

ENSURING A HUMAN RIGHTS-BASED APPROACH FOR PEOPLE LIVING WITH DEMENTIA



THE NEED FOR A HUMAN RIGHTS-BASED APPROACH

It is widely recognized that people living with dementia are frequently denied their human rights both in the community and in care homes. In many countries people living with dementia are often physically and chemically restrained, even when regulations are in place to uphold their rights. Furthermore, people living with dementia can also be victims of abuse. For example, they may be beaten for being "stubborn" or exhibiting challenging behavior. Third parties may also use a diagnosis of dementia to their own benefit, such as using deceit to acquire a person's assets. This reflects the ethical challenges inherent in the support and protection of people living with dementia, and legislation alone will not be sufficient to ensure the protection of their rights.

PANEL+: A HUMAN RIGHTS-BASED APPROACH FOR PEOPLE LIVING WITH DEMENTIA

Human rights are universal in that all people in the world are entitled to them, and these rights are inherent to the dignity of every human. This holds for people living with dementia and their family caregivers, however, their rights are often overlooked or even deliberately trampled. It is therefore important to address the issue of dementia through a human rights-based approach. This also allows for the reinforcement of the obligations of states and other stakeholders to protect the rights of people living with dementia. PANEL+¹ provides a framework with important elements to keep in mind if we want to promote the respect for the rights of people living with dementia (1).

PANEL+

P articipation
A ccountability
N on-discrimination
E mpowerment
L egality

PARTICIPATION

People living with dementia and their caregivers have the right to participate in all decisions which affect their lives and wellbeing. Additionally, people living with dementia and their caregivers have the right to participate in the formulation and implementation of policies that affect them. Therefore, to assist recruitment of people living with dementia into academic research and the development of policies and services affecting them, funding should be made available and consent procedures should be put in place.

Related to participation is the right of people living with dementia to have equal access to community services and facilities. This includes access to adequate food, water, clothing, education, health, public buildings, transport, housing schemes, information and communication. Accessibility also means that people living with dementia and their caregivers should be provided with accessible information and the support they require to empower them to exercise their right to participate in decisions that affect them.

“THE VOICES OF OLDER PEOPLE LIVING WITH DEMENTIA AND THOSE WHO LOOK AFTER THEM NEED TO BE HEARD IN A MEANINGFUL WAY”.

The first UN Independent Expert on the enjoyment of all human rights by older persons, Rosa Kornfeld-Matte (2).

¹ The acronym "PANEL", endorsed by the United Nations and adopted by the Scottish parliament, represents the basic principles of human rights. Taking into account the development of the international human rights framework, PANEL+ embraces other important human rights concepts and principles, such as accessibility, transparency, legal capacity and autonomy.

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CASE STUDY: DEMENTIA FRIENDS, ENGLAND, UNITED KINGDOM

To allow people living with dementia to fully participate in society, Public Health England and the Alzheimer's Society UK have developed the joint initiative "Dementia Friends". Anyone in England can become a dementia friend by signing up online, and currently, over 1 million people have taken part. Dementia friends are given advice on how to help people with dementia living in the community. The initiative both increases awareness of dementia and encourages the general population to offer help and support enabling people living with dementia to participate in society for longer.
<http://alzheimers.dementiafriends.org.uk/>

CASE STUDY: ELDER JUSTICE COURTS, SOUTH CAROLINA, THE UNITED STATES OF AMERICA

Elder Justice Courts, which will be trialed in South Carolina, entertain both civil and criminal cases and are designed to cater to the needs of the ageing population and people living with dementia. This will include cases of financial exploitation, domestic violence, landlord and tenant disputes to name a few. The court and staff will be trained to be "senior and dementia" friendly and sensitive to their needs. This will be a problem solving court focusing on using local and state agencies and services as key resources in case resolution.
<http://www.eldersandcourts.org/states/South-Carolina.aspx>

ACCOUNTABILITY

People living with dementia should be able to exercise their human rights and fundamental freedoms in all aspects of their daily lives including full respect for their dignity, beliefs, individual circumstances and privacy. Public and private bodies, non-governmental organizations and individuals who are responsible for the care of people living with dementia should be held accountable for the respect and protection of their care recipients and adequate steps should be adopted to ensure this is the case.

States, organisations and individuals who care for people living with dementia are therefore, responsible for respecting and protecting their human rights. If they fail in this duty then a person with dementia should have access to justice, on an equal basis with others, as well as to be able and supported to initiate proceedings for appropriate redress before a suitable court. Therefore, it is important that the creation and implementation of laws and policy, which affect people living with dementia, are transparent to ensure that people know their rights and how to claim them.

NON-DISCRIMINATION AND EQUALITY

People living with dementia and their caregivers have the right to be free from discrimination based on any grounds such as age, disability, gender, race, sexual orientation, religious beliefs, health status and also directly because of their dementia. However, within society there is a lack of understanding of dementia. This causes fears about developing dementia and consequently, discrimination and stigma associated with dementia. For those who have dementia, their caregivers and their families, this contributes to social isolation and to delays in seeking and receiving help.

Awareness-raising and understanding are important for countering the fatalism and stigma associated with dementia. Awareness-raising campaigns should include education on human rights. Campaigns should also, discuss dilemmas related to ethical issues which arise when providing dementia care. These campaigns often involve celebrities and more recently, people with dementia and their caregivers who provide a realistic and more positive image of living with dementia.

CASE STUDY: ALZHEIMER'S ASSOCIATION CAMPAIGN, BRAZIL

To increase awareness of dementia in Brazil, the Brazilian Alzheimer's Association organised a televised campaign using a famous actress. The purpose of this campaign was to raise general awareness and educate the population about dementia thereby, decreasing stigma. Additionally, the campaign encouraged people to talk about dementia and the number of calls to the Association's help line doubled.
<http://www.alz.org/br/dementia-alzheimers-en.asp>

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EMPOWERMENT

People living with dementia should be empowered to claim their rights rather than simply wait for policies, legislation or the provision of services. As rights-holders, they should be able to exercise their rights in all circumstances.

Related to this, people living with dementia should be able to enjoy legal capacity on an equal basis with others. Therefore, clear distinction should be made between mental capacity and legal capacity in order to clarify that the right to exercise **legal capacity** should not hinge on mental assessments. People living with dementia have, regardless of diagnosis, the right to recognition everywhere as people before the law and the right to choose the support that he or she may need or require. Conversely, in many countries, there exist legal provisions that allow forced treatment and substitute decision-making in relation to psychiatric and other medical treatments. This affects people with psychosocial and intellectual disabilities and people with dementia. Those legislative provisions should be abolished and replaced by legislation that ensures free and informed consent to treatment, supported decision-making, and procedures for implementing advance directives.

The first UN Special Rapporteur on the rights of persons with disabilities, Catalina Devandas-Aguilar, will continually address the barriers related to living independently in the community in her coming thematic work (3).

To preserve a person's **autonomy**, and to uphold the right of people with dementia to live independently, it is important to create a dementia-friendly environment. This includes, but is not limited to, encouraging healthy and active ageing with consistent primary care throughout one's life. Furthermore, people living with dementia have the right to access appropriate levels of care providing protection, rehabilitation and encouragement.

“MORE UNDERSTANDING ABOUT THE HOLISTIC NEEDS OF PERSONS WITH DEMENTIA IS NEEDED. BUT WE ALSO NEED PROPERLY TRAINED HEALTH PROFESSIONALS TO COPE WITH CARE OF PEOPLE WITH DEMENTIA”.

The UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Dainius Pūras (4).

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. Therefore good long-term care should encompass accessibility, availability and affordability of good quality health and social care without fear of discriminative treatment. This is important because access to health care is often prevented by multiple factors, including low literacy levels, living in a rural area, unsuitable or unavailable transport and poverty. Moreover, in low- and middle-income countries out of pocket payments and high costs of health care often deprive people living with dementia from accessing necessary health and social services.

People living with dementia and their caregivers have the right to an adequate standard of living and social protection. Whilst in high-income countries there is often access to some financial benefit, many people in low- and middle-income countries cannot access benefits such as retirement benefits or benefits for caregivers which can lead to severe financial difficulties (Figure 1). In some countries, people living with dementia are even forced to give up their legal capacity in order to access those benefits. Social protection strategies should also address issues affecting women with dementia. Women with dementia are often disabled from supporting themselves due to gender inequality and so, often lack education and adequate pensions. Moreover, older women may be subject to violence due to symptoms of dementia being misinterpreted as witchcraft.

CASE STUDY: SHARED DECISION MAKING RELATED TO HEALTH AND DAILY CARE, NORWAY

A Norwegian study was conducted to understand how people with dementia participate in decision making, and the role that their caregivers and health professionals play in the decision making process. It was found that people with moderate dementia were involved in decision making to different extents for example, some people with dementia delegated decision making to a caregiver or health professional, whilst others made decisions autonomously. The study also showed that the best approach to involve people living with dementia in decision making was to: Recognize that the person living with dementia was capable of making decisions, ensuring that he or she understood the decision to be made, and if necessary structuring and simplifying the environment to support decision making, providing cues to prompt memory, narrowing the range of available choices and clearly stating alternatives if the person did not understand (5).

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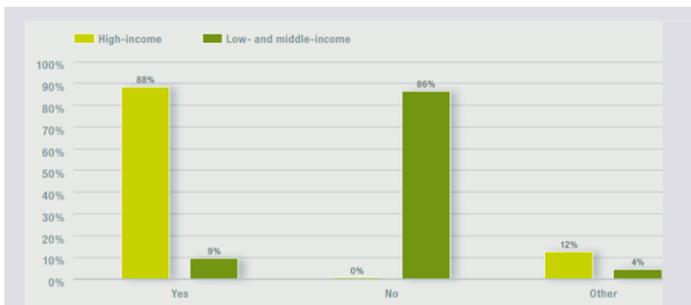


FIGURE 1 WHO dementia survey: Percentage of countries reporting availability of social / financial benefits for people living with dementia

LEGALITY

All measures related to dementia adopted by States and other stakeholders should be linked to human rights standards contained in, and principles derived from, the Universal Declaration of Human Rights and other international human rights instruments.² This includes all measures adopted related to dementia, including the development of policies and legislation, the implementation, monitoring and evaluation system and the entire care chain, from raising awareness to prevention, diagnosis, care and services and research programmes.

CASE STUDY: CHARTER ON HUMAN RIGHTS AND PEOPLE LIVING WITH DEMENTIA, SCOTLAND, UNITED KINGDOM

In Scotland, it was recognised that people living with dementia are entitled to the same human rights as everyone else. Nevertheless people living with dementia were still often being denied their rights due to social and cultural barriers. These barriers included a lack of understanding within the population, and a lack of training for care staff in how to respect and protect the human rights of people living with dementia. Therefore in 2009 the Scottish parliament adopted the human rights-based approach to dementia, PANEL. The aim was to uphold the human rights of people living with dementia both in the community and in care facilities in Scotland (1).

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International strategies and national frameworks for protecting the rights of people living with dementia should include PANEL[†]. It should be highlighted that people living with dementia have the right to participate in society, and ensure that those responsible for protecting the human rights of people living with dementia should be held accountable for any human rights violations. In addition, there should be increased education about dementia to change attitudes of society and reduce stigma. Lastly, people living with dementia should be empowered to participate in decision making processes and to maintain their legal capacity.

² Please see the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of People with Disabilities and the UN Principles for Older Persons, among others.

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Acknowledgments

This thematic briefing was prepared for the First WHO Ministerial Conference on the Global Action Against Dementia by Emma Craddock and Anne Margriet Pot (WHO). Contributions to this report were made by Becky Farren (Department of Health, United Kingdom); Khaled Hassine and Lydia Gény (Office of the High Commissioner for Human Rights (OHCHR)), Rosa Kornfeld-Matte, the UN Independent Expert on the enjoyment of all human rights by older persons; Catalina Devandas-Aguilar, the UN Special Rapporteur on the rights of persons with disabilities; Dainius Pūras, the UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, and; Tarun Dua and Michelle Funk (WHO).

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Design by: Erica Lefstad