

Booklets in the Living with dementia series



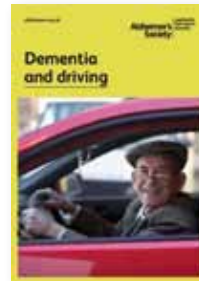
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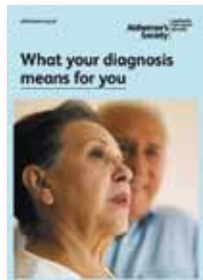
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Alzheimer's Society

Devon House
58 St Katharine's Way
London E1W 1LB

T 020 7423 3500
F 020 7423 3501
E info@alzheimers.org.uk
alzheimers.org.uk

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Alzheimer's Society National Dementia Helpline
England and Wales 0845 3000 336 Northern Ireland 028 9066 4100

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Employment



Dementia increasingly affects younger people, and consequently you may well still be working when you get your diagnosis. This doesn't necessarily mean that you must stop working: it may be better for your physical and emotional well-being to carry on as long as you are happy or able to do so. This booklet looks at the issues you may face and suggests ways of coping so that you can carry on working. It also looks at the legal issues and obligations you and your employers face.

Nobody can predict how long they will be able to keep working. Dementia affects everyone differently. It also depends on the work you do. But earlier diagnosis and medication are helping more people with dementia stay in work for longer.

How dementia can affect you at work

Many people say that their first symptoms appeared at work. You may have found that you forgot meetings or appointments. You may have been unable to concentrate or make decisions as well as you used to. It may have become difficult to cope with noise, or perhaps you have found it hard to manage more than one thing at a time.

Some of these things may have caused you difficulties at work before you had a diagnosis. It may have been hard to understand why you weren't working as well as you used to. In fact, many of the symptoms of dementia could also have been put down to tiredness, stress or depression.

Once you have a diagnosis of dementia, you can start to put your problems into context. You can make plans: you can think about how your employer can help you. You can also think about how long you want to carry on working, or whether perhaps you would prefer to retire early.

'Because Christine had worked in the store for many years they couldn't understand why she kept forgetting where things were.'

Talking to your employer

Having dementia does not necessarily mean that you have to stop working. But once you have a diagnosis, it's probably best to tell your employer if you want to carry on working. In many jobs, you have no legal obligation to tell your employer, but check your contract as this does vary. In some jobs, you must tell them – for example, if you are in the armed forces, or work on a plane or ship.

If you drive as part of your job, you should also talk to your employer. You are also legally obliged to tell the DVLA that you have dementia. See Alzheimer's Society booklet Dementia and driving for more information about continuing to drive safely.

You may feel anxious about telling your employer, but it is likely that they will already have noticed something is wrong. If you don't tell them your diagnosis, they may not have any legal duty to help you.

A disability employment officer at a Jobcentre Plus office can advise you about speaking to your employer. You may want to ask a family member or close colleague to be with you when you talk to your employer. Your supporter could help you make decisions about what to say and also suggest how to modify your job to make it more manageable.

You don't have to tell everyone you work with that you have dementia. But sometimes colleagues can be a great help and source of support if you do want to share your diagnosis with them.

Take time to make your decisions. You need to make sure that whatever you decide is right for you, and that your future is secure financially. Your employer should help with these decisions. You could also talk to an organisation such as the Citizens Advice Bureau. They can advise on rights, pensions and benefits entitlement.



For practical information on all aspects of living with dementia contact the National Dementia Helpline on 0845 3000 336 (England and Wales) or 028 9066 4100 (Northern Ireland) or visit [alzheimers.org.uk](https://www.alzheimers.org.uk)

What the law says

The law protects the rights of people with dementia in some basic ways.

Disability Discrimination Act (1995)

This act protects people with disabilities against unfair treatment. It covers people with dementia from when they are diagnosed. It also protects against unfair treatment at work. Your employer must show that they have tried to make it possible for you to continue to work.

This can mean changes to your workplace, or to the hours you work. Your employer cannot refuse to make 'reasonable adjustments' unless they have a good reason. This might be that the changes would be very expensive or use too many other resources, or not work very well.

Talk to the Citizens Advice Bureau or your union if you are unsure whether your employer is making reasonable adjustments to your work.

Adjusting your role

Think about what you can and can't do, and talk openly with your employer. These are some suggestions you could make that might help you work better:

- changing your work schedule, giving you time to rest if you are tired
- arranging meetings for times when you are likely to be at your best
- simplifying your routine, and giving you tasks separately instead of all at once
- reducing noise and distraction around you
- using technology such as computerised diaries that can remind you of meetings and deadlines
- moving to a less senior role and accepting a lower wage and less responsibility.

'They suggested creating a job especially for her in the staff canteen, where she'd be working with her peers.'

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Pensions

You may find that work becomes too much, even with a supportive employer and changes to your job. And some jobs are simply not possible when you have dementia. Remember that it is not a failing to have an illness that makes work impossible.

If this happens, for whatever reason, it is important that you are aware of your pension rights and any other entitlements you may have.

State pensions

The state pension age is changing. It is currently 65 for men, and 60 for women. But from 2010 the age for women is increasing: in 2020 it will be 65. The age for men will also increase. You can work out what age you would normally be entitled to a full state pension at The Pension Service website (see Useful contacts at the back of this booklet).

If you leave work before you reach retirement age, you may be able to protect your pension by getting national insurance contribution credits. These are automatically given to people who receive certain benefits (such as incapacity benefit) or people who the benefits agency decide are 'incapable of work'.

Call the government's Pension Service (see Useful contacts) to discuss your pension rights.

Occupational and personal pensions

If you have a company pension plan (occupational pension) or a personal pension plan, leaving work early will affect the amount of money you will receive. However, many pension plans will allow you to take your pension early if you retire because of illness. Check with your pension provider about what you should do.

Advice from an independent financial adviser can be very helpful. Ask someone you trust for a recommendation, or contact the Independent Financial Advisers Promotion (see Useful contacts): they will recommend four advisers in your area and give you a voucher for a free consultation.



Benefits

Living with dementia can be difficult financially, especially if you have to leave work unexpectedly. You can access a range of benefits to help with the costs of living – and some are available when you are still working. It is important to get good advice. Talk to your local Citizens Advice Bureau or Jobcentre Plus adviser.

Statutory sick pay

This is paid by your employer for up to 28 weeks. To qualify, you must earn a certain amount of money each week before tax and be too ill to work.

Incapacity benefit

You can claim incapacity benefit if you are unable to work because of an illness or disability. You would normally qualify after statutory sick pay has ended or if you do not qualify for statutory sick pay. It is paid at three different weekly rates, depending on how long you have been claiming it.

Income support

This benefit is paid to people under 60 who have a low income and limited savings. It can be paid in full or as a top up to other pensions and income. How much you receive depends on:

- your age
- your existing income and savings
- how many hours you work
- your family circumstances.

If you qualify for income support, you may be entitled to other benefits such as housing benefit, free prescriptions or dental care.

If you are between 60 and 65, you cannot claim income support, but you may qualify for pension credit, which works in the same way.



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Disability living allowance

This provides extra help to deal with the practical effects of a disability. You may be entitled to it whether or not you are working. There are two components:

- a personal care component to help with daily activities
- a mobility component to help with getting around.

The two components have different rates depending on how much your illness affects you. Your own situation will determine which component you are entitled to, and at which rates. If your situation changes, you may become entitled to another component or a higher rate.

After work

Dementia needn't stop you from doing the things you want to do, even if you decide you can no longer work at the job you've been doing. Many people with dementia keep active and involved, whatever they decide to do. You might want to consider a different or part-time job, for example, or voluntary work, hobbies, study, travel or group activities. Anything, in fact, that any other retired person might think about doing.



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Useful contacts

Age UK

York House
207-221 Pentonville Road
London N1 9UZ
T 0800 169 8787 (general enquiries)
0800 169 6565 (advice line)
E contact@ageuk.org.uk
www.ageuk.org.uk

Age UK has been created by the merger of Age Concern and Help the Aged.

Alzheimer's Society

Devon House
58 St Katharine's Way
London E1W 1LB
T 020 7423 3500
E info@alzheimers.org.uk
alzheimers.org.uk

Benefit Enquiry Line (BEL)

Red Rose House
Lancaster Road
Preston PR1 1HB
T 0800 88 22 00
(free helpline open
8.30am-6.30pm weekdays and
9.00am-1.00pm Saturdays)
0800 243 544 (textphone)
E BEL-Customer-Services@dwpgsi.gov.uk
www.direct.gov.uk/disability-money

Citizens Advice Bureau (CAB)

www.citizensadvice.org.uk
www.adviceguide.org.uk

Department for Work and Pensions

For details of your local office, go to
www.dwp.gov.uk/localoffice
For details of various helplines, go to
www.dwp.gov.uk/contact-us/contact-a-z/
T 08457 123456
E use the enquiry form on the website below
www.dwp.gov.uk

Disability employment advisers

www.jobcentreplus.gov.uk

Driver and Vehicle Licensing Agency (DVLA)

Swansea SA99 1TU
T 0300 790 6801
E drivers.dvla@gtnet.gov.uk
www.dvla.gov.uk
www.direct.gov.uk/motoring

IFA Promotion

E contact@ifpa.org.uk
www.unbiased.co.uk
The industry body responsible for promoting independent financial advice in the UK. The website enables people to confidentially search for details of independent financial advisers in their local area.

The Pension Service

T 0845 6060265
(8.00am-8.00pm weekdays)
0845 6969275 (Welsh language)
0845 6060285 (textphone)
0845 6060295 (Welsh textphone)
E use the enquiry form on the website
www.thepensionservice.gov.uk