



Brief for Alzheimer associations:

Access to the United Nations Convention on the
Rights of Persons with Disabilities by people living with dementia

Introduction

This document was created in collaboration with Dementia Alliance International (DAI), the international organization of people living with dementia, in order to enable Alzheimer associations to monitor the protection of the rights of persons with dementia under the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

The questions this brief seeks to answer are:

1. *How can the CRPD enable people with dementia to claim their human rights in their country?*
2. *Who are the Alzheimer associations' potential partners in monitoring the Convention?*
3. *When is a country due to present its national report on the implementation of the Convention?*

The terminology used in this brief will be:

CRPD: The United Nations **Convention** on the Rights of Persons with Disabilities, which came into force in 2006.

CRPD Committee: the **Committee of Experts** monitoring the implementation of the CRPD in UN member states who have ratified.

Articles: the **Articles of the UN Convention** on the Rights of Persons with Disabilities (2006). The Articles comprise 33 core articles covering both the obligations of duty bearers and the rights to be upheld; e.g. the right to accessible health care (Article 25); and the obligation to raise awareness about disability rights (Article 8).

Why is this brief important?

The CRPD provides a tool to enable people with dementia to claim their rights.

People with dementia are often denied their human rights and can experience social isolation and poor quality support.

People with dementia are protected by the CRPD because dementia is a major cause of disability and dependency influenced by symptoms, environments, discrimination and inequality.

This brief:

- Provides information on the CPRD Committee.
- Connects the Articles of the CRPD to key concerns of people with dementia and current developments in dementia. For example, efforts to improve the awareness of dementia such as dementia friendly communities relates to Article 8 of the Convention.
- Explains how Alzheimer associations can highlight issues for people with dementia under the system in place for monitoring the Convention.
- Provides helpful resources and links and an example of a submission made by a group of Canadian disability organizations, including the Ontario Dementia Advisory Group (people with dementia) and the Alzheimer's Society of Canada.

Alzheimer associations are encouraged to work with national country disability groups and persons with dementia to influence decision-makers about how the rights of people with dementia are required to be upheld by governments under the CRPD.

What is the CRPD Committee?

The CRPD Committee is the body of 18 independent experts which monitors the implementation of disability rights in countries that have ratified the CRPD. People with dementia face discrimination and barriers to participation in society, and as such their rights must be promoted, protected and respected.

As of 1st April 2017, 172 out of 198 UN Member States have now ratified the CRPD. To see a map of Members States who have ratified, please visit the [Resources and Links](#) section at the end of this document.

All ratifying Member states must submit regular reports to the CRPD Committee on how all the rights and obligations reflected in the Articles are being implemented. The Committee examines each State report, notes concerns and makes recommendations on actions to take in the following four years.

Civil society organizations such as ADI, national Alzheimer and related dementia societies, as well as organizations of persons with disabilities such as DAI have an opportunity to feed into this process. ***Civil society organizations can identify specific articles of the CRPD of particular relevance to people with specific disabilities (such as dementia) and submit statements or reports to the Committee on their country's compliance with the Articles.***

To find out more information about human rights in general, visit www.ohchr.org.

Two educational videos are available on YouTube: *What is a human rights treaty body?* (1 min 22 sec), and *The Human Rights Treaty Body system* (40 min). Please visit the links in the [Resources and Links](#) section at the end of this document. The session list of which countries are due to meet the Committee in the next two years is also provided in the [Resources and Links](#) section.

What do human rights mean for people with dementia under the CRPD?

Article 1 of the Convention 'ensures the full and equal enjoyment of all human rights and fundamental freedoms.' For people with dementia, this includes access to community, support, health and care from early symptoms to end of life.

As dementia progresses, people have varying abilities and disabilities depending on their individual symptoms and stage of the progression of the condition. The following broadly defined stages provide a way to interpret the Articles.

Mild stage

People can live for many years in the **mild stage** of dementia before symptoms are severe enough to require more support or care.

The priority for people in the mild stages of dementia is not care but rehabilitation and disability-supports to enable them to remain active citizens in their own communities; and to use local opportunities for recreation, continuing education, sports, arts and crafts, theatre and music. Such supports are referred to as dementia-enabling and help people with dementia to feel included in their communities rather than excluded by the stigma surrounding dementia.

The **moderate stage** describes the progression where professional support may be needed to support a person's independence and in continuing with dementia-enabling supports referenced above. Personal care may be needed with eating and personal hygiene. Prompting and cues can be helpful to ensure the person maintains as much control over their independence as possible.

The **late stage** describes people who require more intensive personal care. Every effort should be made to create activities that will be of interest to individuals and to ensure that visits from family and friends continue even when individuals appear no longer able to recognise them. There is evidence that people at this stage are able to experience emotion such as sadness and joy and can still respond to music and speech.

End stage

The **end stage** describes people who are close to the end of their life where a focus on comfort care, sensory stimulation, and reducing pain are essential to nurturing a person's quality of life.

The rights of people with dementia experiencing all of these stages are covered by the Articles of the CRPD, but each Article must be examined in terms of how a country meets the requirements of people with dementia nationally. There are 33 core Articles which offer key common elements including capacity and supported decision-making. A full listing of Articles can be found at the link in the [Resources and Links](#) section at the end of this document.

Articles related to people with mild to moderate dementia

Many Articles affect the ability of people in the mild to moderate stages of dementia to remain active in the community and continue to pursue their interests. People are still able to articulate their opinions and needs which relates to **Consult with and actively involve people in decision-making** (Article 4.3). For example, DAI members have individually and jointly influenced policies globally and within their own countries which also relates to **Freedom of Expression** (Article 21), as well as **Participation in Political and Public Life** (Article 29) with a continued right to vote.

One of the first objectives identified by people living with dementia was their right to know their own diagnosis and obtain the information needed in order to understand the progression of their condition. This is relevant to the **Right to Health** without discrimination (Article 25); essential in order for people with dementia to make their own decisions as early as possible.

Articles of the CRPD

Examples for people with mild and moderate dementia

- 4.3 Participation in decision-making
- 5 Equality and non-discrimination
- 8 Awareness raising
- 9 Accessibility
- 12 Equal Recognition before the law
- 19 Living independently and being included in the community
- 21 Freedom of expression and opinion; access to information
- 24 Education
- 25 Right to health
- 26 Habilitation and rehabilitation
- 27 Work and employment
- 29 Participation in political and public life
- 30 Participation in cultural life, recreation, leisure and sport

The right to supported decision-making rather than guardianship via **Equal Recognition before the law** (Article 12) will assist people with dementia to make decisions regarding daily life and determine how they wish to be cared for in the later and end stages of the condition.

Awareness Raising and **Accessibility** (Articles 8 and 9) apply to the work being promoted by dementia friendly communities to address stigma and discrimination and to facilitate access to transport, shops and community amenities.

Living Independently and **Habilitation and Rehabilitation** (Articles 19 and 26) relate to post-diagnostic support such as occupational, speech and physiotherapy, specialist nurses and other health professionals including counselling, psychological support and social work.

Cultural Activities, Recreation, Sports and Leisure (Article 30) encourage opportunities for people with dementia to be fully included in the community in meaningful ways that support their interests.

All of these articles working together could improve the lives of people with dementia.

Articles related to people with late and end stage dementia

People with dementia deserve a good quality of life equal to their fellow citizens, regardless of the stage of their illness.

For people in the late and end stages of dementia, the ability to live a good quality of life is dependent on how they are treated by others.

Liberty and Security of the Person (Article 14) and the right to **Freedom from Exploitation, Violence and Abuse** (Article 16) are major concerns in dementia.

People are often restrained through the use of physical limitations or given unnecessary medications in order to control them or to manage someone with behaviours that are perceived to be challenging by people providing care. However, much is known today through research and practice which suggests that influencing policies to provide better education for families, training for staff at all levels, and support to care workers reduces these behaviours, and therefore reduces the perceived need for physical, mechanical and/or chemical restraints.

Another concern for people with dementia, particularly in care facilities includes the right to express their intimacy and sexuality. The right to have **Respect for Privacy** (Article 22) by sharing rooms with multiple individuals must be addressed. Difficulties arise based on the varying capacities of consenting partners, staff cultural beliefs and a family's consent of the individual to have relationships.

Respect for Home and Family (Article 23) suggests that steps should be taken to eliminate discrimination in matters relating to relationships. People have the right to live in a place of their choosing, whether home or facility, with appropriate supports in place and with whomever they prefer to live with. Separating life partners into different residences may affect the ability of life partners to maintain relationships.

Articles of the CRPD*

Examples for people with late and end stage dementia

14 Liberty and security

16 Freedom from exploitation, violence and abuse

22 Respect for Privacy

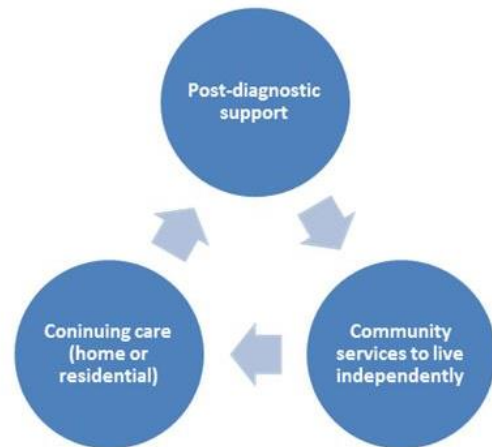
23 Respect for home and family

*many articles in the previous section also apply to people with late and end stage dementia due to the unique and individualized experience of dementia

The Right to Health (Article 25)

The right to health includes preventative, acute and long term care. Access to doctors, clinics and hospitals with well-trained professionals is essential to Right to Health (Article 25).

Long term care supports include **post-diagnostic**, **community services** and **continuing care**. These multi-level supports are also reflected in Article 25 which suggests that States must ensure that people have access to the **'highest attainable standard of health without discrimination on the basis of disability.'**



It is essential that these types of services are well known and well-funded in order to provide the best possible foundation for quality care to occur whether provided by families, professionals or care systems.

The knowledge and infrastructure currently exists in many countries but is often unknown or inaccessible to people with dementia and their families. Infrastructures can be developed in countries which lack adequate resources. The CRPD Committee reporting process, in tandem with the detailed monitoring now being put in place for the UN 2030 Sustainable Development Goals (SDGs or Action 2030) would enable civil society organizations to collect information and provide feedback to their governments on the availability, accessibility and quality of these supports.

Articles related to lower and middle income countries (LMIC) compared to high income countries (HIC)

Freedom from Torture and Inhuman Treatment (Article 15) and freedom of **Liberty and Security** (Article 14) especially relate to experiences in some Lower and Middle Income Countries (LMICs), where there have been recent examples of the torture of people with dementia such as being chained or burned alive following accusations of witchcraft. In some High Income Countries (HIC), chemical and physical restraint is used, despite evidence that such restraints are harmful.

Adequate Standard of Living (Article 28) is relevant to all countries with food insecurity and increasing numbers of people facing hunger.

Articles of the CRPD

LMIC compared with HIC

- 10** Right to life
- 13** Access to justice
- 14** Liberty and security
- 15** Freedom from torture or cruel, inhuman or degrading treatment or punishment
- 16** Freedom from exploitation, violence and abuse
- 28** Adequate standard of living and social protection

How can an Alzheimer association feed into the report process?

There are three main ways that Alzheimer associations can use the report process in their countries.

1. Connect with other disability organizations in a country and write a combined report describing which Articles of the CRPD are priorities for the stakeholder group.
2. Connect with the National Human Rights Institution (NHRI) in a country, if available. They are [listed here](#). NHRIs are independent of government under an international treaty known as the Vienna Convention (1983). The NHRI is appointed by the government to undertake independent monitoring of the CRPD and all other human rights treaties, such as those to protect the rights of women, children, and refugees. They will know a country's upcoming reporting dates and other organizations who could provide support.
3. Write a dementia-specific report after convening stakeholder meetings of people living with dementia to determine which articles are priorities for them.

How can an Alzheimer association choose which Articles are priorities for a report and presentations at CRPD meetings?

It is important to choose Articles that are priorities for people with dementia in the country (see above #3). In collaboration with other disability groups, Articles can be divided up so all of the Articles are addressed by different disability groups. In most meetings and reports, the CRPD Committee expects brief written or spoken representations that relate specific issues affecting people with dementia to the relevant CRPD Articles.

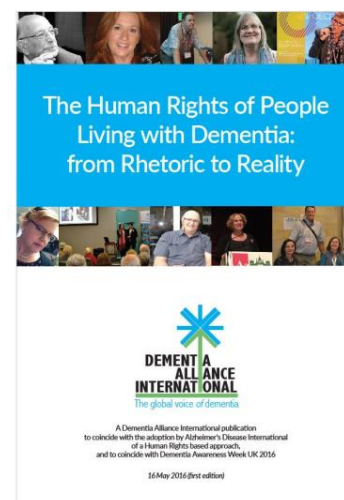
What happens after a report is submitted?

The CRPD reporting process is one way to influence individual countries to recognize the rights of people with dementia which are protected by the CRPD, and they must meet their obligations to protect, promote and respect all human rights. The CRPD Committee can offer expert advice and send consultants to countries on request to help a country improve their human rights agenda under Article 37 of the CRPD.

How can ADI and DAI help?

ADI and DAI are planning a series of joint publications, workshops, training events and web seminars. This brief is the first of a series of Human Rights Updates. In addition, examples from Alzheimer associations will be collected and uploaded onto the ADI website. For an example from Canada and other countries as they become available, please visit the ADI website at www.alz.co.uk/human-rights.

Many countries lack the meaningful involvement of people with dementia. DAI's booklet, [*The Human Rights of People Living with Dementia: From Rhetoric to Reality*](#), is a useful resource. Connect with DAI to identify possible people with dementia in your country who would like to help with this process or for DAI to advise on their interpretation of the Articles that might help the country most from the perspectives of people with dementia. Please contact DAI for more information at info@infodai.org.



Resources and links

Videos

The following video links are provided for convenience. A review will take place periodically to ensure the links remain up to date.*

- **'What is a human rights treaty body?'** (1 min, 22 sec)
<https://www.youtube.com/watch?v=vE0T45t040k&sns=em>
- **The Human Rights Treaty Body System** (40 min)
https://www.youtube.com/watch?v=JP0fB-_X0I8

Links

The following links are provided for convenience. A review will take place periodically to ensure the links remain up to date.*

- **Map of UN Member States who have ratified**
<http://indicators.ohchr.org/>
- **Meeting List of Upcoming Countries**
http://tbinternet.ohchr.org/_layouts/TreatyBodyExternal/SessionsList.aspx?Treaty=CRPD
- **Full Listing of the Articles in the Convention on the Rights of Persons with Disabilities**
<http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx>
- **Office of the High Commissioner for Human Rights (OHCHR)**
www.ohchr.org
- **National Human Rights Institution (NHRI) or Ombudsman**
See if your country has one here: <http://nhri.ohchr.org/EN>
- **UN Enable**
<https://www.un.org/development/desa/disabilities/>
- **Link to examples from ADI members**
www.alz.co.uk/human-rights

*Please notify ADI if problems are found accessing the links above.