



**DementiaUK**  
Helping families face dementia

# Dementia at work

**A guide for people living with dementia,  
their families and carers**



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dementia  
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## “Don’t make any rash decisions about employment”

“When I was diagnosed with dementia, I was a senior lecturer teaching graduate and undergraduate nurses, medical staff and allied health professionals. I loved teaching, exchanging information and knowledge. I was never one of those who would sit at a desk and put up a PowerPoint. We would get into discussions, and I would walk around the room and talk.

“Before I was diagnosed with dementia in September 2021, I was aware of my symptoms and how they might affect my work, so I made the decision to carry on working but step down from my managerial role. My employer was extremely supportive.

“It had always been my intention to work until I was 65 but I ended up retiring when I was 60. I’ve missed out on five years of full-time income, however I’m grateful that I was able to work for another two years after my dementia diagnosis before eventually retiring in October 2023. That was because of good support in the initial stages, and my awareness of being able to manage things.

“If you receive a diagnosis of dementia, you are the same person as you were before. Don’t make any rash decisions about employment at all. Talk to your loved ones or somebody else about what you want to do; talk to your employer; go to Occupational Health. The most important thing is to decide what you want to do and then find a happy medium.”

**Phil, 61, who lives with Lewy body dementia**



# Welcome to your Dementia at work guide

If you are living with dementia and are working – or if you are working while also caring for someone with dementia – it is natural to have lots of questions and concerns. You might be worried about how to tell your employer about the diagnosis or how you will manage financially if you decide to leave work. If you are a carer, you may have concerns about how you will juggle your caring and work responsibilities.

## **This guide is for you.**


Today, nearly one million people in the UK are living with dementia, and over 70,000 of those have young onset dementia (where symptoms develop before the age of 65). And with many of us working longer due to the increasing State Pension age, a growing number of people with dementia – and those who care for them – are still in employment.

This guide will help you understand your rights and your employer's responsibilities, and offers practical tips and coping strategies for working when you are living with dementia or supporting someone with the diagnosis.

Along the way, you will also hear from other people in similar circumstances who have shared their experiences of working while living with, or caring for someone with, dementia.

We hope you find this guide helpful.

Warm regards,



## **Vic Lyons**

Admiral Nurse

Head of Digital Services

Delivery and Dementia at Work

## **What is an Admiral Nurse?**

Admiral Nurses are specialist dementia nurses who are there for the whole family. Supported and developed by Dementia UK, they provide tailored advice, practical solutions and compassionate emotional support to help people with dementia and their carers have the best life possible, for as long as possible.



**Vic Lyons**

# What's inside

This guide is divided into two sections: one focusing on people with dementia who are working, and the other on people who are working while caring for someone with the diagnosis. Throughout, you will find essential information to guide you through the next stages of your working life, divided into the key issues you may be facing.

## For people with dementia who are working

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### Leaving your role

How to decide when it is time to leave work, and how to handle this sometimes difficult transition.



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You do not need to read this guide from front to back – skip to the sections that sound most useful right now.

While we have separated the guide into sections for people with dementia and carers, do dip into both – you are likely to find useful information in both parts.

You will also find helpful resources and contacts at the back, on p37-39.

## For people who are working while caring for someone with dementia

### Supporting the person with dementia to keep working

The role you can play in supporting the person to continue to work and have a positive experience.



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Tips and resources for maintaining your own health and wellbeing.



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# Meet the Dementia at Work Team

**Our Dementia at Work programme is led by our team of dementia specialist Admiral Nurses who have over 100 years' experience between them. They are experts in supporting employees, carers and employers to manage the challenges of dementia in and out of work.**



**Vic Lyons, Head of Digital Services Delivery and Dementia at Work**

I became an Admiral Nurse in 2003 having worked in dementia care since 1998. Five members of my own family have had dementia, and I've seen first-hand the impact the condition can have. I am also currently in a sandwich carer role, providing care for my 86-year-old mother-in-law with dementia and my own dependent children.

I long for the day when we can say we have a cure for dementia, or that we can prevent it. Until that day, we need to make sure no one faces dementia alone by providing specialist support and advice whenever people need it. I feel privileged to share my time and knowledge to make life a little easier for those affected by dementia.



**Pam Kehoe, Lead Admiral Nurse for Dementia at Work**

I joined Dementia UK in November 2017 having become an Admiral Nurse in 2002. Prior to that, I worked as a Mental Health Nurse supporting families affected by dementia since 1992. I am now Lead Admiral Nurse for Dementia at Work, focusing on dementia within the workplace.

The main focus of our role as the Dementia at Work Team is to work alongside organisations to help reduce the stigma of dementia and enable them to create an inclusive workplace for everyone – employees with dementia, their carers, and customers and clients.

I have a passion for supporting people with dementia and their family members and carers. I feel privileged to be able to work alongside them and to be welcomed into their lives.



### **Gary Burnham-Jones, Admiral Nurse**

I've been a Mental Health Nurse since the 1990s and have always had a passion for working with people with dementia and their families. I joined Dementia UK in 2019, where I currently cover the national Helpline and virtual clinic appointments and also deliver a range of Dementia at Work services. I am a working carer myself with a young dependent family and an elderly parent living with dementia, so I understand many of the challenges this can bring.

Whether you are living with dementia yourself or caring for someone with the condition, it is vital for you to have access to the right information, advice and expert support. I hope this guide will give you just that.



### **Rachel Watson, Admiral Nurse**

Supporting people living with dementia is a deeply personal and fulfilling passion of mine. As an Admiral Nurse, I am committed to raising awareness, ensuring that those affected by dementia feel valued and understood. Witnessing and experiencing the daily struggles and triumphs of families living with dementia has strengthened my resolve to make a positive impact.

I have been an Admiral Nurse since 2016 and a Mental Health Nurse since 1995. As a working family carer myself, I know this involves emotional support, celebrating small victories, and offering comfort during challenging times. It is so important that everyone living with dementia or supporting someone with the diagnosis – from family carers to employers – has the right information at the right time.



# Working with dementia symptoms

Many people first notice the early signs of dementia at work. Here's what you need to know about what to look out for – and what to do next.

## 5 things you need to know

**1 Experiencing symptoms:** the first signs of dementia often become apparent in the workplace, such as forgetting meetings, struggling with multitasking, or finding it hard to concentrate. These early signs are often attributed to things like stress, tiredness or menopause, but it is important to recognise that they may be symptoms of dementia.

**2 Colleagues may notice first:** your line manager or colleagues might see changes in your work, behaviour or performance before you do. They may notice that you are having difficulty remembering tasks, following conversations, or completing familiar activities.

**3 Masking symptoms:** it is natural to want to hide your symptoms at work, and many people with dementia mask them for some time. But struggling in silence could delay you getting a dementia diagnosis – and being able to access the support you need in and out of work.

**4 Stigma and discrimination:** you might be afraid of losing your job as a result of having dementia, or of your colleagues thinking about you differently. But if you are diagnosed with dementia, you are legally protected against discrimination at work, and may be able to access adjustments to help you manage better (see p16).

**5 Common misconceptions:** it is a myth that you must immediately stop working after a dementia diagnosis; many people with dementia continue to work for some time. You may also be worried that you will have to stop driving, which may affect your ability to get to work and/or do your job – but while you will need to notify the [Driver and Vehicle Licensing Agency \(DVLA\)](#) or the [Driver and Vehicle Agency \(DVA\)](#) in Northern Ireland, it does not necessarily mean your licence will be taken away.



## The impact of dementia on working-age people

Developing dementia when you are still in employment can bring additional concerns. You may have:

- financial commitments, like rent/mortgage, loans, and pension contributions
- dependent children
- older parents who rely on you
- a partner who is also in employment, and whose ability to work is affected by taking on a caring role

While initially, you may be able to continue to work with dementia, it will become more challenging as your condition progresses and may lead to you ending your working life earlier than planned. However, with the right support, many people stay in employment for some time – so a diagnosis of dementia does not mean your working life is over.

## Signs to look out for

Many people think of memory problems as the main symptom of dementia, but there are many other signs too – and when someone under the age of 65 develops dementia, you might notice these first. These include:

- difficulties with concentration
- finding it harder to solve problems and make decisions
- making uncharacteristic mistakes at work
- problems with communication, such as finding the right words
- struggling with literacy and numeracy
- becoming disorientated and losing your bearings – even in familiar places, like at work
- changes in personality and behaviour that affect your work, eg becoming unusually angry or upset if tasks do not go to plan

## Why seek a diagnosis?

Is it really necessary to seek a diagnosis if you are experiencing the early symptoms of dementia? Admiral Nurse Rachel Watson explains why it is important to see your doctor.



### It could be something else

There are a number of other conditions that can have similar symptoms to dementia, such as stress, depression, menopause, vitamin deficiency and infections. Many of these are treatable – and you might be able to rule dementia out.

### Diagnosis can be a long process

Waiting lists for memory clinic assessments can be long, and for people with young onset dementia in particular, getting a diagnosis can take a number of years, not just because of waiting lists but also because the signs of dementia may be missed in working-age people. Waiting until your symptoms are more advanced may mean that your struggles at work become unmanageable.

### Early diagnosis means early support

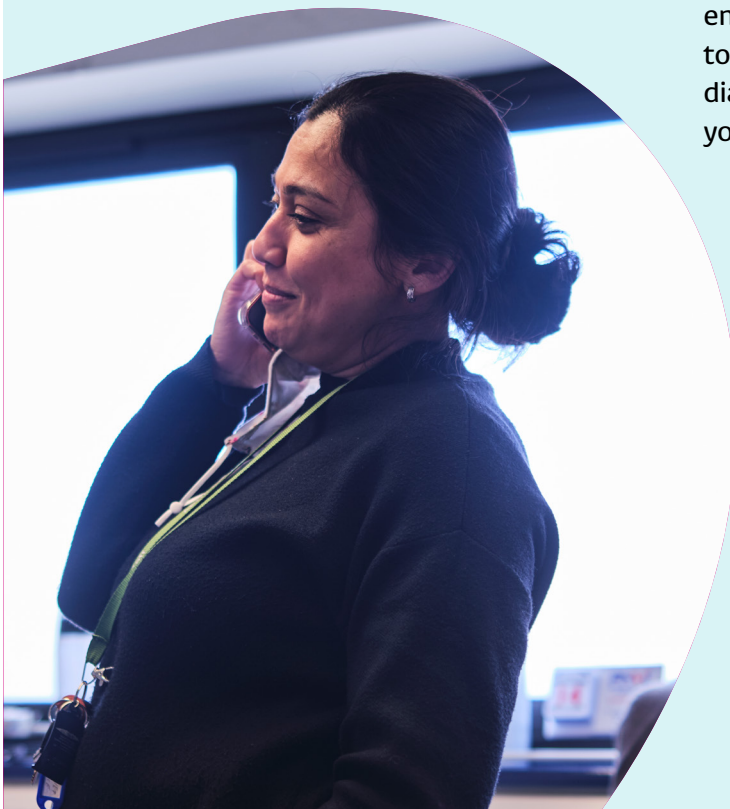
The sooner you get a diagnosis of dementia, the sooner you can access support – at work and in your wider life. Medication is also available which may help with some of the symptoms of some types of dementia, so it is important not to delay.

### You will be protected at work

Employers sometimes mistake the signs of dementia for laziness or carelessness. Some people are put on a performance improvement plan or even dismissed as a result. But dementia is classed as a disability in law so if you have a diagnosis, you are protected from discrimination.

### You can access support

If you have dementia or any other disability, your employer has to make reasonable adjustments to help you in your role, so getting a dementia diagnosis means you can request the support you need.







## What to expect if you seek a diagnosis

If you think you are experiencing signs of dementia, your first port of call is your GP. It is helpful to keep a record of what is happening: your symptoms, when they occur (time, date, place) and anything you think might have triggered them, eg a stressful situation at work.

You might want to take a family member or friend with you for support; they can also tell the doctor about any changes they have noticed in you.

Your GP should ask you about your symptoms, take a detailed medical and family history, and request tests, including blood tests, to see if there is a physical cause. They may ask you to do some simple tests like drawing a clockface and remembering an address, but as memory may not be an early symptom of dementia in younger people, some people under 65 perform well in these tests.

If the GP believes there is cause for concern they should refer you to a memory clinic for more detailed tests and a brain scan. Based on the results, you may be diagnosed with dementia.

You might find our leaflets on getting a diagnosis of dementia and getting a diagnosis of young onset dementia helpful at this time – please see Sources of support on p37.



“If you need support around getting a diagnosis of dementia, please call our Helpline on **0800 888 6678**. We’re here to help.”

**Admiral Nurse Vic Lyons**

# Telling your employer about a dementia diagnosis

It is natural to be worried about telling your employer that you have been diagnosed with dementia – but having an open conversation can help you get the support you need.

## 5 ways to prepare for the conversation

**1 Be prepared:** write down what you want to say and practise the conversation. Include information about the type of dementia you have been diagnosed with, its symptoms, and any treatment you are receiving. Make notes about anything you are finding difficult at work, and any adjustments or support you would like put in place.

**2 Choose the right time and place:** arrange a private meeting in a quiet place where there will be minimal interruptions and none of you will feel rushed. Think about who should be at the meeting – just your line manager, the head of your department or the manager of the company, an HR representative? Make sure you allow sufficient time for the meeting and choose a time of day where you are likely to feel calmest and most focused.

**3 Consider having support:** you might find it helpful to have someone with you, such as a trusted colleague, your partner or another family member or friend. They can offer reassurance and advocate for you if the conversation becomes difficult. If you are a member of a union, you may wish to have your rep with you.

## Did you know?



Your employer should not share your diagnosis with anyone else, unless you are happy for them to do so. If so, you should agree who you want them to tell, what you want to tell them, and whether you would like to share the information yourself or would prefer the employer to do it.

**4 Give your employer the heads-up:** you might want to give your employer advance notice of what you would like to discuss. You do not need to be specific at this point – you could just say that you have been diagnosed with a health condition and would like to talk to them about it.

**5 Think about outcomes:** what do you want to achieve from the meeting? Do you simply want your employer to know about your diagnosis? Are there specific adjustments you need them to consider? Please see p16 for more on requesting reasonable adjustments.

## Top tips for a successful conversation



**Admiral Nurse Gary Burnham-Jones shares advice on ensuring that telling your employer goes smoothly.**

### Be open and honest

Explain your diagnosis, any current symptoms and how they affect your work, if at all.

### Take notes during the meeting

If you cannot do this yourself, take someone with you who can do it on your behalf. If the meeting is online, eg on Teams or Zoom, you can record the session.

### Try to remain calm

Disclosing your diagnosis can be emotional, so if you are becoming stressed or anxious, ask to take a break, or to end the meeting and reconvene at a later date.

### Do not expect to resolve everything in one meeting

Both you and your employer may have questions that you cannot answer in this initial conversation. It is okay to go away, reflect on the meeting, do some research into anything you are unclear about, and meet again in the near future.

### Be ready with information

Suggest that your employer visits Dementia UK's website for information pages and advice leaflets on dementia symptoms, including our guide for employers. This will help them understand more about how your condition is affecting you. Please visit

➔ [dementiauk.org/information-and-support](https://dementiauk.org/information-and-support)

### Be clear about the next steps

What needs to be done, who will do it, and when will it be done by? Make sure someone writes this down and circulates it to everyone who is involved.



## “Do I have to tell my employer I have dementia?”

**Some people may be worried about telling their employer about a diagnosis of dementia, which is understandable. However, dementia is a progressive condition so even if you do not feel it is affecting your work right now, it is likely that over time, more challenges will arise.**

If your employer is unaware that you have dementia and you start to struggle in your role, they may make incorrect assumptions about what is happening. For example, they may think that if you are making mistakes, you are being careless, or if you forget to attend a meeting, you are disorganised. They may not realise that the problems are beyond your control and start a disciplinary process which could even lead to your contract being terminated.

On the other hand, if your employer knows about your diagnosis, they can support you to consider adjustments that will make your working life easier and keep you in employment for as long as possible. Being open and honest will help them offer you the best level of support.

You will also be legally protected from discrimination at work on the grounds of disability – please see p16 for information on your rights.

You are not obliged to disclose your private medical information or attend referrals, such as to the Occupational Health Team. But if you do not, your employer may make decisions about your employment without all the information they need, so it is best to be open and honest.

If you are concerned about telling your employer about your diagnosis, we are here to help on our Helpline or in a virtual clinic appointment – please see p36 for our contact details.

### “My boss was 100% supportive”

“When I was first diagnosed with dementia I took nearly three months off work. My mental health took a nosedive, and I was angry and depressed. Work was the last thing on my mind.

“Throughout this time, my employer was 100% supportive. My boss phoned me on a regular basis – not to put pressure on me to come back to work, but just to see how I was doing. They were genuinely concerned about what they could do to help me and my wife, Christine.”

**Andy, who works as a school sports technician and was diagnosed with dementia at the age of 52**





## Your legal obligations

In some occupations, you are legally and contractually obliged to tell your employer if you are diagnosed with dementia. In general, these are roles where your own and other people's health and safety could be at risk, for example:

- the armed forces
- medicine/healthcare
- jobs that involve handling chemicals
- jobs that involve using heavy machinery
- jobs that involve driving as part of your role

If you are unsure, please refer to your employment contract or speak to your

employer or HR Team, if you have one.

If you drive, you are also legally obliged to tell the DVLA (DVA in Northern Ireland) and vehicle insurer. If you drive a company vehicle (including a company car) your employer's insurance company will need to be notified.

This does not necessarily mean you will have to stop driving straight away, although this is a possibility – you may be issued with a shorter driving licence that will then be reviewed or asked to take regular driving assessments (usually annually).

Please see p37 for our leaflet on driving and dementia.

# Working with dementia

**A diagnosis of dementia does not mean your working life has to come to an immediate end. Here is what you need to know about continuing in employment or self-employment.**

## Reasonable adjustments to help you at work

Dementia is classified as a disability under the Equality Act 2010 in England, Scotland and Wales, and the Disability Discrimination Act 1995 in Northern Ireland. These laws protect you from discrimination and unfair treatment at work.

It also means that if your employer knows about your dementia diagnosis, they must make reasonable adjustments to help you continue to work. These could include:

- allocating tasks individually, rather than all at once
- simplifying your work routines
- providing a quieter workspace with fewer distractions
- enabling supported homeworking
- allowing flexible working, eg working shorter hours, changing your start and end times, part-time work
- offering regular rest breaks
- providing assistive technology like alerts, reminders, voice recognition software
- developing a buddy system
- providing regular support sessions
- a reduction in hours (if needed or requested)
- removing elements of your role that you are finding particularly difficult

- moving to a role with less responsibility (if needed or requested)

You should be fully involved in deciding what reasonable adjustments you need. If there is an Occupational Health Team, they too should be involved. Make sure you have someone with you who can take notes and help you with any documentation that needs completing.

The adjustments you need may change over time, so be sure to arrange regular meetings with your line manager to check in and discuss any new adjustments and support you may need.

Sometimes it may be difficult for your employer to make an adjustment to your role. For example, if you work for a small business where you are the only employee, there may not be an alternative role for you to move into.

However, if your employer says the adjustment you have asked for is not reasonable, they should work with you to find an alternative that would help.

## Your legal rights

It is against the law for your employer to discriminate against you because you have dementia. This covers things like:

- refusal to make reasonable adjustments
- harassment (from your employer or





colleagues) eg making jokes about your symptoms

- unfair dismissal, eg losing your job because of your absence record – however, it may be lawful to terminate your employment on capability grounds if reasonable adjustments fail to enable you to fulfil your role
- being made redundant on disability grounds

If you believe you are being discriminated against, first talk to your employer or HR Manager to try to resolve the issue informally, putting your concerns in writing.

If this does not resolve the issue, you should follow the steps in your employer's complaints policy, which all employers should have. It may help to use a mediator or advocate at this stage – for example a trusted colleague or union rep.

If the outcome is still unsatisfactory, you may wish to take your complaint to an employment tribunal. **▶ The Advisory, Conciliation and Arbitration Service (Acas)** can help with this. You could also seek advice from your trade union, if you have one, or a solicitor.

## Self-employment

If you are self-employed, a diagnosis of dementia could have a big impact. You may have to reduce your workload (perhaps taking on fewer projects or clients), allow extra time to complete tasks, make adaptations to your workspace (such as assistive technology), and eventually stop work altogether.

However, there may also be advantages to self-employment, including greater flexibility, being able to pace yourself and manage your own workload, and in some cases, working from home.

If you are self-employed and have a diagnosis of dementia it is important to claim any benefits you are eligible for – please see p18.

## Employment benefits for people with dementia

You may be able to claim certain benefits if you are working and have dementia. These include:

### Adult Disability Payment (Scotland)

A benefit for adults with a disability or long-term health condition that affects daily living and/or mobility. It is the equivalent of PIP in the rest of the UK (see below).

### 'New Style' Employment and Support Allowance (ESA)

A financial benefit to help with living costs if you are unable to work due to a disability or health condition, or to support you to get back into work.

### Personal Independence Payment (PIP)

A benefit to help with living costs if you have a long-term physical or mental health condition or disability that causes difficulty doing certain everyday tasks or getting around.

### Statutory Sick Pay (SSP)

A weekly payment for people who are too ill to work, paid by your employer for up to 28 weeks.

### Universal Credit

A benefit to help with living costs if you are on a low income, out of work or unable to work. It is paid monthly (fortnightly or monthly in Scotland).

You can use a benefits calculator to find out what you might be entitled to – for example [entitledto.co.uk](https://entitledto.co.uk) or [benefits-calculator.turn2us.org.uk](https://benefits-calculator.turn2us.org.uk)

## The Access to Work scheme

The Access to Work scheme can help you get or stay in work if you have a physical or mental health condition or disability. The support you get will depend on your needs, but may include:

- a grant to help pay for practical support with your work, eg assistive technology, a support worker or help with travel costs if you cannot drive or use public transport
- support with managing your mental health at work, eg one-to-one sessions with a mental health professional or a customised mental health support plan
- communication support for job interviews

The scheme does not depend on how much you earn and will not affect any other benefits you receive. For more information, please visit [gov.uk/access-to-work](https://gov.uk/access-to-work) (England, Scotland and Wales) or [nidirect.gov.uk/articles/access-work-practical-help-work](https://nidirect.gov.uk/articles/access-work-practical-help-work) (Northern Ireland).

### Did you know?

There is no set amount for an Access to Work grant. How much you get will depend on your specific needs, and will usually be reviewed annually.



## “My wife’s employer kept faith in her”

“When my wife Yvonne was diagnosed with dementia in December 2013, she was working for Sainsbury’s, picking orders for home delivery customers. She had had several warnings over the slowness of her work, so when it came to telling her employer about her diagnosis, we naturally expected the worst. We both thought they would immediately let her go – but instead they asked, ‘What can we do to help you keep working?’

“Over time, as Yvonne’s dementia progressed, her employer made gradual adjustments to her role so she could continue to work. They changed her working hours, so she didn’t have to do shifts early in the morning, when she often struggled. They reduced the number of aisles she worked in, so it was less confusing, then reduced her hours overall.

“By the time Yvonne stopped working, she was working purely at the back-end of the store, cleaning the crates shopping was packed in – a job that suited her perfectly, as she was so meticulous. It was clear she was adding hardly any value to the business, but the company still kept faith in her.

“Finally, in 2017, Yvonne and I decided she should give up her job. Her employer arranged a final occupational health assessment to make sure there was nothing else they could do, but we knew it was the right time. Yvonne was able to leave on her own terms, with her dignity intact. Sainsbury’s was truly exemplary and we couldn’t be more grateful.”

**Trevor, whose wife Yvonne has young onset Alzheimer’s disease**



# Leaving your role

**While some people with dementia continue to work for some time, the increasing challenges may eventually mean you leave your job earlier than you had planned. Read our advice on coping with this period of transition.**

## Is it the right time?

Deciding when to leave your job or stop working completely due to dementia will be influenced by how the condition affects you, the nature of your job, and your personal circumstances – including your financial position and whether you are able to access a pension early.

There is no definitive time to stop working, but if work is feeling too stressful, you are finding it increasingly difficult to manage tasks, or no further reasonable adjustments can be made to help you keep working, it could be time to consider leaving.

Before making a decision, it is important to talk things through with your family or other people close to you. You may also want to talk

to your health professionals about how your condition is affecting your work. Consider the financial implications of leaving work and the support systems you can access.

It is also a good idea to discuss your situation with your employer, HR and Occupational Health Teams (if available) and your union rep, if you have one, to make sure you understand your options.

This is especially important if you feel your employer is putting pressure on you to leave work when you believe that with reasonable adjustments, you could continue. In this situation, you may want to consult a solicitor or [Acas](#).

## 5 top tips

**1** Read your employment contract thoroughly to check what it says about leaving work, eg the resignation process and your notice period.

**2** Check your benefits eligibility through your council's Welfare Rights Service, [Citizens Advice](#) or a charity such as [Age UK](#). Please see p18 for details of benefits you may be entitled to.

**3** Review your insurance policies, pensions and workplace retirement support to make sure your finances are in order.

**4** Consider taking advice from your Employee Assistance Programme, if you have one, or a financial adviser about your finances after leaving your job. You can also visit [Pension Wise](#) for free, impartial advice.

**5** Plan how to spend your time when you leave work. This may be a difficult period of transition so it is important to line up things to do so that you maintain your confidence and independence.



## Support from your employer

If you wish to retire or leave your job on medical grounds, your employer is likely to have a process to make sure the situation is handled properly for everyone's benefit. The exact process will vary depending on your employer's policies and the terms of your employment contract, and smaller businesses may not be able to offer the same level of support. However, it may include a medical and/or occupational health assessment. Your employer may also consider whether any reasonable adjustments that have been put in place could be enhanced, or new ones introduced. If you feel your employer is not supporting you, be specific about what would help you – for example, you may want to ask for help

with completing any retirement paperwork. You could also talk about what you would like to happen when you eventually leave, eg would you like to tell your colleagues yourself, or would you like your manager to tell them? Would you like a farewell celebration, or would you prefer to keep it low key?



### Did you know?

Some people who need to leave their role are able to keep working by moving to another job, rather than retiring straight away. This could be an opportunity to try something completely new.

## Ill health retirement and pensions: what you need to know

- Retiring early on medical grounds is known as ill health retirement
- The normal minimum retirement age for claiming a private or workplace pension is 55, but you may be able to claim your pension sooner if you retire because of ill health
- You will need to show medical evidence, eg a doctor's report, and your employer will need to confirm that your health condition is the only reason for you taking early retirement
- Some pension schemes allow early access if you are unable to do your specific job due to physical or mental illness. Others might say that you can only claim your pension if you cannot do any job at all
- Accessing your pension may affect the benefits you are entitled to – we recommend seeking advice from a financial adviser to understand the implications of taking ill health retirement
- You cannot claim your State Pension until you are **▶ State Pension age**

## Critical illness and mortgage insurance policies

Critical illness and mortgage insurance policies provide financial support if you are diagnosed with a specified critical illness, which, for many insurers, includes dementia.

If you are diagnosed with dementia and have a critical illness policy, it may pay out a lump sum. If you have mortgage insurance, this is likely to cover your mortgage payments in the event of no-fault unemployment or incapacity due to illness or injury, usually for a maximum 12 months.

Each insurer has different terms and conditions, so it is vital to check the small print to ensure it covers your circumstances. It is also important to note that if you already have dementia when you apply for critical illness cover, your application is likely to be refused.





## Meaningful activities after leaving work

For many people, work provides independence, a sense of purpose and achievement, and a community and relationships. This may make leaving work very difficult, so it is important to think of alternative ways of spending your time. These could include:

- volunteering
- physical activities like walking, cycling, swimming, golf, team sports or group exercise classes
- joining social or community groups, eg a book club, choir or gardening club
- learning a new skill like photography or DIY
- attending support groups for people with dementia
- creative activities like painting, pottery, crochet or craft
- mentally stimulating activities like reading, chess, board games, jigsaws and memory games
- spending time with family and friends
- everyday living activities like going shopping, looking after the garden, and walking your dog – these will help you maintain your skills and independence

It is important to tailor these activities to your own interests and abilities. Adjustments might be needed over time, but continuing with these tasks and activities will enhance your wellbeing and promote a sense of dignity and self-worth.

## “Volunteering has given me purpose and a community”

“When I was diagnosed with dementia, I was working for a pharmacy and the consultant told me I had to stop work immediately. I had no reason to get up in the morning and felt like my life was over. But then my support worker encouraged me to try a craft group for people with dementia and their carers. I didn’t think I was at all artistic, but I really enjoyed it and learnt new skills.

“When the group lost its funding and was faced with closure, another member and I decided to take it over. We applied for financial and practical support and were able to keep it running as a pottery and ceramics group. We now have a number of regular members and more who drop in.

“Volunteering has given me purpose and a community, and in between sessions, the paperwork and planning give me a routine. If you have left work and are looking for something to do, I would say not to disregard anything without trying it – you might find something you love.”

**Karen, who has young onset Alzheimer’s disease and runs a pottery and ceramics group for people affected by dementia**



For people who are working while caring for someone with dementia

# Supporting a person with dementia to keep working

The support of family and friends can help a person to remain in work for longer after a dementia diagnosis. Here are some ways you can help.

## 5 ways to support the person with dementia

- 1 Offer practical support:** for example, you could drive the person to work; help them research assistive technology that would make their working life easier, such as voice reminders and memory aids; or take over some of their household tasks to simplify their routine.
- 2 Communicate with their employer:** with the person's consent and collaboration, you could consider being involved in conversations with their employer to help them request reasonable adjustments, provide support in appraisals and reviews, and advocate for them if there are any difficulties. You could also share strategies that are helpful at home with the employer so they can try the same techniques.
- 3 Help them stay healthy:** good physical health can have a positive impact on cognitive functions such as attention, decision-making and problem-solving, so support the person to have a healthy lifestyle with a balanced diet and regular exercise.
- 4 Research their entitlements:** you could help the person explore their legal rights and any employment or disability benefits they may be able to claim, and help them fill in application forms and other paperwork.
- 5 Be a listening ear:** emotional support is crucial, providing reassurance and understanding during challenging times. As well as offering this yourself, you could look into any support they can access through their employer, for example through an Employee Assistance Programme.



## Supporting a person with dementia when they leave work

**At some stage, the person living with dementia will need to leave work, which might be earlier than they had planned. Admiral Nurse Pam Kehoe shares tips for supporting them during this transition.**

- Make time to discuss how work is going regularly, and sensitively talk about areas where the person with dementia needs support. This means that when they do leave work, they will know every adjustment to keep them working has been tried
- Consider offering support with any workplace meetings the person has about leaving their job
- With the person's consent, help them review their finances, apply for any post-retirement benefits they may be able to claim, and find out how they can claim their private or workplace pension, if they have one
- Support the person with planning how they will use their time once they have finished work to ensure they have a regular routine and opportunities for meaningful activities and socialising



# Working when you are caring

Balancing your job and caring responsibilities while also looking after your own health can be difficult – but not impossible.

## 5 ways to manage working and caring

**1 Consider telling your employer about your caring role:** make them aware that you may need extra flexibility such as time off to take the person with dementia to appointments (sometimes at short notice), or a change or reduction in your working hours. It will also help your employer and other colleagues to understand your situation and offer emotional support if it is needed.

**2 Find out about your rights:** as a carer, you have employment rights, including the right to time off for dependants, emergency carer's leave and to request flexible working hours. Please see p30 for information about rights for working carers.

**3 Look into your employer's policies:** these will set out any rules and accommodations that are specific to your employer or your role, in addition to your legal rights. They might include policies for carer's leave, compassionate leave, emergency leave and flexible working.

You might also have access to an Employee Assistance Programme that provides support such as counselling and financial advice.

**4 Keep your employer up to date:** try to maintain regular, open communication with your employer about your situation so they understand any changes and can adjust the support they offer as necessary.

**5 Build a support network:** this could include informal support from family members or friends who can help with care, or professional care services such as day centres or paid home carers.

## Am I a carer ?

Many people who support a person with dementia do not consider themselves to be carers. However, as a carer, you have certain rights at work and may be able to access benefits, so it is important to recognise this important role.

You are considered a carer if you regularly look after the person with dementia, and help them with:

- washing and dressing
- getting out and about
- attending medical appointments
- taking medication
- household tasks like shopping, cleaning and laundry
- looking after their bills and finances
- providing company, or watching over them if they cannot be left alone



## Dealing with issues during your working day



**Admiral Nurse Vic Lyons shares advice on what to do if difficulties arise during working hours.**

Many carers find themselves trying to deal with issues during the working day, such as receiving multiple phone calls from the person with dementia. If this happens, try to understand what might be driving the issue. For example, is the person anxious, lonely or needing reassurance?

You could try planning regular check-ins with the person that fit with your work schedule, or leaving written reminders next to the person's phone explaining that you are at work but they can call you at a certain time, eg in your lunch break.

During your working hours, see if the person's calls could be forwarded to another family member or friend, or consider using your voicemail – but do make sure there is someone they can phone in an emergency.

Liaising with professionals is a key aspect of being a carer but it can be difficult to take calls during working hours. Do let them know when the best times are to call you, or ask if you can call them at a convenient time for you.

It is also a good idea to discuss this with your line manager and explain that there may be times when you need to take a call during your workday.

If an emergency occurs that means you need to leave work immediately, you could use your right to time off for dependants. Please see p30 for information.



## Caring and working from home

Working from home while caring for someone with dementia has its pros and cons. On one hand, it may give you more flexibility in managing caring duties alongside work responsibilities, and you can provide immediate care, supervision and company. However, it can also blur the boundaries between work and personal life, potentially leading to stress and burnout. And distractions and interruptions from the person you care for may impact your productivity.

It is important to try to establish a structured routine, create a separate workspace, and set clear boundaries. Ask if family members or friends could come in to provide the person with company or help with some of the caring duties that arise during the working day – you could set up a weekly rota of visits, if people are willing.

You could also consider using support services like home care or adult day centres. You or the person with dementia may be able to claim benefits to help with the cost of care, such as Carer's Allowance or Attendance Allowance.

Think about ways to structure your day so you have times when work receives your full focus. For example, if you need to have remote meetings, you could arrange these for times when the person with dementia watches a regular TV programme or has a nap.

Remember to keep communicating with your employer about your situation – if you try to conceal the difficulties from them, they will not be able to support you in your role or ensure they respect your working rights.



## Top tips for managing crisis situations

- Compile an emergency plan with key contacts and medical information – keep one at your workplace and one at home, and give copies to other people who support the person you care for
- Consider signing up for the Lions Club’s **Message in a bottle** scheme – this involves storing important details in a bottle in the fridge, with a sticker on the front door and/or fridge door to alert emergency services so they can find it easily in an emergency
- Check your organisation’s emergency leave policy and speak to your line manager so they know that you may need to leave work swiftly in a crisis
- Think about fitting a key safe so carers, family members, friends or the emergency services can access the property if the person needs assistance while you are out or at work
- Fill in a **Herbert protocol form** if the person with dementia is likely to leave home alone when it is not safe for them to do so – this is a record of important information about a vulnerable person, like their appearance, health conditions and places they may go, which emergency services and other services can use if they go missing
- Consider giving the person a GPS device so you can see where they are – this could be a mobile phone, a smartwatch, or a smart tag/tile that can be placed in a jacket pocket or handbag
- A fall alarm pendant could give you reassurance that help can be summoned if the person falls
- Taking care of your own physical and mental health will ensure you are equipped to handle crises. Remember, it is okay to seek help and take breaks when needed

### “I have been so lucky to have amazing managers.”

“Around the time my wife, Helen, saw a neurologist for the first time about symptoms that turned out to be dementia, I was meant to go to California for work for a few days, but I was concerned about leaving her. I spoke to my boss, Paul, and said, ‘I don’t feel comfortable leaving Helen and going 6,000 miles away,’ and he was brilliant. He supported me then and has ever since.

“That was five-and-a-half years ago, and I have been so lucky to have Paul and then two other amazing managers. When there were issues at home, I would just say, ‘I’ve got to go.’ I worked flexible hours even before Covid, and there’s a mutual trust and respect in my team that we’ll all get the work done. Knowing my managers believe in me and believe I’m doing the best job I can in the circumstances has sustained me.”

**Glenn, who works for a broadcasting company. His wife, Helen, was diagnosed with young onset Alzheimer’s disease aged 51**



For people who are working while caring for someone with dementia

# Your rights as a working carer

Working while caring for someone with dementia can be challenging – but as a working carer, you have certain legal rights.

## Statutory rights for working carers in the UK

Statutory rights are rights given by law to everyone. Working carers have the following statutory rights:

### Time off for family/dependants

You have the right to take a reasonable amount of time off work to deal with emergencies involving dependants, which could include the person you care for. There is no set amount of time you can take off, and no limit to how many episodes of time off you can take. However, your employer may raise concerns if they think it is affecting your work.

Legally, your employer does not have to pay you for this time off, but some employers do – please check your employment contract for details.

### Right to request flexible working

From the first day of your employment, you have the right to request flexible working under the Employee Relations (Flexible Working) Act 2023. This could include part-time working, flexitime, job sharing, or working from home. You must put your request in writing – Acas has a useful [template](#).

Your employer has two months to respond. They can reject your application for flexible working if there is a genuine business case against it, but they must tell you the reasons, and you may be



able to complain to an employment tribunal if you disagree with them.

The rules are slightly different in Northern Ireland, eg you do not have the statutory right to request flexible working in the first 26 weeks of working for your employer.

## Protection from discrimination

The Equality Act 2010 makes it unlawful to discriminate against employees directly or indirectly, including those who are carers. This means your employer cannot treat you less favourably because of your caring responsibilities – for example, disciplining you or denying you a promotion for taking time off for family/dependants.

## Unpaid carer's leave

In England, Scotland and Wales, the Carer's Leave Act 2023 gives you the right to:

- up to five days' unpaid leave in 12 months, pro rata for part-time employees – leave can be taken as a whole week, or in half or full days across the year
- the same terms and conditions of employment that would have applied if you had not been on carer's leave (eg holiday entitlement, pensions and other benefits)
- return to your job with the same seniority, pension and similar rights as before taking leave
- not be detrimentally affected because you took carer's leave (for example, your employer

must not change your role or duties without consulting you)

- protection from unfair dismissal and redundancy if this is related to you taking carer's leave

Reasons you might want to take carer's leave include the person with dementia being admitted to hospital, covering a period when their home carer is on holiday, or moving them into a care home.

Currently, there is no statutory right to carer's leave in Northern Ireland, although employees are still entitled to emergency time off for dependants.



### Did you know?

Many people think time off for dependants only applies to emergency situations involving children, but it can be taken for a spouse, partner, parent or anyone else who depends on you for care.

## Your rights: useful resources

- ▶ [Caring for someone when working \(Northern Ireland\)](#)
- ▶ [Flexible working requests \(England, Scotland and Wales\)](#)
- ▶ [Flexible working requests \(Northern Ireland\)](#)
- ▶ [Time off for family/dependants \(England, Scotland and Wales\)](#)
- ▶ [Time off for family and dependants/compassionate leave \(Northern Ireland\)](#)
- ▶ [Unpaid carer's leave \(England, Scotland and Wales\)](#)





### Contractual rights for working carers in the UK

Contractual rights are given by your contract of employment, and may be more generous than statutory rights.

Increasingly, employers are recognising the value of supporting carers in the workplace, and many are offering additional support as part of their contractual rights. Examples include paid carer's leave, additional carer's leave, access to an Employee Assistance Programme or a workplace carers' network.

It is always worth checking your contractual rights to see your exact entitlement. You can find them in your contract of employment, staff handbook, HR policies or letter of appointment. As well as clarifying your rights, it will help you understand the process to follow if you want to request support.

All contractual rights through your employer must include the statutory provisions of employment law as standard.

### Making a complaint

All employers should have a complaints policy, so if you are having difficulty accessing your statutory or contractual rights as a carer or feel you are being discriminated against, request a copy and find out the steps you need to follow if you wish to complain.

In the first instance, you will usually need to raise the issue with your line manager. If this does not resolve the issue, you can escalate it to their manager, and/or speak to your organisation's HR Team, if you have one. Put all correspondence in writing.

If you need additional support with accessing your working rights, you can contact [Acas](#). If you are a member of a union, contact your rep about how they can support you. You may also wish to speak to a solicitor who specialises in employment law: the [Law Society](#) has a searchable list of approved solicitors.

## Self-employed, agency and contract workers

As a carer, being self-employed can have both advantages and disadvantages. It may give you more control over your work schedule, which can be particularly beneficial when balancing work with caring responsibilities.

However, being self-employed while caring can also have its downsides – for example, if you have to reduce your working hours or workload or take time off to support the person you care for, your income may drop. And as you are not directly employed, you do not have the full protections of statutory employment rights.

Agency, contract and freelance workers might be given a contract for services. This means they may still be classed as self-employed or could be a ‘worker’ or an ‘employee’. Someone is legally classed as a worker if they do not work a regular shift pattern or have regular guaranteed hours from an employer. Workers are not usually entitled to time off for dependants.

It is recommended that contract and freelance workers clarify their employment status with the agency or employer, as contracts can differ and will offer differing employment rights. Ensure you are clear about your employment status, which should be stated in the contract. Also, do make sure how you are treated matches the contract and consider seeking legal advice if not.



### Did you know?

Some employers offer free access to Jointly: an app developed by Carers UK that helps everyone involved in a person’s care coordinate responsibilities and share information. Visit [Carers UK’s website](#) for more details.

### “There was a lack of understanding of my situation”

“At the time I was caring for my mum, I was working for a local charity. I loved the job but there was a lack of understanding about my situation. My employer knew I was a carer but rarely spoke to me about it or offered any flexibility. I worked part-time and would often have to swap my working days around to take Mum to appointments.

“The organisation eventually introduced a carer’s leave policy but it only entitled me to three days off a year – and I didn’t even take them because I felt uncomfortable asking.

“Even after Mum died, there was no empathy or understanding – I was expected to work on a project about bereavement, which was too close to home at the time. Eventually, I decided to leave my job because I felt so unsupported.

“Caring for Mum while looking after two young daughters and working nearly pushed me to breaking point; a supportive employer would have made all the difference.”

**Alison, whose mum had Alzheimer’s disease**



For people who are working while caring for someone with dementia

# Looking after yourself as a working carer

Taking care of your own mental and physical health is vital when you are a working carer. Read our advice on managing the many responsibilities.

## 5 tips for avoiding stress and burnout

**1 Think about adjustments:** a flexible work schedule can help you balance the joint responsibilities of working and caring, so think about what you need and be open with your employer. Make sure you know about your statutory and contractual rights and any additional support offered by your employer like counselling through an Employee Assistance Programme.

**2 Share the caring responsibilities:** do not feel guilty about asking family or friends to help, or accepting their help if they offer. Even if they cannot help regularly, they may be able to step in if you have an important meeting, need to attend your child's parents' evening or school play, or simply need some time off. People are often happy to help and glad to be asked.

**3 Consider outside support:** look into what external care and support you could access, such as day centres, befriending or volunteer schemes, home carers or, eventually, a care home. You may be able to access benefits or adult social care support to help with the cost of care.

**4 Make time for self-care:** you cannot care for someone if you do not care for yourself, so make sure you attend any appointments for your own physical or mental health. Try to maintain a healthy diet and take regular exercise. Stay connected to family and friends – if it is difficult to meet up, even a phone call could help you feel less isolated. And make time for activities you find relaxing and enjoyable, whether that is playing sport, singing in a choir, going to the cinema or just sitting down with a book.

**5 Recognise the balancing act:** the dual responsibility of maintaining your work commitments while caring for a person with dementia may put you under immense strain.

You may also be in a 'sandwich carer' role, looking after dependent children and a parent or other older relative with dementia.

Remind yourself that you are in a role that you did not choose and have not been trained for, so it is important to be kind to yourself and acknowledge that you are doing the best you can.





## Assessments of support needs

Both you as a carer and the person with dementia are entitled to free assessments to establish your support needs. You can request these through your [▶ local social services](#).

**Carer's assessment:** this is an assessment of how your caring role impacts upon your life, and what support you might need to make it easier. This might include things like:

- practical training in caring skills, eg how to lift someone safely
- gym membership or exercise classes to maintain your wellbeing
- help with transport if you do not drive
- help with tasks like housework and gardening
- signposting to support groups
- respite care for the person with dementia

Carer's assessments are carried out by your local council. Even if you feel you are coping

well, it is still worth requesting an assessment so support can be put in place to help you keep working and caring for the person with dementia for as long as you want to.

**Needs assessment (also known as adult social care assessment):** this is an assessment carried out by social care professionals to identify the care and support needs of the person with dementia. It helps determine suitable care and support options that promote independence and wellbeing, which might include day centre care, care at home or temporary care in a care home (respite) – all of which could help you balance work and caring.

**Financial assessment:** this is usually offered alongside a needs assessment to establish whether you and/or the person with dementia are entitled to any financial support with the cost of care.

## Your finances as a working carer

**Being a carer can involve significant financial challenges. You may need to reduce your working hours or leave employment entirely to provide care, leading to a loss of income. You may also be partly or wholly covering the cost of any professional care.**

However, there are benefits that you may be able to claim to support you financially. The main one is Carer's Allowance. This is a benefit for people who provide care for someone for at least 35 hours a week and have earnings beneath a set threshold. The person you care for must be receiving a disability benefit such as Attendance Allowance, Personal Independence Payment (PIP) or Disability Living Allowance.

In Scotland, Carer Support Payment is replacing Carer's Allowance and is being rolled out across the country.

If you receive Carer's Allowance, you will automatically receive National Insurance credits. This is not a paid benefit, but covers any gaps in paying National Insurance that result from your caring role (eg if you stop work or your earnings drop below the National Insurance threshold). It protects your entitlement to your State Pension.

Other benefits you may qualify for as a carer include:

- Council Tax reduction
- Universal Credit (if you are unemployed or on a low income)
- Carer's Allowance Supplement (an additional benefit payable in Scotland to some people who receive Carer's Allowance)

Please see Sources of support on p38 for more information on benefits.

### “I reached the point of burnout”

“When I was caring for my mum, who had dementia, I was working as a Detective Constable in the police force. It became impossible to juggle the long hours and shift work with caring, so I left my job and took a position as a lecturer in policing. I thought it would be less stressful, but there was no policy for carers and no support from my manager.

“I eventually reached the point of burnout and was signed off work sick with depression for four months. Something had to give, and for me, it was work.

“The message I would like to give to employers is that if you don't support the person to continue working, you lose them. And to carers, I would say listen to your body, notice what's going on within you both mentally and physically, and get help before you reach breaking point.”

**Joanna, who works as a university lecturer and cared for her mum**



# How we can support you

## Dementia UK sources of support

If you have any questions about work and dementia, or any other aspect of dementia, our specialist Admiral Nurses are here to help.

**Read our dementia information and advice**, including leaflets to download and print, at [▶ dementiauk.org/information-and-support](https://dementiauk.org/information-and-support)

Some of our information leaflets are also available in other languages:

- Bengali
- Chinese (traditional and simplified)
- Gujarati
- Polish
- Punjabi
- Tamil
- Urdu
- Welsh

**Sign up for our free online sessions**, ‘Dementia: what next?’, at [▶ dementiauk.org/dementia-what-next](https://dementiauk.org/dementia-what-next)

**Contact our free Helpline** on 0800 888 6678 (Monday-Friday 9am-9pm, Saturday, Sunday and bank holidays 9am-5pm – except 25<sup>th</sup> December) or email [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

**Book a free video or phone appointment** with an Admiral Nurse at a time that suits you at [▶ dementiauk.org/book](https://dementiauk.org/book)

## Dementia UK resources

- ▶ Attendance Allowance
- ▶ Carer’s Allowance
- ▶ Carer’s assessments
- ▶ Council Tax discounts for people with dementia
- ▶ Driving and dementia
- ▶ Employment and young onset dementia
- ▶ Finance and young onset dementia
- ▶ Financial and legal support
- ▶ Finding help and support at home
- ▶ Getting a diagnosis of young onset dementia
- ▶ Living aids and assistive technology
- ▶ Looking after yourself as a carer
- ▶ Young onset dementia section
- ▶ Young onset dementia groups and services



## Benefits

- Access to Work (England, Scotland and Wales)
- Adult Disability Payment (Scotland)
- Attendance Allowance
- Benefits calculators
- Carer's Allowance
- Carer's Allowance Supplement (Scotland)
- Carer Support Payment (rolling out across Scotland)
- Employment and Support Allowance (England, Scotland, Wales)
- Employment and Support Allowance (Northern Ireland)
- National Insurance Credits
- Jobseeker's Allowance
- Pension Credits (England, Scotland and Wales)
- Pension Credits (Northern Ireland)
- Personal Independence Payment (PIP)
- Self-employment and Universal Credit
- State Pension
- Statutory Sick Pay
- Universal Credit



## Other resources

- **Acas**  
Free, impartial advice on workplace rights, rules and best practice  
Helpline: 0300 123 1100
- **AgeUK**  
Support for older people, including advice on employment, money and rights  
Advice line: 0800 055 6112
- **Carers UK**  
Information, advice and support for unpaid carers
- **Citizens Advice**  
Free, confidential advice and support, including work, benefits, debt and money  
Adviceline (England and Northern Ireland): 0800 144 8848  
Advicelink (Wales): 0800 702 2020  
Helpline (Scotland): 0800 028 1456
- **Dementia Carers Count**  
Support for people who care for someone with dementia
- **Disability Rights Commission**  
Information about the Disability Discrimination Act and support for people who have been discriminated against  
Helpline: 08457 622 633
- **Employment support information for people with disabilities (Northern Ireland)**
- **Equality Advisory and Support Service**  
Advice on equality and human rights across England, Scotland and Wales  
Advice line: 0800 800 0082
- **Flexible working requests (England, Scotland and Wales)**
- **Flexible working requests (Northern Ireland)**
- **Jointly**  
An app developed by Carers UK to help informal carers coordinate plans and share information about the person they support
- **Law Society: find a solicitor**
- **Reasonable adjustments for disabled people (England, Scotland and Wales)**
- **Reasonable adjustments in the workplace (Northern Ireland)**
- **Pathways through Dementia**  
Financial and legal information for people with dementia  
Legal helpline: 0203 405 5940
- **Pension Wise**  
Pensions information for people over 50, including free appointments  
0800 011 3797
- **tide: Together in Dementia Everyday**  
Carer support including online courses
- **Unbiased: find a financial adviser**  
Helpdesk: 0800 023 6868

**To speak to a dementia specialist Admiral Nurse  
about any aspect of dementia:**

Contact our Helpline:  
**0800 888 6678** or [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Book a virtual appointment:  
[▶ dementiauk.org/book](https://dementiauk.org/book)

**Our charity relies entirely on donations to fund our  
life-changing work. If you would like to donate to help us  
support more families:**

- Call **0300 365 5500**
- Visit [▶ dementiauk.org/donate](https://dementiauk.org/donate)
- Scan the QR code

**Thank you.**



**DementiaUK**  
Helping families face dementia



[dementiauk.org](https://dementiauk.org) • [info@dementiauk.org](mailto:info@dementiauk.org)

Dementia UK, 7<sup>th</sup> Floor, One Aldgate, London EC3N 1RE  
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