



The UK Network of
Dementia Voices

The United Nations Convention on the Rights of People with Disabilities.....

Your chance to have a say! A real opportunity to influence the United Nations and keep dementia on the agenda.

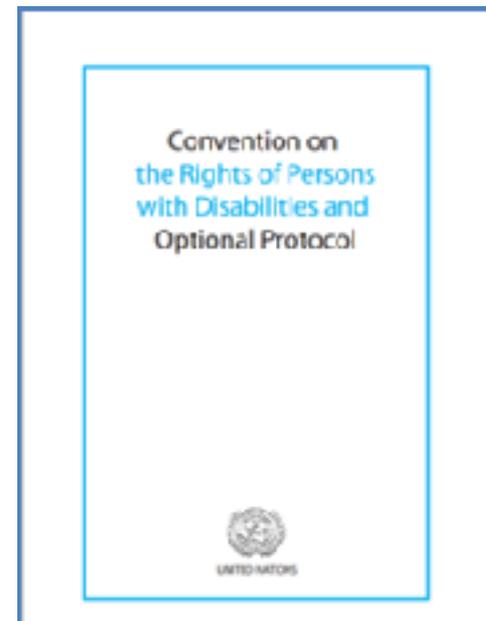
What is it?

The Convention tries to make sure that disabled people, including people with dementia, are treated equally.

It's a big document - you can find a link to it below - together with an 'easy read' version.

For people with dementia, the most relevant parts are probably those that say:

- People should be able to make their own choices
- People shouldn't be discriminated against
- People have the same rights to be included in society as everyone else
- People should have equal access to the same things as everyone else, which includes buildings, services, and opportunities.



Why are you asking us about it now?

The UK Government has ratified the Convention - which means that it has agreed to do all it can to make sure that people can enjoy the rights enshrined within it.

Later this year a United Nations Committee is due to explore the extent to which the UK has done this. It will hold the government to account.

DEEP will be working with Alzheimer's Society to produce what is known as a 'shadow report' - this is our chance to tell the committee about our rights, and whether they are respected, or not. We can use it to tell the UN Committee what kind of questions they should be putting to the UK government about their way people with dementia are treated.

This report will be considered by the UN Committee of disabled people at a meeting in August 2017.

What would you like DEEP groups to do?

The shadow report we want to send will be an account of the reality of people's lives - and how this relates to the Convention - and will be used to hold the UK Government to account.

The conversation is a big document. Rather than going through the whole thing it would be really helpful if you could let us know about your experience in a number of key areas which we think are particularly important for people with dementia.

- Accessibility
- Information
- Dementia Friendly Communities
- Independent living and support
- Standard of living
- Employment
- Health
- Protection from exploitation violence and abuse
- Autonomy and integrity, including restraint.

You might want to start by asking your group which of these areas are of most interest to people. Then use the questions below to guide your conversation. Feel free to use your own questions - the important thing is that we get at people's real experience in whichever way best suit them.

These are laid out below, with some questions to guide your conversation.

One way to approach this might be to decide which of these issues are most relevant to your group - it might be just one - it might be more.

You could either discuss these as a group, or email us directly if you want to make some individual comment.

Oh and one more thing - we are looking not just for problems but for good experiences too - if there are things that are going right its only fair that we report on that.

Reporting back

Philly Hare from Innovations in Dementia will be writing the report - based on what DEEP groups say.

The easiest way to do this would probably be to take some brief notes of what was discussed, along with any particularly good quotes - and then email them to Philly at:

philly@myid.org.uk

Please get your feedback to Philly by the 26th May

More reading. This is not essential, but.....

If you would like to read the whole convention - this link will take you to it:

<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

There is an easy-read version (not done by us!) here:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/345108/easy-read-un-convention.pdf

Questions you might want to consider

ONLY work on the areas that people are most interested in !!!

YOU don't need to fill this in like a questionnaire - just let us know what people said in the way that best suits you!!!

Accessibility

This is a BIG area that covers lots of relevant issues for people with dementia - so we wouldn't be surprised if you spent all your time on one of these.

Article 9 of the Convention says that governments should take steps to make sure that disabled people have equal access to:

- Information
- Services and facilities
- Transport
- The 'built environment'
- Housing

Although there is a long way to go - a lot of changes have to be made to make the world an easier place for people with disabilities. Ramps into buildings and buses and information in large print are just 2 examples.

There is a lot that can be done to make things easier for people with dementia to use too - but there are still many areas where we know that people struggle.

Question - do you have any experiences of finding these things difficult?

Question - do you think things have improved over recent years?

Awareness of dementia

Article 8 of the convention says that governments should raise awareness to increase respect and reduce stigma against disabled people (which includes people with dementia)

Question - Have you had a recent experience suggesting poor attitudes towards dementia?

Question - Do you think that recent awareness raising campaigns have helped?

Dementia Friendly Communities

These aren't mentioned specifically in the Convention - but potentially 'dementia friendly communities' can do a lot to strengthen rights to things like access and better awareness.

Question: Do you know about the work going on around dementia friendly communities?

Question: If so - what difference has it made to you or people with dementia that you know?

Independent living and support.

Article 19 of the convention says that disabled people have an equal right to live in the community and be a part of it.

To do this people need the right support.

Question - do you feel you have the right support to live as independently as possible and be part of your community?

A good standard of living

Article 28 says that disabled people have a right to an 'adequate' standard of living.

Question - do you feel that you have an adequate standard of living?

Question - does having dementia have an impact on your living costs - and if so do you get help with that?

Employment

Article 27 says that people should be protected from discrimination in the workplace and offered support if they become disabled.

Question - what is your experience of developing dementia whilst at work - what kind of support did you get?

Health

Article 25 says that disabled people should have the same access to healthcare as everyone else

Question - do you feel that you get the healthcare you need for your dementia?

Question - do you feel you get their healthcare you need for any other health conditions you might have have, or have had?

Exploitation violence and abuse

Articles 15 and 16 say that people have the the right to protection from violence exploitation or abuse.

Question - have you ever experienced mistreatment like this?

Autonomy and integrity, including restraint.

The issue of control is covered by at least 4 articles of the convention - and the notion that people with disabilities should be able to make decisions is central to the convention.

Question: Have you ever been forced to live, or be somewhere that you didn't want to be?

Question: Have you ever been restrained - either physically or by the use of drugs?

Question: Have you ever had someone else making decisions for you against your wishes?