



THE ALZHEIMER
SOCIETY *of* IRELAND



I have dementia...
I Have Rights
Know Your Rights



Contents

Each section of the booklet has its own colour to make it easy to locate the section you want to read.

Acknowledgements	pg 2
About this booklet	pg 3
What is dementia?	pg 3
Understanding equality law	pg 4
Do equality laws protect me?	pg 5
What does 'discrimination' mean?	pg 5
Your rights under the Equal Status Acts 2000-2011	pg 7
Your rights under the Employment Equality Acts 1998-2011	pg 8
Must I tell my employer that I have dementia?	pg 10
Can my employer fire me because I have dementia?	pg 10
What if my dementia gets worse?	pg 10
What happens if I need to leave my job?	pg 11
Your right to make decisions	pg 12
Can I make a will?	pg 14
Making a complaint of discrimination	pg 15
Where can I get more information?	pg 16

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Other useful publications

The Alzheimer Society of Ireland has a range of publications including:

- 👁 I have dementia... First steps after diagnosis

- 👁 I have dementia... How do I plan for the future

- 👁 Practical tips for living well with dementia

- 👁 Driving and dementia

For further information contact the Alzheimer National Helpline

Phone: 1800 341 341

Email: helpline@alzheimer.ie

Visit: www.alzheimer.ie

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About this booklet

People with dementia have the same civil and legal rights as everyone else. This booklet is for people with dementia and their families. It explains:

- what equality laws say;
- how equality laws can help you;
- your rights when buying goods or accessing services;
- your rights in employment;
- your right to make decisions;
- how to make a complaint.

This booklet is not a legal document; it is for information purposes only.

What is dementia?

Dementia is the name for a range of conditions which cause damage to the brain. This damage can affect memory, thinking, language and the ability to perform everyday tasks.

The most common form of dementia is Alzheimer's. Other forms of dementia include Vascular dementia, Lewybody dementia and Fronto-temporal dementia.

Understanding equality law

Dementia is a disability under Irish equality laws and under the United Nations (UN) Convention on the Rights of People with Disabilities.

There are two main equality laws in Ireland:

- The Equal Status Acts 2000-2011
- The Employment Equality Acts 1998-2011

These laws protect certain people against discrimination when they are:

- buying goods;
- using everyday services; and
- at work.



Do equality laws protect me?

There are nine categories named in equality law. These are called the 'nine grounds'. People are protected against discrimination when buying goods, accessing services or in employment, if the discrimination is linked to any one of the nine grounds. Disability is one of the nine grounds and dementia falls within the definition of disability. This means that equality laws protect you.

What does 'discrimination' mean?

'Discrimination' has a specific meaning in the Equal Status Acts and in the Employment Equality Acts. In general, it means that a retailer, a service provider or an employer cannot treat you differently because of your dementia. Types of discrimination include:

Direct discrimination is when a person is treated in a less favourable way than another person in the same situation under any one of the nine grounds covered by the Acts. Dementia is a disability and disability is one of the nine grounds.

Indirect discrimination happens where an individual or group of people are placed at a disadvantage as a result of conditions or rules which they might find hard to satisfy and which cannot be reasonably justified.

Key Fact...

People with dementia are covered by the disability ground.



If you feel that someone has discriminated against you because you have dementia, ask yourself these important questions:

- 🕒 Were you treated less well than someone who did not have dementia would have been treated in a similar situation?

- 🕒 Did the discrimination happen when you were shopping, using services or socialising?

- 🕒 Did the discrimination happen when you were at work?

Sometimes retailers, service providers and employers can treat you differently and this will not count as discrimination. The next section will explain more about your rights under equality laws.

Key Fact...

Equality law protects you when you are using everyday services.

Your rights under the Equal Status Acts 2000-2011

You have the right to 'reasonable accommodation'. This is a very important concept in equality law and can be very useful in improving your access to services.

'Reasonable accommodation' means that if a service is difficult for you to access because of your dementia, the service provider must put in place services or special facilities to make it easier for you. For example, if you were a wheelchair user, that might mean providing a ramp. If you have dementia, it might mean giving information clearly, or allowing you to avoid a long queue.

There are limits on what service providers have to do. The law says that making 'reasonable accommodation' must not cost the service provider more than a small amount. However, in many cases the type of adaptation that would really help someone with dementia will cost the service provider very little.

If you think you have experienced discrimination, you should contact the Equality Authority to find out what to do next.

See page 15 for more information about making a complaint.

Key Fact...

An example of 'reasonable accommodation' might be a service provider allowing you to avoid a long queue.

Your rights under the Employment Equality Acts 1998-2011

If you are in employment, you are entitled to 'appropriate measures' to help you carry out your work. 'Appropriate measures' is an important concept in equality law and can be very useful in relation to employment.

'Appropriate measures' means the same thing as 'reasonable accommodation'. 'Appropriate measures' means that if you have difficulty carrying out your work because of your dementia, your employer must put in place supports or special facilities to help you. For example, this could be flexible working hours or allowing your colleagues to help you.

There are limits to what employers have to do. The law says that taking 'appropriate measures' cannot place a 'disproportionate burden' on an employer. This means that a small employer with few resources would not be expected to do as much as a big employer with more resources.

Key Fact...

Employers must make 'appropriate measures' within certain limits.

Here are some examples of ‘appropriate measures’:

- 🕒 Time off to attend medical appointments;
- 👥 Mentoring and peer support within the workplace;
- 🔄 Consulting with you so that you can return to work;
- 🕒 Adjusting your work hours or allowing you to work from home;
- 🔄 Changing your work duties in consultation with you.



Must I tell my employer that I have dementia?

You do not have to tell your employer. But, if you do not, your employer will not be able to see if 'appropriate measures' would help you to stay in work.

Can my employer fire me because I have dementia?

Your employer cannot dismiss you simply because they find out that you have dementia. Your employer would need to show that you are not able to do your job, even though special supports have been put in place to help you or that the cost of supporting you would be too high.

What if my dementia gets worse?

At some point, you may not be able to do your job even with extra help and support. Also, in some types of work, there may be very little that an employer can do to support you. In these types of cases, your employer may dismiss you and it will not count as discrimination.

If you get a diagnosis of dementia while working, you should look for detailed information and advice on your rights. You can get this from the Equality Authority or your local Citizens Information Service. You will find their contact details on the back page of this booklet.

Key Fact...

Your employer cannot dismiss you just because you have dementia.

What happens if I need to leave my job?

If you are under 66 and have to leave work because you have developed dementia, or your dementia has got worse, you may be entitled to financial support from the Department of Social Protection. This may be:

- Illness Benefit or Invalidity Pension based on your PRSI contributions;
- Disability Allowance which is a means-tested payment;
- Household Benefits Package which includes electricity and gas allowances, a free TV Licence and telephone allowance;
- Partial Capacity Benefit – you can get this if you are on Illness Benefit or an Invalidity Pension and it becomes possible for you to work part-time.

You are also entitled to Supplementary Welfare Allowance while your claim for financial support is being processed.

Talk to your local Citizens Information Service to find out which financial supports you can apply for. They can also help you to fill out the application forms. You will find their contact details on the back page of this booklet.

Key Fact...

A diagnosis of dementia does not automatically mean you cannot make decisions.

Your right to make decisions

Getting a diagnosis of dementia does not automatically mean that you cannot make decisions about things that affect you. The UN Convention on the Rights of People with Disabilities says that nobody may be denied 'legal capacity' because they have a disability.

'Legal capacity' means being recognised by the law as someone who can make decisions. Ireland will soon bring in laws to comply with the UN Convention.

Dementia can affect your ability to hold onto and weigh up information. It can also affect your ability to see the consequences of your decisions or the effect they may have on yourself or on other people. At some stage most people with dementia will need some support with decision-making.



This support may be very little, such as having information explained clearly to you and having extra time to make a decision. Or it may mean that someone else is appointed to make a decision on your behalf.

If someone makes a decision on your behalf, they must do so based on what they believe you would want and not necessarily on what they think would be best for you.

Nobody can assess you and say that you are not capable of making a particular decision unless they have done all they could to support you to make the decision yourself. Examples of support might be extra time, a quiet environment, information presented in a different way, or the support of someone you know and trust.

Even if you cannot make one kind of decision, for example a major financial decision, you may be able to make other kinds of decisions such as what you want to do during the day.

Key Fact...

Support with decision making can involve having extra time or having information presented in a different way.



Can I make a will?

Making a will involves decisions about what will happen to your estate after your death. Anyone who makes a will must be able to understand what they are doing and the likely consequences of their decisions. This is called having “**testamentary capacity**”. It is the solicitor’s responsibility to check this. They must explain things to you clearly and carefully and check that you understand.

If you have dementia, your solicitor may look for a report from your doctor about how your dementia affects your understanding.

If you would like information about legal and financial planning, contact the **Alzheimer National Helpline at 1800 341 341** or visit **www.alzheimer.ie**.

When Ireland brings in the new law about decision-making, you will be able to get information about what it may mean for you from The Alzheimer Society of Ireland.

Making a complaint of discrimination

If you feel you have experienced discrimination, you can contact the Equality Authority to talk to them about the situation, the steps involved in making a complaint and to get the forms you need.

Complaints of discrimination are made to the Equality Tribunal, who can also provide you with the forms you need.

If you are thinking about making a complaint, here are some important things you should know.

- There are strict time limits for making a complaint so do not delay. You will find details about the time limits on www.equalitytribunal.ie

- If your dementia makes it difficult for you to make a complaint yourself, a relative or friend can make a complaint on your behalf.

- You can represent yourself at the tribunal hearing or you can ask a lawyer, trade union official or someone else to speak for you. In some cases, the Equality Authority may give legal help to someone who wants to make a complaint.

- If you and the person or organisation you are complaining about agree, the Equality Tribunal can appoint a mediator to handle the case.

- If your complaint is successful, the Equality Tribunal can award compensation or order an employer or service provider to change their systems or procedures. You can find out more about levels of compensation from the Equality Authority or Equality Tribunal.

For more information:

Useful publications



I have dementia...
First steps after diagnosis



I have dementia...
How do I plan for the future



Practical tips for living well with dementia



Driving and dementia

You can order free copies by calling **1800 341 341** or emailing helpline@alzheimer.ie

Disclaimer

The Alzheimer Society of Ireland has taken great care to ensure the accuracy of the information contained in this booklet. We are not liable for any inaccuracies, errors, omissions or misleading information.

If you would like to comment on this booklet, please contact Samantha Taylor, Information and Helpline Manager at **01 207 3800** and staylor@alzheimer.ie

The photographs featured in this booklet are models.

The Equality Authority has two useful leaflets

Your Employment Rights Explained:

Plain English Guide to the Employment Equality Acts 1998-2011

Your Equal Status Rights Explained:

Plain English Guide to the Equal Status Acts 2000-2011

Useful contacts

The Equality Authority, Public Information Centre

LoCall: 1890 245 545

Phone: 0505 24126 (Head Office)
01 417 3336 (Dublin Office)

Email: info@equality.ie

Website: www.equality.ie

The Alzheimer Society of Ireland

Freefone Helpline: 1800 341 341

Email: helpline@alzheimer.ie

Website: www.alzheimer.ie

The Equality Tribunal

Phone: 01 613 6800

Website: www.workplacerelations.ie

Email: info@workplacerelations.ie

Citizens Information Service

LoCall: 0761 074000

Website: www.citizensinformation.ie

The Alzheimer Society of Ireland

National Helpline: 1800 341 341

Email: helpline@alzheimer.ie

Website: www.alzheimer.ie