

People living with dementia, their carers and family members have the right to be free from discrimination on any grounds, such as age, disability, gender, ethnicity, sexual orientation, religious beliefs, social, civil, family or any other status. All public health and social care policies and programmes must be developed and provided by professionals with dementia expertise, be person-centred, support equality and be accessible for all.

EMPOWERMENT

People living with dementia, their carers and organisations representing them must be empowered and supported to participate in dementia advocacy, policy, planning, legislation, service provision, monitoring and research.

People living with dementia and their carers have the right to access any social and legal services to enhance their autonomy, and ensure their full inclusion and participation in all aspects of their lives. They should be fully supported to ensure quality of life, maintain maximum independence; physical, psychological and social wellbeing, through access to work, education and meaningful daily activities.

LEGALITY

People living with dementia have the right, to the same civil and legal Human Rights as any other citizen. Duty bearers, acting on behalf of someone who does not have the capacity to take a specific action or decision due to their cognitive impairment, must have regard for the principles and provisions of national legislation on capacity and disability, consistent with the Universal Declaration of Human Rights, the Convention on the Rights of Persons with Disabilities and any other international Human Rights instruments.

Where rights are not observed, people living with dementia and their carers have the right to seek remedy through effective complaint and appeal procedures and the right to be supported in that process.

