Living with dementia

Employment
Receiving a diagnosis of dementia can be difficult to accept if you are still working. However, dementia affects everyone differently and a diagnosis doesn’t necessarily mean that you have to give up your job.

In fact, it may be better for your physical and emotional wellbeing to carry on for as long as you are happy or able to do so.

You may have a mortgage to pay off or children to support. The type of work you do will also affect your decision. It is difficult to predict how long you will be able to keep working, but early diagnosis and medication can help you stay in work for longer.

This booklet outlines the issues you may face and suggests ways of coping so that you can continue working if you want to. It also looks at the legal position and other issues that may arise for you and your employer.
Working with dementia

Many people say that their first symptoms of dementia appeared while at work.

You may have found that you forgot meetings or appointments, or were unable to concentrate and found it difficult to follow conversations. Perhaps you found it hard to manage more than one thing at a time, or were unable to complete a routine task. You may have dismissed many of the symptoms as tiredness, stress or depression.

Getting a diagnosis of dementia is an important first step. You can make plans, and think about how your employer can help you. You can also think about how long you want to carry on working, or whether you would prefer to retire early or do voluntary work instead.

‘I continued in employment for eight years after diagnosis, retiring at age 65.’

Person with dementia

For more information visit alzheimers.org.uk
Talking to your employer

Once you have a diagnosis of dementia, it’s best to tell your employer whether you want to carry on working.

Not everyone has to do this legally, but check your contract as this does vary. In some professions, you must tell them – for example, if you are in the armed forces, or work on a plane or ship.

The same applies if you drive as part of your job. You are also legally obliged to tell the DVLA that you have dementia. See booklet 1504, Driving, for more information about continuing to drive safely.

It is normal to feel anxious about telling your employer. However, they may have noticed if you’ve had difficulties. If you don’t tell them your diagnosis, they may not have any legal duty to help you.

A disability employment adviser (DEA) at a Jobcentre Plus office can advise on speaking to your employer. You can ask a family member or close colleague to accompany you for support when you talk to them. Your supporter could advise you on what to say and also suggest possible changes to your job to make it more manageable.
It is up to you whether you tell your other colleagues that you have dementia. However, sometimes the people you’ve worked with can be a great help and source of support if you do decide to share your diagnosis with them.

Take time to make your decisions. Your employer should be able to help you. You need to make sure that whatever you decide is right for you, and that you can financially plan for your future as much as possible. Consider the financial aspects of your decisions. You could also talk to an organisation such as the Citizens Advice Bureau. They can advise on rights, pensions and benefits entitlement (see ‘Other useful organisations’).

‘It may be worthwhile thinking about whether there are other roles you could safely and effectively fulfil within the organisation.’

Relative of a person with dementia
How the law protects you

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

Equality Act 2010
The Equality Act 2010 protects people from discrimination, and applies in England, Scotland and Wales. It protects people against unfair treatment at work, and covers areas such as your terms of employment (eg pay, dismissal and redundancy). If you have a diagnosis of dementia then you are automatically protected by the Act.

Under the Equality Act 2010, your employer has to make ‘reasonable adjustments’ in the workplace to help you do your job. This ensures that you are not put at a disadvantage compared with your colleagues. For example, your employer may move your desk to a quieter area or agree to change your working hours.

If funding is required to make an adjustment, you can apply for this from Access to work – a scheme run by Jobcentre Plus. It provides support and funding to help with work-related costs for people in paid employment with a disability or a health condition. The Act also means that you cannot be chosen for redundancy or be forced to retire because of your dementia. The Citizens Advice Bureau or your union (if you belong to one) can advise you if you require further support.
‘I left work as I could no longer learn new information, which was needed to do the job. I still do a part time job, which I have been doing for about five years and hope to continue.’

Person with early-onset Alzheimer’s disease
The Disability Discrimination Act
The Disability Discrimination Act (DDA) protects people from discrimination in Northern Ireland. It works in the same way as the Equality Act in that it protects people from being discriminated against on the basis of their disability. The Act imposes a duty on employers to make reasonable adjustments for disabled people to remain in employment.

Constructive dismissal
Some people with dementia have reported cases where they were either sacked or pushed out of work before they received their diagnosis. If you think you were unfairly dismissed from your job because of your dementia, then you may be able to make a complaint about your previous employer’s actions. If this is something you wish to look into, you should seek support from an expert, such as a trade union. You can also get in touch with a disability employment adviser in your area who will be able to better advise you (see ‘Other useful organisations’).

Applying for a new job
If you have received a diagnosis of dementia and want to apply for a new job, the Equality Act protects you from being discriminated against in the application process. You can speak to a disability employment adviser for further advice on this topic.
Changes to your role

Think about what you can and can’t do, and talk openly with your employer.

There may be changes you could make to help you work better, including:

- changing your work schedule to give you time to rest if you are tired
- arranging meetings for times when you are likely to feel and perform better, simplifying your routine, and requesting one task at a time
- requesting to be moved to a quieter area with less distraction
- using technology and equipment such as computerised diaries that can remind you of meetings and deadlines
- moving to a less senior or demanding role.

‘If it’s worthwhile to try to carry on working and your self-esteem can handle the challenge, try taking on a more junior post.’

Carer of a person with dementia
Leaving work

You may find that work just becomes too difficult, even with a supportive employer and changes to your job.

There are some roles that are simply not possible when you have dementia. There are many reasons why people have to give up work – it is not a failing to have a condition that makes it impossible to continue working.

Pensions
If you do have to leave work, for whatever reason, it is important to be aware of your pension rights and other benefits you may be entitled to. Advice from an independent financial adviser can also be helpful. Ask someone you trust for a recommendation, or contact the organisation Unbiased at www.unbiased.co.uk to find an independent financial adviser who will best suit your needs (see ‘Other useful organisations’).

State pensions
A State pension is a taxable payment given to people who reach state pension age if they have made enough National insurance (NI) contributions. The state pension age for men is currently 65. The state pension age for women born on or before 5 April 1950 is 60. The pension age for men and women is gradually rising so that by 2020 it will be 66. After that it will rise to 68 for both men and women. For more information, see Alzheimer’s Society factsheet 413, Benefits.
If you are below state pension age but unable to work, you may be able to protect your state pension rights by getting National insurance contribution credits. These are automatically given to people receiving certain benefits, such as Incapacity benefit and Employment and support allowance. Contact the government’s Pension Service (see ‘Other useful organisations’) to discuss your pension rights.

**Occupational and personal pensions**
If you have a company pension plan (workplace 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 whether you qualify.

‘We volunteered for charity work giving out information about dementia. We really enjoyed talking to people in one of the major supermarkets.’

Wife of a person with dementia
Benefits

Living with dementia can present many financial challenges, especially if you have to leave work unexpectedly and still have a mortgage or children to support.

People with dementia do not automatically qualify for disability benefits – tests are required to determine the level of need. However, there are a range of benefits available to help with the costs of living – and some you can access when you are still working. It is important to ask for a benefits check to ensure that you are receiving everything you are entitled to. Talk to your local Citizens Advice Bureau or disability employment adviser for further advice.

Employment and support allowance (ESA)
Employment and support allowance (ESA) has two forms – contributory ESA and income-related ESA. ESA may be claimed by people who are under the State pension age for women (see ‘State pensions’) and who have a limited capacity to work because of an illness or a disability. For more details see Alzheimer’s Society factsheet 431, Benefits rates and income/savings thresholds. Between October 2013 and October 2019 the new Universal credit is replacing income-related ESA and Income support, and a number of means-tested benefits for people of working age.
Attendance allowance (AA) and Personal independence payment (PIP)

If your care needs started after the age of 65, or you have not made a claim until then, you should claim Attendance allowance (AA). This is for help with personal care such as dressing or taking medication, not mobility.

If you have care and/or mobility needs and are under the age of 65, you should claim Personal independence payment (PIP). You must be under 65 when you make your first claim. For more information on this topic see Alzheimer’s Society factsheet 413, Benefits.
Keeping involved and active

Dementia doesn’t have to stop you from doing the things you want to do, even if you decide you can no longer remain at work.

Many people with dementia keep active and involved, whatever their decision. You might find it gives you more time to enjoy varied hobbies or activities. This may include going to the cinema, taking part in sport – or going to watch it – or taking short breaks or further travel. There may also be a number of ways to take part in your community through group activities. Your local Alzheimer’s Society may be able to help you or you can visit alzheimers.org.uk/dementiaconnect to find groups of interest to you in your area.

You might want to consider a different or part-time job, or volunteering. For example, Alzheimer’s Society has a wide range of opportunities available for people who can spare some time. You can call our volunteering enquiry number on 0845 504 9300 or email volunteers@alzheimers.org.uk to find out more.

Call the National Dementia Helpline on 0300 222 1122
Other useful organisations

Age UK
Tavis House
1–6 Tavistock Square
London WC1H 9NA
T 0800 169 6565 (advice line)
W www.ageuk.org.uk

Provides information and advice for older people in the UK.

Citizens Advice Bureau (CAB)
Various locations
W www.citizensadvice.org.uk

Your local Citizens Advice Bureau (CAB) can provide information and advice in confidence or point you in the right direction. To find your nearest CAB, look in the phone book, ask at your local library or look on the Citizens Advice website (above). Opening times vary.

Department for Work and Pensions (DWP)
W www.gov.uk
The government department responsible for employment and social security.

Disability Benefits Centre
W www.gov.uk/disability-benefits-helpline
Personal independence payment (PIP)

Existing claims
T 0345 850 3322 (Weekdays, 8am–6pm)

New claims
T 0800 917 2222 (Weekdays, 8am–6pm)

Disability living allowance
T 0345 712 3456 (Weekdays, 8am–6pm)

Attendance allowance (also for DLA claimants who are 65+)
T 0345 605 6055 (Weekdays, 8am–6pm)

State pension and Pension credit enquiries
T 0345 60 60 265 (8am–6pm weekdays)
W www.gov.uk/state-pension

Unbiased
W www.unbiased.co.uk

The industry body responsible for promoting independent financial advice in the UK. The website enables people to search confidentially for details of independent financial advisers in their local area.

Society of Later Life Advisers
T 0333 2020 454
E admin@societyoflaterlifeadvisers.co.uk
W www.societyoflaterlifeadvisers.co.uk

The society connects consumers and their families with recognised later life advisers who specialise in the financial issues of older people.
This publication has been reviewed by people affected by dementia and health and social care professionals. A full list of sources is available on request.

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Alzheimer’s Society is the UK’s leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 3,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

If you have any concerns about Alzheimer’s disease or any other form of dementia, visit alzheimers.org.uk or call the Alzheimer’s Society National Dementia Helpline on 0300 222 1122. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)