If you have been diagnosed with dementia while you are still working, you may be wondering how this will affect your job. If so, this booklet can help you.

Deciding whether or not you want to continue working after your diagnosis depends very much on your feelings and personal situation. Some people find it is good for their physical and mental health if they keep working for as long as they’re happy and able to. Your work may be very important to you. It may give you a sense of purpose and help you connect with other people. You may also have a mortgage to pay off or children to support.

Having dementia doesn’t mean you automatically have to give up work. Dementia affects everyone differently, and you might be able to stay in work for a while if your symptoms mean that you can carry out most aspects of daily life with a little help.

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

Person with dementia
Similarly, if you are taking medication, this may help you stay in work for longer. Your employer may also be able to give you support so you can continue to work.

This booklet gives advice on talking to your employer and looks into some of the ways they can support you. It also explains the ways in which the law protects you at work.

However, you may not want to keep working after your diagnosis, or you might not feel comfortable carrying on in your role. The type of work you do will also affect your decision. In some cases, it may not be possible to continue working for legal reasons.

This booklet covers things to think about if you decide to leave work. It also suggests ways to stay active and involved after you stop working.
Many people say their first symptoms of dementia appeared while they were at work.

You might forget meetings or appointments, or find that you can’t remember where certain places are. Or you might find it hard to concentrate and follow conversations. Maybe you’re struggling with doing more than one thing at a time or something you’re normally familiar with.

People often put these symptoms down to tiredness, stress or depression. This is why getting a diagnosis of dementia is an important first step. It can help you plan how long you want to carry on working and think about how your employer can help you. Having a diagnosis can also provide some legal protection for you in the way you are treated at work. You can also think about whether you would prefer to retire early and try other things or do voluntary work.
Talking to your employer

You may need to tell your employer that you have dementia.

Not everyone has to tell their employer about their diagnosis, but legally some people have to. This will depend on the type of work you do and on the terms of your contract. For example, you’ll need to tell your employer about your diagnosis if your job has an impact on the health and safety of other people. This includes work that involves driving or operating machinery. If this is the case, it might also affect any insurance that covers you.

If you have been diagnosed with dementia and you drive, you have to tell Driver and Vehicle Licensing Agency (DVLA) in England and Wales, or Driver & Vehicle Agency (DVA) in Northern Ireland. You must also tell your car insurance company about your diagnosis. DVLA will then advise you on whether or not you have to stop driving.

If you drive as part of your job, this will have an impact on whether you can continue in that role. Your employer’s car insurance company may also need to know that you have dementia – for example if you are covered by the insurer while you are driving for work. You will need to discuss the impact of this with your employer.
Even if your job does not involve driving, your ability to get to work may be affected if you stop driving – for example if you usually travel any part of the journey to work by car.

For information about continuing to drive safely see booklet 1504, Driving.

There may also be other insurance issues that you will need to discuss with your employer – for example, if you have responsibility for health and safety in the workplace. Check your employment contract and speak to a solicitor if you need legal advice.
Tips for talking to your employer

It is normal to feel anxious about telling your employer that you have dementia. However, this conversation can be helpful for you. Your employer may have noticed if you’ve been having difficulties. If you don’t tell them about your diagnosis, they may not have any legal duty to help you. This means that telling them can be a positive thing and may lead to changes being made to help you in your role.

You could ask a colleague you trust to accompany and support you when you talk to your employer. You could also ask if a family member could come with you. It can help to discuss what to say with the person who is supporting you. Together you may be able to suggest changes to your role that may make it easier for you to do your job – see the section ‘Changes to your role’ on page 18 for more advice.

It is up to you whether you tell your colleagues that you have dementia. People you work closely with can be a great source of help and support.
Talking to your employer

Making decisions with your employer

Give yourself time to make decisions. You don’t have to decide everything when you first speak to your employer. You can tell them that you need time to think about things and to get advice, if necessary.

You need to make decisions that are right for you and those decisions may change again with time. Any decision you make should be an informed decision. This means you should make it based on information about your legal and financial options, such as your pension and benefits entitlement. See ‘Pensions’ on page 23 and ‘Benefits’ on page 26 for more information.

“What kept me going, see, the guys that I worked with, an absolutely fantastic group of guys, couldn’t ask for better honestly and I think that’s what really kept me going.’

Person with dementia
Read your employment contract and look at any workplace policies that might apply to you. For example, there might be policies dealing with equality or disability issues or early retirement. If you are not sure what policies there are or where to find them ask your employer or the Human Resources (HR) team if there is one.

You can find out about your legal and financial options in a number of ways. For example, if you are a member of a union or staff association, they should be able to give you advice and support. There are also organisations that can give you advice about your rights and financial options. See ‘Other useful organisations’ on page 34 for suggestions and relevant contact details.

Your employer must pay you Statutory sick pay if you are unable to work. The amount is set by the government and it can be paid for up to 28 weeks. For more information see the government website (GOV.UK). Your employer may have a more generous sick pay scheme so you should also check your contract or ask your employer about that.

You may already be on sick leave when you get your diagnosis, which may make it more difficult for you to think about things and to talk to your employer. If this is the case, you might want to get legal advice about your rights and your financial options.
Your employer might not have dealt with a situation like this before. They may not know much about dementia, what a person with dementia is capable of, and what changes might help you. They may not know what legal rights you have. Alzheimer’s Society produces a range of guides for organisations and businesses in all sectors to help support their employees with dementia. There is more information about these at alzheimers.org.uk/organisations
There are a number of important laws that can protect people with dementia at work.

The Equality Act 2010


The Equality Act 2010 protects people from being treated unfairly at work. It covers areas like:

- recruitment
- terms of employment (including pay)
- performance in the role
- promotion
- dismissal (including selection for redundancy).

If you have been diagnosed with dementia you will be protected by the Act.

Under the Act your employer has to make ‘reasonable adjustments’ in the workplace to help you carry on working. For example, they could move your desk to a quieter area or agree to change your working hours. See ‘Changes to your role’ on page 18 for more examples of reasonable adjustments.
They only have to make adjustments if they know about your diagnosis (or could reasonably be expected to know about it). This is to make sure you are not at a disadvantage compared with your colleagues.

You can also apply to a government scheme called Access to Work for funding to give you extra support in work (see ‘Other useful organisations’ on page 34). This scheme provides support and funding for people with a disability if they need help at work that isn’t covered by their employer making ‘reasonable adjustments’. It might pay for special equipment or computer software to help you do your job. It might also pay for any help you need getting to and from work.

The Equality Act also protects you from being chosen for redundancy or forced to leave just because you have dementia. See ‘Other useful organisations’ on page 34 for examples of organisations you can talk to for advice about your rights, or for more support.

“I’m determined to continue working for as long as I can.’

Person with dementia
The Disability Discrimination Act 1995

The Disability Discrimination Act 1995 protects people from discrimination in Northern Ireland. It works in the same way as the Equality Act. It protects people from being discriminated against because of a disability. The Disability Discrimination Act also gives employers a duty to make ‘reasonable adjustments’ so that people with a disability can continue to work. This includes people with dementia.

There is also a separate Access to Work scheme in Northern Ireland that is similar to the scheme in England and Wales (see ‘Other useful organisations’ on page 34).
Unfair dismissal

Some people with dementia have said they were sacked or pushed out of work after telling their employer about their condition. Other people have said they were dismissed when they first began to have symptoms because their employer had noticed changes in how they performed the role. They were dismissed even before they got their diagnosis.

Employers have a legal duty to make reasonable adjustments to help you continue working if they know about your condition (or if they could reasonably be expected to know). So if your employer forces you to retire without thinking about making reasonable adjustments, this may be ‘unfair dismissal’. Or if your employer makes things so difficult that you feel you have to leave, this may be ‘constructive dismissal’ (it might also be ‘unfair dismissal’, depending on the circumstances).

If you think your job was terminated unfairly because of your dementia you may be able to challenge the actions of the employer who dismissed you. Ask an expert for support. See ‘Other useful organisations’ on page 34 for suggestions about organisations that can help you do this.

If you want to take legal action through an employment tribunal, you should do so as soon as possible after dismissal. This is because there are strict time limits for starting the process (often within three months of dismissal).
Applying for a job

The law protects you when applying for jobs as well. Perhaps you weren’t working when you received your diagnosis, but you were planning to apply for a job. Or maybe you can’t keep working in your current position, and you are looking to apply for a different or part-time role.

If you want to apply for a job, the Equality Act 2010 (in England and Wales) and the Disability Discrimination Act 1995 (in Northern Ireland) protect you from being discriminated against during the application process. If the employer knows (or should reasonably know) that you have dementia, they must try to ensure that you are not at a disadvantage. This means making reasonable adjustments to their application and interview processes.

You may be able to ask a disability employment adviser at your local Jobcentre Plus for advice and support about looking for work and applying for jobs (see ‘Other useful organisations’ on page 34).

“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 young-onset Alzheimer’s disease
Changes to your role

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

If you want to keep working, there might be changes you can make to help you work better, such as:

- changing your work schedule to give you time to rest if you’re tired
- changing your working hours
- working from home some or all of the time
- arranging meetings in familiar locations and at times when you’re likely to feel and perform better
- simplifying your routine
- doing one task at a time
- working in a quieter area where there are fewer distractions
- using technology and equipment, such as a computerised diary to remind you about meetings and deadlines
- moving to a different role – for example, moving to a non-driving role if you are not able to continue driving.
If any of these changes are ‘reasonable adjustments’, your employer has to make them for you. The decision about what counts as ‘reasonable’ will depend on your specific situation, including:

- how practical the changes are
- how much they cost
- the size of the organisation you work for
- the type of adjustment.

Your employer should think about reasonable adjustments they could make and how those may help you before they ask or force you to leave. If you stay in work, and your employer doesn’t make adjustments when they should do, this is known as ‘unlawful discrimination’.

‘My initial fear after diagnosis was that I would have to stop working, but my employer has made it possible for me to continue working by making adjustments to my role.’

Person with dementia
Flexible working

Flexible working can include things like working from home, working part-time or job sharing.

Whether or not they have a disability, all employees who have worked for the same employer for more than six months have the right to request flexible working. This is under the Flexible Working Regulations 2014 (in England and Wales) or the Flexible Working Regulations (Northern Ireland) 2015.

However, employers do not have to approve requests for flexible working.

You can request flexible working like anyone else (if you’ve worked in your current role for more than six months). However, you have more protection under the Equality Act (see page 12). This is because under the Equality Act the employer has a duty to make reasonable adjustments for you, and this might include giving you flexible working arrangements.

For more information see ‘Other useful organisations’ on page 34 and www.gov.uk/flexible-working
Getting advice and support

When making decisions, it is good to know what all of your options are. You can get advice and support in a number of ways. Some of these are free. See ‘Other useful organisations’ on page 34 for suggested organisations that you can contact for advice on different topics.

It is also worth checking whether you have any insurance policies that include ‘legal expenses cover’. This is sometimes added to household, car, credit card or mobile phone insurance policies. Many people don’t realise they have legal expenses cover until they check their policy. If you do have it, you might be able to get your insurance company to pay for legal help. Contact your insurance company (or companies) to find out if you have legal expenses cover and what the conditions of your policy are.
You may choose to leave work, or you may not find it possible to continue working even if you have a supportive employer.

Some people find that it is a relief to leave work. Other people may find it very hard to leave. Or you may have mixed feelings. There are many reasons why people give up working. You have not failed if your condition means you cannot continue working. Having dementia means many jobs are simply not possible.

It’s a good idea to find out about your financial options so that you can plan ahead as far as you can. This can help you make an informed decision about leaving work. See ‘Other useful organisations’ on page 34 for ideas about who to contact for advice.

‘I have to confess it was a huge relief to me to be able to go, “Oh, enough is enough.”’

Person with dementia
Pensions

Before making a decision about leaving work, you should find out about your pension rights. See ‘Other useful organisations’ on page 34 for ideas about where to get free advice.

State pensions
A State pension is paid to people who reach the state pension age. A person will receive a State pension only if they have made enough National insurance (NI) contributions.

The state pension age (the age when people can start to receive the State pension) is gradually rising. By 2028 it will be 67.

For more information see factsheet 413, Benefits for people affected by dementia.

If you are younger than the state pension age but you are not able to work, you may be able to get National insurance contribution credits to protect your State pension rights if you are receiving certain benefits. Contact the government’s Pension Service for information about your pension rights (see ‘Other useful organisations’ on page 34).
Occupational and personal pensions
If you have a company pension plan (a ‘workplace pension’) or a personal pension plan, leaving work at an earlier date will affect how much money you will receive. However, many pension plans will let you take your pension if you retire early because of illness. Ask your pension provider whether you qualify to take your pension early.

Taking your pension early may have some impact on your financial situation – you might want to talk to a financial adviser about this. Pension Wise is a free and impartial government service that can give you advice about options for your workplace or personal pension. See ‘Other useful organisations’ on page 34 for the Pension Wise contact details.

Insurance
Check if you have any relevant insurance policies, such as critical illness cover. This might mean you could receive a lump sum if you have to give up work for medical reasons. Look at the terms of any policy you have to see whether it covers dementia and if there are any restrictions or conditions. Talk to the insurance company if you need more information about your policy.

Financial advice
If you are facing challenges with your finances, you may find it helpful to get advice from an independent financial adviser. Ask someone you trust to recommend an adviser. Citizens Advice or the Money Advice Service can also suggest ways to find a suitable adviser (see ‘Other useful organisations’ on page 34). If you do speak to a financial adviser, make sure they confirm how much they will charge you at the start of your conversation.
Benefits

There are a range of benefits that can help with the cost of living after leaving or reducing work.

If you have to leave work suddenly or reduce your hours, you may face challenges with your finances. For example, you may have a mortgage to pay or children to support. You may be entitled to receive some benefits to help you with these costs. These will differ depending on your circumstances. Some benefits that may be relevant to you are Personal independence payment (PIP), Employment and support allowance (ESA) and Universal Credit.

**Personal independence payment (PIP)**

PIP is designed to support people of working age who have daily living or mobility needs. It is gradually replacing Disability living allowance. Whether or not you can claim it depends on your needs, not on your diagnosis. It isn’t ‘means-tested’ which means that it doesn’t depend on your financial situation. It is paid at different rates depending on your needs and is reviewed regularly. If you are over state pension age when you claim, you should claim Attendance allowance instead (see factsheet 413, Benefits for people affected by dementia).
‘New style’ Employment and support allowance (ESA)

You can make a claim for ESA if you are of working age and are unable to work due to ill health. Whether or not you qualify for ESA depends on your National insurance contributions record. If you don’t have sufficient National insurance contributions, you may be able to claim Universal credit instead (see page 28).
Universal credit

Universal credit is replacing many working age means-tested benefits. It’s being rolled out across the country and is now expected to be completed by September 2024 – but this date may change. Universal credit is paid as one single monthly amount to meet living costs, housing costs, costs of supporting children and any extra costs arising from disability or caring responsibilities.

Some benefits are being replaced by Universal credit and new claims for these aren’t normally accepted. If you are currently claiming any of the following benefits, at some point you’ll be invited to claim Universal credit instead.

- **Working tax credit** – this is a means-tested benefit that you may receive if you are in work but on a low wage.

- **Income-related employment and support allowance (ESA)** – you could previously claim a means-tested version of ESA if you were unable to work due to illness or disability.

- **Income support** – this is a means-tested benefit paid to some people who aren’t expected to look for work. It can help you with basic living expenses.

For more information see factsheet 413, *Benefits for people affected by dementia*. You may also be entitled to other benefits, such as help with council tax. This is why it’s important that you get a full benefits check. Talk to Citizens Advice or Turn2us for more advice (see ‘Other useful organisations’ on page 34).
Staying involved and active

If you decide to leave work, having dementia doesn’t have to stop you doing other things you want to do.

Many people who have dementia stay active and involved, whether they are working or not. A possible benefit of stopping work is that it gives you more time to enjoy other activities. This may include taking part in or watching sport, travelling or studying. Or it could include doing hobbies and creative activities like writing, painting, gardening or singing. It could also include going to the cinema or museums, political campaigning or walking. You may also want to try new activities.

There may also be ways that you can be active in your community, including taking part in group activities. You may be able to find some groups that are specifically for people with dementia, if you prefer that. Your local Alzheimer’s Society may be able to help you find groups in your area. Or you can use our online dementia directory at alzheimers.org.uk/dementiadiary.
You might also want to spend time volunteering. Alzheimer’s Society has a wide range of opportunities for people who want to volunteer. To find out more call 0845 504 9300 or email volunteers@alzheimers.org.uk. There are also many volunteering opportunities that don’t have a connection with dementia. For information about a wide range of volunteering opportunities see www.gov.uk/government/get-involved/take-part/volunteer

If you do decide to do some volunteering, it’s a good idea to double check whether that will have an impact on any benefits that you may be getting. You are allowed to volunteer while receiving benefits as long as you continue to meet all the conditions of your benefit. You should tell your benefits office about any volunteering that you are planning to do. For more information see www.gov.uk/guidance/volunteering-and-claiming-benefits (England and Wales) and www.nidirect.gov.uk/articles/volunteering-while-benefits (Northern Ireland).

‘Focus on what you can do and keep striving.’
Younger person with dementia
Another option is taking part in dementia research. You could get involved in a clinical trial to test a new treatment. Or you could give your views on the quality of healthcare and support services. Ask your GP about research that is happening in your local area. Or register with Join Dementia Research at www.joindementiaresearch.nihr.ac.uk. This is a national service that helps to match people affected by dementia with suitable research studies in their area. You can register online or call Alzheimer’s Society on 0333 150 3456.

If you don’t want to take part in a study, there are other ways you can contribute to dementia research. For example, you can join Alzheimer’s Society’s Research Network to help influence how we fund research. Email research@alzheimers.org.uk or phone 020 7423 3563 to get involved.

“I fill my time as a volunteer – hearing children read in a local primary school. The school accepts what I can do and the fact that this can be variable.”

Person with dementia
Other useful organisations

Access to Work
www.gov.uk/access-to-work

This government scheme provides support and funding for people with a disability at work. This applies if they need help at work that isn’t covered by their employer making ‘reasonable adjustments’. People in Northern Ireland can read more information at www.nidirect.gov.uk/articles/access-work-practical-help-work

Advisory, Conciliation and Arbitration Service (Acas)
0300 123 1100 (Helpline, 8am–6pm Monday–Friday)
www.acas.org.uk

Acas can give you impartial information and advice about situations at work, including employment law. Its website has guidance and publications. You can also phone the helpline for information and advice.

Benefit Enquiry Line
0800 232 1271 (Helpline, 9am–5pm Monday–Wednesday and Friday, 10am–5pm Thursday)

The Benefit Enquiry Line provides advice and information on Attendance allowance, Disability living allowance, Personal independence payments, Carer’s allowance and Carer’s credit. This service is for people living in Northern Ireland.
Other useful organisations

Citizens Advice
03444 111 444 (Adviseline, 9am–5pm Monday–Friday)
www.citizensadvice.org.uk

Citizens Advice can give you information and advice about legal and financial issues, including benefits. It can also suggest ways to get more legal and financial advice. To find your nearest Citizens Advice look in the phone book, ask at your local library, or look on the Citizens Advice website (above).

Civil Legal Advice (CLA)
www.gov.uk/civil-legal-advice

Civil Legal Advice (CLA) can explain whether you qualify for legal aid (money to help with legal costs) in England or Wales. It is not common for people to get legal aid in employment cases, but it may be available if discrimination is involved.

Department for Communities
028 9082 9000
www.communities-ni.gov.uk

The Department for Communities can give information about benefits in Northern Ireland.

Department for Work and Pensions (DWP)
www.gov.uk/government/organisations/department-for-work-pensions

DWP is the government department that looks after employment and social security in England and Wales. The DWP website has information about the State pension and benefits for people who are of working age.
Living with dementia: Employment

For more information go to alzheimers.org.uk

Disability Law Service
020 7791 9800
(advice line, 10am–1pm and 2–5pm Monday–Friday)
advice@dls.org.uk
dls.org.uk

The Disability Law Service may be able to give you free advice about employment and discrimination in England and Wales.

Disability Service Centre
www.gov.uk/disability-benefits-helpline

Personal independence payment (PIP)
0800 121 4433 (9am–5pm Monday–Friday)

Disability living allowance (DLA)
For people who were born after 8 April 1948 – 0800 121 4600
(9am–5pm Monday–Friday)

For people who were born on or before 8 April 1948 –
0800 731 0122 (9.30am–3.30pm Monday–Friday)

Attendance allowance (AA)
0800 731 0122 (9.30am–3.30pm Monday–Friday)

The Disability Service Centre provides advice and information on Attendance allowance, Disability living allowance, Personal independence payments, Carer’s allowance and Carer’s credit. This service is for people living in England and Wales.
Other useful organisations

Equality Advisory and Support Service
0808 800 0082
(helpline, 9am–7pm Monday–Friday, 10am–2pm Saturday)
www.equalityadvisoryservice.com

The Equality Advisory and Support Service helpline can give you free advice and support about your employment rights in England and Wales.

Equality and Human Rights Commission
www.equalityhumanrights.com

The Equality and Human Rights Commission produces information about discrimination in the workplace. This includes information about reasonable adjustments in England and Wales. The Commission signposts people to the Equality Advisory and Support Service helpline for free advice and support (see above).

Equality Commission for Northern Ireland
028 90 500 600
information@equalityni.org
www.equalityni.org

If you live in Northern Ireland, the Equality Commission for Northern Ireland has a helpline that can give you free advice and support on employment law.

Jobcentre Plus
www.gov.uk/contact-jobcentre-plus

Your local Jobcentre Plus can help you apply for a job. It can also give you information and support about applying for benefits. Find the contact details for your nearest Jobcentre Plus office using the website above.
Living with dementia: Employment

Law Centre NI
028 9024 4401 (Advice line)
admin@lawcentreni.org
www.lawcentreni.org

If you live in Northern Ireland, Law Centre NI can give you free legal advice on a range of issues including employment.

Law Society
solicitors.lawsociety.org.uk

If you live in England or Wales, the Law Society can help you find a solicitor to help with employment law. Unless the solicitor agrees to give you free advice, make sure they confirm how much they will charge at the start of your conversation.

Law Society of Northern Ireland
www.lawsoc-ni.org/solicitors

The Law Society of Northern Ireland can help people who live in Northern Ireland find a solicitor to help with employment law. Unless the solicitor agrees to give you free advice make sure they confirm how much they will charge at the start of your conversation. A solicitor can also let you know if you qualify for legal aid (money to help with legal costs).

LawWorks
www.lawworks.org.uk

This charity can help you find a free legal advice clinic in your area. You can use the search on the LawWorks website to help you do this. It also provides information about other ways you can get free legal help.
Other useful organisations

**Money Advice Service**
0800 138 7777 (8am–6pm Monday–Friday)
enquiries@maps.org.uk
www.moneyadviceservice.org.uk

The Money Advice Service is funded by the government. It can give you information about a range of financial issues, including work and benefits.

**Pension Service**
0800 731 7898 (9.30am–3.30pm Monday–Friday)
www.gov.uk/contact-pension-service

The government’s Pension Service can give you information about whether and when you are entitled to receive the State pension in England and Wales. See the relevant contact details on the website for help to claim the State Pension for the first time or for help if you’re already getting the State pension.

**Pension Wise**
0800 138 3944
contact@pensionwise.gov.uk
www.pensionwise.gov.uk

Pension Wise can give you advice about workplace and personal pensions.

**Turn2us**
www.turn2us.org.uk

Turn2us is a national charity that can help you understand what benefits you are entitled to. It also provides information about other financial support such as charitable grants.
Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

Reviewed by: Dr Louise Ritchie, Reader in Dementia Research at the University of West Scotland and Ann Robson, Consultant, Employment Group, Mayer Brown International LLP.

To give feedback on this publication, or for a list of sources, contact publications@alzheimers.org.uk
Alzheimer’s Society is the UK’s leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

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 support line on 0333 150 3456.
(Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need. To make a single or monthly donation, please call us on 0330 333 0804 or go to alzheimers.org.uk/donate