

Dementia, Disability and Hope

A vision in practice
created with and for
people who are living
with dementia



Dementia, Disability and Hope is a vision created with and for people who are living with dementia.

We believe that there are things we can all do to make people's lives more hopeful.

It helps to look beyond the condition itself and its symptoms. Social attitudes and ignorance can disable you; for example, how your employer behaves towards you and the physical environment.

We want to help you find solutions to these barriers. Accepting that dementia is a disability can bring you many benefits and better support. And it can give you hope because attitudes and environments can be changed.

Staying hopeful

Some people think and talk about dementia as an incurable, hopeless illness. But even with a diagnosis of dementia, your life can still be meaningful. With the right support and adjustments, you can continue doing what you love for longer – or even learn new things. And you still have skills, life experience, wisdom and a role to contribute, whether as a partner, parent, family member, friend, employee or volunteer.

The social model of disability

The social model of disability is a way of viewing the world, developed by disabled people. It can help us all to look at dementia in a different way. In the model, the word 'impairment' is used to mean your medical condition, diagnosis, or how you function. The word 'disability' describes the social impact of your impairment.

Thinking about dementia like this may help you to focus on how the disabilities associated with your dementia connect with society, attitudes, and the environment. Acknowledging this can help you to recognise that these things may disable you, but your life is meaningful, has purpose and you still have abilities and a right to be included.

Dementia, disability and equality law

All of us, disabled or not, have rights. In equality law, dementia is classed as a disability. The requirement to make ‘reasonable adjustments’ to help you is already enshrined in equality law, but is often overlooked. Requesting ‘reasonable adjustments’ because of your dementia is simply about seeking equity or parity with other people.

It doesn’t matter whether or not you identify yourself as disabled; you may not want that label. But you can still use equality law to help you get what you need to live a fulfilling life. Recognising this can empower, and give hope to, you and your family/supporters.

Common barriers – and potential solutions

Here are some examples of obstacles people experience, and possible solutions based on equality law:

- **Feeling pressured into leaving work.** Request an assessment and ask your employer to make reasonable adjustments, such as working fewer hours or in a less demanding role
- **Feeling pressured into giving up driving.** Insist on an assessment of your individual capabilities
- **Not being offered – or being denied – rehabilitation, counselling or help to adapt.** Contact your health and social care service to request an assessment of your individual needs, not based solely on the fact that you have dementia
- **Being excluded from clubs or societies.** Educate fellow members by explaining and demonstrating that you can take part if they accommodate your needs
- **Being expected to cope with environments which are overwhelming and oppressive for you because of your dementia.** Request adjustments such as less noise, better lighting, or clearer signage

Understanding your rights and how to ask for the adjustments and support you are entitled to could be life changing both for you and for others. So, we encourage you to share the Dementia, Disability and Hope vision and to actively embed it into your life.

Information and resources

Further information about **Dementia, Disability and Hope** and additional resources are available here

youngdementianetwork.org/dementia-disability-hope

You may also find the following sources of support helpful:

Dementia UK

The Young Dementia Network is hosted by Dementia UK. Anyone with a question or concern about dementia can call the Admiral Nurse Dementia Helpline on **0800 888 6678** or book a phone or video appointment in the virtual clinic. dementiauk.org

Alzheimer's Society

For England, Wales and Northern Ireland.

Tel **0333 150 3456**

alzheimers.org.uk

Alzheimer Scotland

For Scotland.

Tel **0808 808 3000**

alzscot.org

Equality Advisory and Support Service

Tel **0808 800 0082**

equalityadvisoryservice.com

Liberty

Tel **0800 988 8177**

libertyhumanrights.org.uk

Rare Dementia Support

Tel **020 3325 0828**

raredementiasupport.org

The Young Dementia Network is a community of people living with young onset dementia, their family and friends, and professionals who work in health and social care and the voluntary sector.

We are working together to improve services for all people affected by young onset dementia.

To find out more about the Network and to join, visit:

youngdementianetwork.org or email

youngdementianetwork@dementiauk.org

