



DementiaUK
Helping families face dementia

Dementia at work

A guide for employers



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

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

When Yvonne and I decided it was the right time to give up her job, she 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

Welcome to your Dementia at work guide

With nearly one million people living with dementia in the UK – including over 70,000 with young onset dementia (where symptoms develop before the age of 65) – it is highly likely that as an employer, you will come into contact with people who are living with the condition, or caring for someone with the diagnosis.

This means it is crucial for businesses to understand and support the unique needs of employees and customers affected by dementia.

This guide contains valuable insights and practical advice to help you, the employer, create a dementia-inclusive environment in your workplace. It is written by Dementia UK's specialist Admiral Nurses who are experienced in helping organisations support the needs of people with dementia and their carers, recognising that your requirements may vary depending on the size and nature of your business.

Additionally, our dedicated Dementia at Work Team is available to provide specialised support and guidance to help you implement effective policies and practices that accommodate the needs of employees and customers affected by dementia. If you would like to speak to our team for advice tailored to your business needs, please see p5 for contact details.

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 eight sections which will help you and your organisation to foster a supportive and understanding workplace for people living with dementia and employees who are carers.

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How to recognise the signs of dementia in your employees, handle difficult conversations, and respect their rights on whether to disclose their condition.

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For more information on all aspects of dementia, please visit our website at dementiauk.org or contact our Dementia at Work Team at dementia.work@dementiauk.org

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Supporting customers and clients

How to create a dementia-inclusive customer environment to ensure all clients feel welcome and supported.



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 organisations to understand and accommodate the needs of employees and customers affected by dementia, whether they are living with the condition themselves or caring for someone with the diagnosis.



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 deliver masterclasses and provide bespoke specialist support and education for both the workforce and the organisation. The aim is to help reduce the stigma of dementia and enable an inclusive workplace for everyone.

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 service 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.

Many organisations will have employees who are caring for someone with dementia, or living and working with dementia themselves, so it's vital for them 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 and family carer, I am committed to raising awareness, ensuring that those affected 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 involved in supporting someone with dementia – from family carers to employers – has the right information at the right time.

Noticing changes in an employee

What to do if you notice signs of dementia in an employee, and how to talk to them sensitively about your concerns.



“It is possible for people with dementia to continue to work – but for that to happen, both employers and employees need to acknowledge the issue, and approach it in the right way.”

Pam Kehoe, Admiral Nurse

Why is dementia a workplace issue?

Although dementia is often thought of as a condition that affects older people, it is becoming an increasing issue for employers and workplaces. Over 70,000 people under 65 in the UK are thought to be living with dementia, and a significant number are still working.

The State Pension age in the UK is increasing over time and many people are working longer, meaning more people are still in employment in their 60s and 70s when they are more likely to develop dementia due to their age.

Also, many employees are caring for family members or friends who are living with dementia.

As the number of people affected by dementia increases, the benefits of employers being dementia-inclusive are clear. You will retain valued and experienced staff; a supportive culture is likely to attract higher quality job applicants; and it shows you care about your employees.

Spotting the signs of dementia in an employee

Dementia is a progressive condition, so while initially, a person with dementia may be able to continue to work with the right support, over time, work will become more challenging and overwhelming.

An employee in the early stages of dementia may:

- have difficulties with concentration and orientation
- struggle with problem-solving and decision-making
- make uncharacteristic mistakes at work
- have problems with communication, such as finding the right words
- struggle with literacy and numeracy
- experience changes in personality and behaviour that affect their work, eg reacting with frustration or distress if tasks do not go to plan



Did you know?

It is important to be aware that younger people who are still working are more likely to have a rarer form of dementia that has different symptoms from the more common types and so may be harder to recognise. For example, they may experience changes in their personality, behaviour and social functioning, rather than memory.



What is dementia?

Dementia is the umbrella term for a group of illnesses that over time, cause damage to the brain and its functions. There are over 200 subtypes of dementia and everyone affected by the condition will have their own experience, but it primarily affects thinking, memory and communication. These issues may make work feel more difficult for the employee and result in distress, embarrassment, and a loss of confidence.



Is it dementia?

It can be difficult to tell if an employee is showing signs of dementia or if there is another cause, but it is important to be aware that it may be an issue.

Work colleagues may be the first to recognise the early changes in a person, but they might attribute them to another cause such as stress, tiredness, menopause, relationship issues or physical or mental ill health. Family members may recognise that the person is struggling at work, but not understand why.

People with possible dementia symptoms may not recognise or acknowledge their difficulties. They may lack insight or be in denial about their symptoms. They may have developed coping strategies to deal

with specific problems; have colleagues who are prepared to cover for them; or have a job where their symptoms have less of an impact. Or they may be aware of symptoms but are trying to conceal them.

With modern working patterns like hybrid working, managers may spend less time working with staff face-to-face, so it may be more difficult to identify if an employee is having difficulties and needs more support. Employers may wrongly assume that these changes are intentional or controllable – for example, that the person is being lazy if they do not complete tasks on time. As a result, they may start a performance management process, and in some cases, even terminate the person's employment.

Talking to an employee about your concerns

If you decide to speak with an employee who you believe is showing possible signs of dementia, keep in mind that many other common health conditions can cause symptoms that can look like dementia. Understand also that the employee may be worried about their future and reluctant to talk about their symptoms or seek support.

Before the meeting:

- Seek advice from your Human Resources (HR) Department, if you have one, on the organisation's policies and procedures
- Choose a time to meet that is convenient to your employee and where neither of you will feel rushed or have competing commitments
- Choose a location that is familiar, private, quiet, and non-threatening for your employee
- Ask if they would like to bring someone to the meeting for support (eg a colleague, family member, friend or union representative)
- Consider how your employee usually likes to approach conversations – for example, do they normally prefer to be given all the information at once, or prefer to take things one step at a time?
- Ensure you or a colleague take notes in the meeting, or record it if it takes place online, and share these with the employee afterwards as a clear record of what you have discussed

During the conversation:

- Start by asking your employee how they have been feeling and if they have noticed any differences or challenges at work
- Share your own observations without judgment or commenting on how they are affecting you or the organisation
- Let your employee know that you are sharing your concerns because you care about them and want to offer support
- Find out if the employee has discussed these changes with a doctor or had a health check
- If not, try to find out what could be stopping them from consulting a doctor – and think about what you share with them to reassure them that doing so is in their best interest (for example, explaining that a timely diagnosis allows for early treatment and support, and assuring them of the support you can provide)
- Encourage your employee to seek support from your Occupational Health Department or Employee Assistance Programme, if you have one
- If your employee expresses concern about how a health issue could affect their employment, inform them about any policies, rights or benefits they can access, including time off to attend medical appointments – your HR Team, if you have one, can help with this

Supporting an employee with dementia

When an employee discloses a diagnosis of dementia, managers should approach the situation with empathy and care. This will help them feel supported and avoid any misunderstanding or confusion about how their diagnosis may affect their employment.

Top tips for responding to your employee's diagnosis

1 Thank them for sharing: acknowledge the courage it took for the employee to disclose their diagnosis and thank them for their openness. Remember that this is likely to be a difficult conversation for them.

2 Normalise the discussion: treat it like a conversation about any other medical issue. Let the employee know that your perception of them as a person has not changed as a result of their diagnosis, and reassure them of your support, including with putting in place reasonable adjustments to help them in their role (please see p22).

3 Reflect and gather information: you do not need to have all the answers about next steps immediately. Tell the employee that you will reflect on what they have shared and get back to them. Consider discussing the situation with your HR Team, if you have one. Make sure you are informed about your legal duties and your company's policies around sickness and disability.

4 Ask about their needs: find out what the employee is having difficulty with at work, and what they would like to happen to make their role easier.

5 Maintain their privacy and confidentiality: ask them if they want their colleagues to know about their diagnosis or not; if they do, find out if they would like to share the news themselves or would prefer you to do it.

6 Remember that each situation is unique: open communication with the employee is crucial. By fostering understanding and providing support that is specific to their individual needs, you can create a positive work environment for employees with dementia.



Recognising the benefits of employment

Many people with dementia continue to work after their diagnosis. This may be necessary financially, especially as younger people with dementia may still have commitments like a mortgage or rent, loans, dependent children or be paying for care for ageing parents.

However, having a job is not just about earning money. It can also provide people with purpose, a daily routine, satisfaction, and a sense of normality. It can help them maintain their self-esteem, and many benefit from the relationships and social connections formed through work. All of these factors can have a significant effect on their wellbeing.



“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 responsibilities as an employer

It is important to understand your obligations and responsibilities as an employer of a person with dementia – for their benefit and yours.

5 things you need to do now

1 Find out about your legal obligations: dementia is classed as a disability, which is one of nine ‘protected characteristics’ set out in the Equality Act 2010. Unfairly discriminating against an employee on the basis of any of these is unlawful, so it is important to know what you are required to do – and not do – by law. Please see p18 for information on employees’ rights.

You can access free advice on UK employment law, HR processes and good practice at work from the

➤ **Advisory, Conciliation and Arbitration Service (Acas):**

a non-departmental public body funded by the Government.

2 Inform yourself about dementia: while everyone with the diagnosis has their own unique experiences, doing some research into the symptoms, how they affect people and what can make life easier will help you understand more about the condition, reduce stigma and offer better support. It is also helpful to pass this information on to other employees, but only with the person’s consent.

3 Signpost the employee to support: for example, you could refer them to the Occupational Health Team, if you have one, and to Dementia UK’s website and Helpline for information and advice: see p38 for contact details. Make sure they know how to access support like private health insurance and an Employee Assistance Programme, if your organisation offers them. If you have an HR Team, they can advise on services like these as well as relevant policies like a sickness policy.



Q Can an employee stay in their role after a diagnosis of dementia?



Admiral Nurse Gary Burnham-Jones says:

Admiral Nurse Gary Burnham-Jones says:

A While some people with dementia may be able to remain in their current role for some time, others may find their diagnosis has an immediate impact. For example, a supermarket employee may be able to continue in their position with adjustments, but a builder who works at height and is having balance problems may find their diagnosis compromises their own safety or that of others.

If you are unsure whether it is safe or appropriate for the person to continue in their role, please seek professional advice. This could be from your HR Team, if you have one, Employer Services at

▶ **Jobcentre Plus** or ▶ **Acas**.

4 **Make ‘reasonable adjustments’:** these are adaptations to the person’s role, working conditions or work environment to enable them to keep working – you have a duty to provide these as far as possible. Set up a meeting with the person with dementia and, if applicable, your Occupational Health Team to discuss the reasonable adjustments that the person needs at work and how they will be put in place. Please see section 5 (p22) for more information on reasonable adjustments.

5 **Provide a ‘Health Adjustment Passport’:** this is a document that the person with dementia can fill out to identify their support needs, including any reasonable adjustments they would like to request. It also contains information about their disability and how it affects them, specific needs such as communication support, and details of how to apply for Access to Work: a scheme that provides people with the support (including financial support in some cases) they need to stay in work (see p25). It will provide clarity for both you and your employee about how to manage their disability going forward. The ▶ **Government website** has a form you can download.

Advice for small and medium enterprises (SMEs)

Employing someone with a disability like dementia may seem a minefield for small and medium enterprises, which may not have the same legal and HR support as larger businesses – however it is just as important to uphold the rights of disabled workers and provide the support they need at work.

Because SMEs are often naturally intimate and close-knit, they can be an ideal work setting for people with disabilities like dementia. A smaller workforce often makes for a more relaxed and supportive environment with stronger relationships, and the business may be more flexible in making adaptations if it is not as tightly bound by higher-level organisational processes.

Employing a person with dementia may present different challenges for SMEs. You may not, for example, have your own HR Team or access to an Occupational Health Department. It may be harder to adjust your employee's role if you do not have other employees who could take over the elements that they are finding difficult. Or you may not be able to support homeworking if the person has a practical role like hairdressing or floristry.

However, your employee still has the same rights, and you have the same legal obligations towards them. If you are unsure how to meet

“Small adjustments to the person's work environment could help them navigate their tasks with greater ease.”

Admiral Nurse Vic Lyons



Did you know?



51% of small businesses currently employ or have recently employed someone with a disability.

these, it is important to seek specialist advice. This might include contracting an independent HR provider for professional support or finding a local [NHS-approved occupational health provider](#) who can help with services like risk assessments.

Additionally, there are several strategies you can implement to support your employee with dementia. For example, providing flexible working hours can make a significant difference, allowing them to manage their condition more effectively. Making small adjustments to their physical working environment, such as clear signage or the use of memory aids, could also help them manage their day-to-day work more easily and efficiently.

It is also beneficial to foster relationships where employees feel comfortable discussing their needs and challenges. Accessing dementia awareness training for yourself and other staff can create a more supportive environment and reduce any stigma associated with the condition.



Q How can I make sure I'm supporting the employment rights of the person with dementia as the owner of an SME?

Admiral Nurse Rachel Watson says:

A As an SME owner employing someone with dementia, it is natural to be worried about whether you are doing the right things to support them and protect their rights, especially if you do not have your own HR Department, Occupational Health Team or legal advisors. However, there are numerous resources available to help you. When dealing with a specific issue like supporting a disabled employee, you may want to consider outsourcing certain elements like reviewing their employment contract or doing a

workplace health and safety assessment to an external provider. There are many independent HR and occupational health providers that can be appointed on a one-off or ongoing basis.

The organisation **Acas** is a great source of free, impartial advice on workplace rights, rules and best practice, as well as training. Our Admiral Nurses and Dementia at Work Team can also offer valuable insights and practical advice that will not only ensure you comply with legal requirements, but also create a compassionate and productive work environment for everyone.

Your employee's rights

Dementia is classified in law as a disability, so it is essential to understand your employee's rights.

Disability rights at work

Disability is one of nine 'protected characteristics' under the Equality Act 2010. This means people with a disability – including dementia – are legally protected from discrimination and have certain rights at work.

The right to 'reasonable adjustments'

These are adaptations to the person's role, work schedule or working environment to allow them to do their work. As an employer, you have the duty to make these adjustments. Please see p22 for more information on reasonable adjustments.

The right to protection from discrimination

It is unlawful to discriminate against employees directly or indirectly on the basis of disability. This means you cannot treat an employee less favourably because they have dementia. For examples of what discrimination might look like, please see p20.

The right to request flexible working

from the first day of their employment, your employee has the right to request flexible working under the [Employment Relations \(Flexible Working\) Act 2023](#). This could include part-time working, flexi-time, job sharing, or working from home. This right applies to all employees – not just those with disabilities.

You have two months to respond to the request. You can reject it if there is a genuine business case against it, but you must tell your employee the reasons, and they may be able to complain to an employment tribunal if they believe they are not reasonable.

The rules are slightly different in [Northern Ireland](#), eg employees do not have the statutory right to request flexible working in the first 26 weeks of working for an employer.





What to do if an employee does not disclose their dementia diagnosis

Admiral Nurse Gary Burnham-Jones shares essential advice on your employee's rights.

In the majority of cases, people do not have to tell their employer that they have dementia or another disability. It is, however, always best if the employee does disclose their diagnosis, as this will enable reasonable adjustments and other support to be put in place. It will also give them legal protection from disability discrimination, although they are still protected against discrimination if you could be 'reasonably expected' to know they have a disability. If you suspect an employee has dementia and has not disclosed their diagnosis, you might want to consider using the tips on p11 to encourage an open conversation. Bear in mind that they may not feel comfortable

talking to their immediate manager – if you have an HR Team, you may want to suggest they can talk to them instead.

There are exceptions to the employee's right not to disclose their own dementia diagnosis, usually for people in jobs where their or other people's health and safety could be affected by their condition. These include:

- the armed forces
- healthcare professions
- jobs that involve driving
- roles that involve working with heavy machinery

The person's employment contract should state whether they are obliged to tell you or the HR Team about their diagnosis.

Types of disability discrimination

There are five different categories of workplace discrimination that employees must be protected from. This table sets out what they are and what they might look like in practice.

Type of discrimination	What it means	Example
Direct discrimination	Putting the person at a disadvantage because of their disability.	The person is selected for a promotion. Before taking up the new position, they tell their employer that they have been diagnosed with dementia. The employer revokes the job offer.
Indirect discrimination	Putting an employee at a disadvantage because of a rule or policy that applies to all staff members but particularly affects them because of their disability.	An absence policy is introduced where disciplinary action results if employees take more days off than are allowed in the policy. This discriminates against the person with dementia (and those with other disabilities or health conditions) if they need to attend frequent medical appointments.
Failure to make reasonable adjustments	Refusal to make reasonable adjustments to allow the person with dementia to work with no business case for doing so.	The person with dementia requests to work from home one day a week. The employer refuses because they prefer employees to work in the office, even though the person's job can be done efficiently from home.
Harassment	Unpleasant or hostile behaviour towards the person with dementia – from the employer themselves or other colleagues.	The person with dementia sometimes struggles to find words. Their colleagues start to make fun of them by mimicking their hesitant speech.
Victimisation	Treating someone unfairly because they have made a complaint or a claim of discrimination at work.	The person with dementia has made a complaint to HR about their manager refusing to implement a reasonable adjustment. Shortly after, they are put on an unjustified performance improvement plan.



Q Can I dismiss an employee with dementia if they are having performance issues?

Admiral Nurse Vic Lyons says:

A Any employee may have times when their performance at work is below the expected standard, such as through poor attendance, issues with misconduct, making mistakes or failing to meet targets.

If your employee has dementia, it is natural to be concerned about taking action to deal with performance issues in case it is interpreted as discrimination. Before you initiate any action, it is important to ensure all reasonable adjustments have been made to help them in their role. If you do not, the employee may have grounds to take you to an employment tribunal.

It may be lawful to dismiss a person with dementia on capability grounds if you can prove:

- they cannot do their job even after all reasonable adjustments have been made and all possible support put in place
- there are no other suitable roles that they could move into
- there is no other way their work can be done, for example by passing responsibility for certain elements to other team members
- the decision to terminate their employment is reasonable, when everything has been considered

We recommend seeking specialist advice before beginning any performance management plan, for example from your HR Team, [▶ Acas](#) or an employment lawyer. Our Dementia at Work Team can also support you with this – please contact us at [▶ dementia.work@dementiauk.org](mailto:dementia.work@dementiauk.org)

Employee complaints

If an employee believes they are being discriminated against, they should first talk to their line manager, a more senior manager or their HR Team (if available). Advise them to put their complaint in writing, and ensure you document the process carefully, including dates, times, the nature of their concern and next steps.

If the issue cannot be resolved, the person should follow the steps in your complaints policy, which all employers should have. It may help to use a mediator at this stage. The person may also have support from a union. If the outcome is still unsatisfactory, the person may be able to proceed to an employment tribunal. Acas can help with this, including supporting with early conciliation.

“My employer docked my pay without telling me”

“When I was diagnosed with dementia 10 years ago, I was working for a pharmacy. The consultant told me I had to stop work immediately – I think because I was handling medication – and signed me off sick.

“I had no support from my employer. They docked my pay without telling me and ordered me to repay the fees for a course I couldn’t complete. When I went for a meeting to discuss the next steps, they wouldn’t even let my husband come with me. I felt I had no choice but to leave. I didn’t realise that they had treated me unlawfully and I could have taken it further.”

Karen, 61, who has young onset Alzheimer’s disease



Reasonable adjustments

By law, employers are required to make reasonable adjustments to enable the employee with dementia to continue in their role, if they wish to do so. We explain what this means in practice.

What are ‘reasonable adjustments’?

Employers must make reasonable adjustments to make sure employees with disabilities, which include dementia, are not substantially disadvantaged when doing their jobs. This applies to all workers, including trainees, apprentices, contract workers and business partners.

It is important for the person with dementia to be involved in all discussions about adjustments to their role and be honest about how their condition affects their work. Decisions relating to how the person can be supported will depend on their unique situation, but reasonable adjustments might include:

- allocating tasks individually, rather than all at once
- giving advice on simplifying routines
- providing a quieter workspace with fewer distractions
- enabling supported homeworking
- offering regular rest breaks during the day
- making changes to their working environment, eg allowing them to work in a step-free area if they have problems with balance/mobility
- removing elements of their role that are particularly challenging or present health and safety risks, eg working at height
- providing assistive equipment eg alerts, reminders, voice recognition software



- setting up a buddy scheme and regular support sessions
- a reduction in hours (if needed or requested)
- a move to a role with less responsibility or that better suits their capabilities (if needed or requested)
- providing emotional support/counselling

Any reasonable adjustments that are made to the employee’s role should be documented in their employment contract.

Reasonable adjustments will be specific to the requirements of the person with dementia. They will need to be reviewed regularly to ensure that they are still meeting their needs. You may need to change the adjustments or introduce new ones as the person’s condition progresses.

Assessing what is reasonable

What is ‘reasonable’ depends on each situation. If possible, it is a good idea to arrange an occupational health assessment to devise an action plan, with the full involvement of the person with dementia. This should include an evaluation of their current role, taking into consideration how dementia affects their ability to do their job.

The employer must consider carefully if the adjustment:

- will remove or reduce the disadvantage
- is practical to make
- is affordable
- could harm the health and safety of others

An employer does not have to change the basic nature of the job. For example, if someone working in a call centre asks for a job that does not involve taking calls, this might not be reasonable if there is no other job to give them.

➤ **Acas** has more information on reasonable adjustments.



“HR had no experience of dementia in the workplace”

“Before getting my initial diagnosis of mild cognitive impairment, I was aware of my symptoms so I made the decision to carry on working but step down from my managerial role at a university. My employer was extremely supportive, suggesting I did it for six months to see how I got on.

“But when the university went through some significant changes, I lost my line manager, who had been outstanding. I had been diagnosed with dementia by this time, and my

new manager didn’t know anything about the condition. I’d always had my own office, but I got moved into an office with other people and hardly any natural light. From that point on, things went downhill, and ultimately, I ended up leaving work five years earlier than I had planned.”

Phil, 61, who has Lewy body dementia



Refusing requests for reasonable adjustments

Some reasonable adjustments are easy to make – but others can be harder to implement. If an employer refuses to make an adjustment that is cheap and easily achievable, this could be considered discrimination. The employee may raise a formal complaint and, if this cannot be resolved, could take it to an employment tribunal.

However, an organisation or employer may legally refuse an adjustment if it is too expensive or would disrupt other people or the business. This is not discrimination. If there is a genuine business case for not implementing a reasonable adjustment, you should:

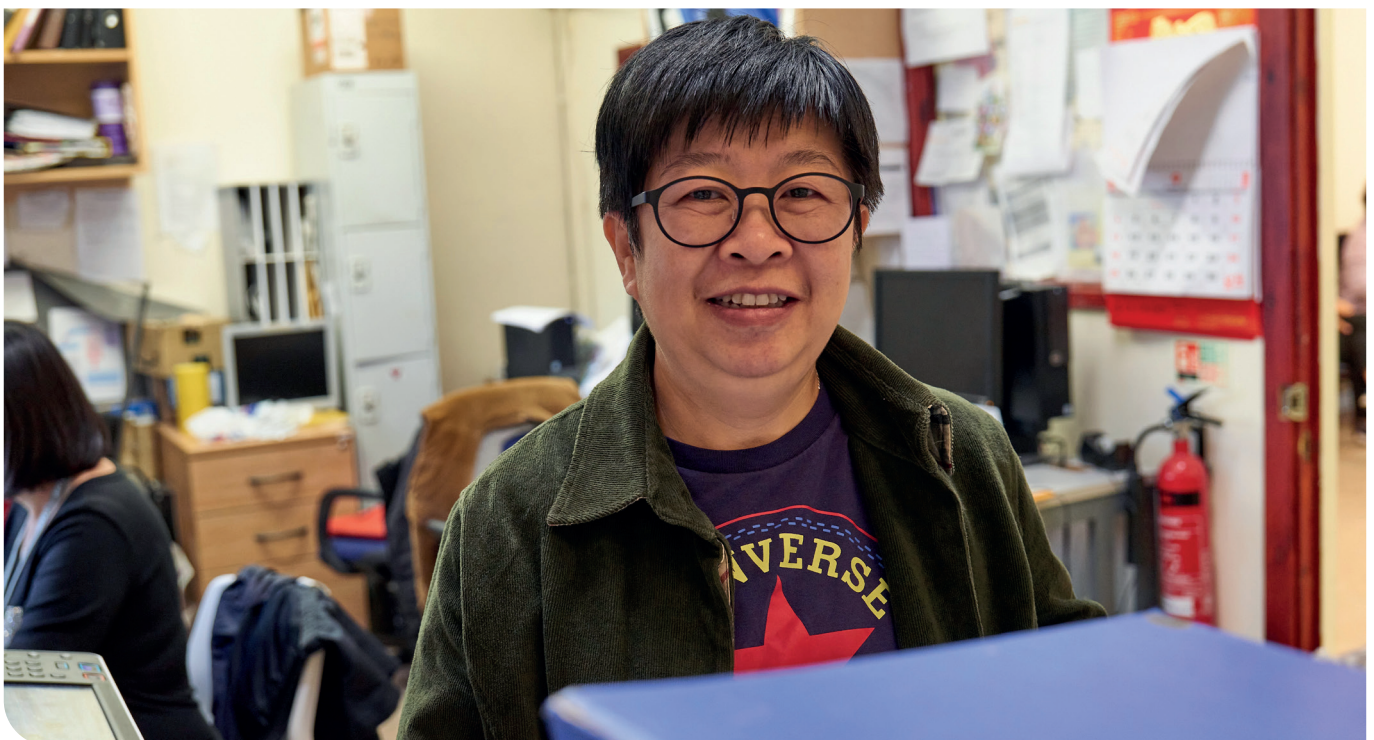
- talk to the person with dementia
- explain your decision
- try to find another way to support them, for example making other adjustments that are reasonable

Making adjustments may be more difficult depending on the person's role, the type of organisation and the number of employees.

For example, if the person with dementia is your sole employee, there may not be another role they could move into that would better suit their needs. However, you may be able to offer different adjustments, such as enabling them to work flexible hours.

Often, reasonable adjustments will involve the support of other employees – for example, if they are asked to take on an element of their role that the person with dementia can no longer do. For this reason, it is advisable for the employee to tell their colleagues about their diagnosis so they understand the reason for the changes and why their support matters.

If an adjustment would have a significant impact on another employee, this may be a business case for refusing the adjustment – for example, if a part-time employee would have to take on a full-time role to enable the person with dementia to reduce their hours. But refusing an adjustment just because the person's colleagues are unsupportive or unhelpful could be considered discrimination.





The Access to Work scheme

Access to Work is a scheme to help people with a mental or physical health condition or disability to get or stay in work. Through the scheme, the employee can apply for:

- a grant to help pay for practical support at work – this could include specialist equipment, support workers (eg a travel buddy), and costs of getting to work if they cannot use public transport
- support with managing their mental health at work
- workplace assessments to work out what barriers they are facing and what adjustments they may need

The Access to Work grant can also be used to provide candidates with communication

support for job interviews, for example if their dementia affects their ability to understand and communicate.

Access to Work grants cannot be used to pay for reasonable adjustments that you, as an employer, are obliged by law to make. However, they may be helpful in implementing an adjustment that you are unable to make for business reasons, eg if the cost of paying for a support worker would be to the detriment of your business.

As an employer, you may need to pay some of the costs of fulfilling Access to Work requirements yourself and claim the money back. [▶ The Government website has more information on Access to Work.](#)

Supporting the person with dementia to leave work

While a person with dementia may be able to continue to work for some time, the increasing challenges may eventually mean their role becomes unsustainable. Read our advice on handling this difficult stage and supporting the person as they transition out of their job.

5 ways to support an employee who chooses to leave their job



1 Find out their reasons: talk to the employee about why they want to leave work. Is it their personal choice, or do they feel there is pressure on them to leave? Assure them of your support as they assess whether it is right to leave work, or whether more could be done to enable them to continue.

2 Reflect on their role: in some cases, it may be possible to implement new reasonable adjustments to support the person to remain in work for longer, if they choose. It is a good idea to review the situation and see if additional adjustments could be made. Always involve the person with dementia, and, if they like, a family member or other trusted person, and a union rep if they have one. An occupational health assessment is useful at this point, if possible. Ensure the employee has support to explore their options. While some may choose to retire, it may be possible for others to find a new job that better suits their capabilities, allowing them to continue in employment for longer; or to take on voluntary work.



“If the person wishes, you could keep in touch with them after they finish work to maintain social contact and help them transition to life after leaving work – for example, you could invite them back into the workplace to catch up with their former colleagues or meet them outside work for a coffee.”

Rachel Watson, Admiral Nurse

3 Signpost them to financial support: for many people, leaving their job can put them under financial strain, whether because they are moving to a new job that may be less well paid or retiring earlier than expected. If the person is retiring and has a workplace pension, they may need support from you, your HR Team or their pension provider on how to access their pension on the grounds of ill health retirement. If you offer an Employee Assistance Programme, it may provide access to a financial adviser who could help the person understand their options, including benefits entitlements. If not, you could provide details of organisations that could help, like [Citizens Advice](#).

4 Help them through the correct processes: make sure the person knows what their contract says about leaving work and help them make the necessary arrangements. For example, they may need support with completing documentation.

5 Offer your support: leaving work can be a difficult transition so the employee is likely to need support. You may be able to offer this yourself, or through your Occupational Health Team or Employee Assistance Programme, if available. Involve the person’s family if they would like. Find out if they would prefer to tell their colleagues themselves, or if they would like you to do it – and would like a big farewell celebration or would prefer to leave quietly.

Is it the right time?

Deciding when to stop working due to dementia is a personal decision that will be influenced by how the person is affected by the condition, the nature of their job, and their personal circumstances.

There is no definitive time to stop working but if the person is finding it increasingly difficult to manage tasks or no further reasonable adjustments can be made to help them keep working, it could be time for them to consider leaving – either to move to a new job that they feel more able to cope with, or to retire.

If you believe the employee is reaching a point where they need to leave work, it is essential to handle it sensitively. Please see p28 for our advice.



What to do if you feel it is time for your employee to stop work

It can be very difficult if you believe your employee can no longer continue at work, but they have not reached that decision themselves. They may be determined to keep working for financial reasons, or because they enjoy the fulfilment of their job. Or they may have difficulties with insight that make them unaware of the extent of their struggles.

It is essential that you do not put your employee under pressure to leave work, as this could be considered discrimination. Likewise, you cannot make the person redundant purely on disability grounds.

If you need to broach the subject of your employee needing to leave work:

- Ensure you understand your obligations and their rights under the [Equality Act 2010](#)
- Talk to them openly about your concerns, making sure that you choose a time and location that suits them, and that they have advance notice of what you would like to discuss
- Give them the opportunity to have an advocate present – this could be a friend or family member, trusted colleague or union rep
- With their permission, consider asking their GP for a medical report – this will help you build a clearer picture of how their condition affects them
- Work together, with the Occupational Health Team if you have one, to discuss whether any further reasonable adjustments could be put in place, and if so, allow enough time to trial them and see if they help
- Document all discussions and decisions and arrange a time to review any actions that you agree to take

Terminating an employee's contract

Ideally, you and your employee will come to an agreement that it is an appropriate time for them to leave work. However, in some cases, it may be necessary and lawful to terminate their employment if dementia means they can no longer do their job. This may be known as 'capability dismissal'.

Dismissal is a last resort and you should take all the steps explained on this page to help your employee stay in work. It is also essential that you fulfil all of your legal and contractual obligations if you need to terminate your staff member's employment; if not, you could be taken to an employment tribunal and may have to pay compensation.

The process must include a 'capability procedure' to support the employee to improve their work (if possible). This could be following your organisation's performance management procedure.

It is vital that you handle this scenario with great sensitivity, respecting the employee's right to confidentiality and dignity. Recognise that this will be a very difficult situation, and ensure they know how to access support, both at work (eg HR Team, Employee Assistance Programme) and outside (eg family and friends, their GP, counselling services).

For more information on dismissing an employee with a disability, please refer to the [Acas Code of Practice](#) or in Northern Ireland, the [Labour Relations Agency](#)



Ill health retirement and pensions

Admiral Nurse Pam Kehoe explains how to support an employee to access their workplace pension early on health grounds.

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 a person may be able to claim their pension sooner if they retire because of ill health.

The pension provider will require the person to provide medical evidence, eg a doctor's report, and their employer will need to confirm that their health condition is the only reason for them taking early retirement. A person cannot claim their State Pension

until they reach [▶ State Pension age](#).

Some pension schemes allow early access if the person is unable to do their specific job due to physical or mental illness. Others might say that they can only claim their pension if they cannot do any job at all.

Accessing a pension early may affect the benefits the employee is entitled to so you should encourage them to seek advice from a financial adviser or local authority benefits adviser. They can also access information through [▶ MoneyHelper's Pension Wise service](#).



Supporting carers in the workplace

Around 700,000 people in the UK care for someone living with dementia. For working carers, support from their employer can make a big difference as they balance the dual responsibilities of working and caring.

Statutory rights for working carers in the UK

Under the [Equality Act 2010](#), people are protected against discrimination that results from someone they are associated with. This means discriminating against an employee because they are caring for someone with dementia is unlawful.

The law provides carers with certain employment rights. These are:

Time off for family/dependants

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

Legally, employers do not have to pay an employee for time off for dependants, but some do. The employee should refer to the organisation's policy around time off for dependants.

Right to request flexible working:

From the first day of their employment, staff members have the right to request flexible working under the [Employment Relations](#)



(Flexible Working) Act 2023. This could include part-time working, flexitime, job sharing, or working from home. They must put their request in writing.

You have two months to respond to a flexible working request. You can reject the application if there is a genuine business case against it, but you must explain this to the employee. They may be able to complain to an employment tribunal if they disagree with your decision.

The rules are slightly different in [Northern Ireland](#), eg an employee does not have the statutory right to request flexible working in the first 26 weeks of working for an employer.

Facts and figures

61%

of people with dementia live at home; many are cared for by a family member.

70%

of carers have felt isolated in the workplace.

21%

of carers reduce their working hours or give up work altogether to provide care.

Over
60%

of carers say their health has been negatively affected by their caring role, but only 17% of carers feel they have enough support.



Most family members who provide informal care – a role that is often physically, emotionally and psychologically demanding – do so without any training or preparation.



The average age of having children has increased over recent decades. This has led to many people becoming ‘sandwich carers’, caring for both young children and ageing parents at the same time – often whilst also working.



5 ways to support a working carer

Carers do not always identify themselves as such, so they may not reach out for support. However, if you are aware that an employee has caring responsibilities, these tips can help you support them.



1 Allow flexibility where possible: for example, staff may need time off to take the person they care for to appointments, or to work flexible hours around their key caring duties. Sometimes, people think of carer's leave as being solely for dependent children, but it could be used for supporting a relative with dementia.

2 Join the 'Carer Passport' scheme: a Carer Passport is a formal record of an employee's status as a carer and what their employer will do in response. It allows the carer to outline their caring commitments, supports employers in having conversations about how to balance the employee's needs with the needs of the organisation, and communicates any existing workplace support for carers. You can find more information on Carer Passports, including guides and templates, on the [Carers UK website](#).



3 Highlight your support offer: this could include informal support from you and the employee's colleagues, or formal support from an HR Team, Carers' Network or Employee Assistance Programme. You could also signpost them to organisations like [Citizens Advice](#) or [Acas](#) for employment issues, and to Dementia UK's specialist Admiral Nurses for emotional and practical support – please see Sources of support on p38.

4 Maintain open conversations: because dementia is a progressive condition, your employee's needs as a carer are likely to change over time. It is a good idea to schedule regular review meetings to check in on how they are managing and see if the current accommodations need revising.

5 Recognise their own needs: being a carer can have a huge impact on someone's physical and mental health and finances. It is important to recognise how this affects their working life and respond with empathy and understanding. While accommodating the carer's needs may at first glance seem detrimental to your organisation, offering them the support they need will help them feel more able to cope with their joint working and caring responsibilities, and help you retain valued members of staff.

“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.

“As well as caring for my mum I was managing a team and had a lot of responsibility. I felt I was juggling too much and was afraid I'd drop the balls. I felt I was never doing a good enough job of anything.

“There was no policy for carers and if I raised my worries with my direct manager, they never wanted to open up the conversation about how they could be more flexible.

“I eventually reached the point of burnout and was signed off work 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.”

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



Supporting customers and clients

The advice in this section will help you ensure a dementia-inclusive atmosphere and environment for everyone who comes into your workplace or business, or uses your organisation's services.

Communicating effectively with a customer with dementia

People with dementia may experience a range of challenges as a customer or client. They may struggle to communicate and express their needs. Difficulties with activities like shopping can be common, for example with deciding and remembering what to buy and handling money. The physical environment may also be overwhelming, with bright lights, noise and obstacles.

These steps will guide you and your employees through communicating with a customer or client with dementia.

1. Initial interaction

- Greet the customer warmly and introduce yourself clearly. Use their name if you know it, or ask what they would like to be called – some people prefer to be addressed as Mr/Mrs/Miss while others would prefer you to use their first name
- Maintain gentle eye contact to show your attentiveness and respect

2. Verbal communication

- Use clear, straightforward language
- Speak slowly and clearly, allowing the customer time to process and respond
- Ask one question at a time to avoid overwhelming them

3. Non-verbal communication

- Use open, friendly body language
- Use simple gestures to support your words
- Use warm and reassuring facial expressions

4. Listening and understanding

- Show that you are listening by nodding and providing verbal affirmations like, "I understand," or, "I see"
- Do not interrupt, even if they are struggling to find words
- Summarise or rephrase what the customer has said to confirm your understanding

5. Visual aids

- Use pictures, symbols, or written notes to help convey your message
- Point to objects or demonstrate actions to make your communication clearer
- Provide easy-read versions of resources like leaflets and forms

6. Empathy and patience

- Recognise and validate the person's emotions. Show empathy if they seem confused or frustrated
- It can be easy to misunderstand or misinterpret something that is related to the person's dementia, for example if they leave a shop with goods without paying. Rather than challenging the person, sensitively remind them that the item may need to be paid for

7. Encouragement and support

- Encourage the customer to express themselves and participate in the interaction
- Provide simple choices rather than open-ended questions (eg "Would you like tea or coffee?" instead of, "What would you like to drink?")
- Do not argue or try to correct the customer if they say something incorrect. Instead, gently steer the conversation or distract with another topic
- Offer assistance proactively but respectfully. Be mindful not to undermine the person's dignity and independence – aim for a 'let's do it together' approach
- Consider introducing a 'slow lane' at checkouts or a 'relaxed hour' where people with dementia and other hidden disabilities can take their time and benefit from increased support and social contact with staff

The benefits of dementia training for staff

Training employees in dementia awareness is crucial in enhancing the customer experience and can also benefit your organisation. It can help to:

Improve service quality

Ensure services are accessible

Reduce stigma

Empower employees

Improve communication

Build confidence

Promote an inclusive environment

Develop advanced skills

To find out how we can support you with dementia training for your organisation, please email dementia.work@dementiauk.org

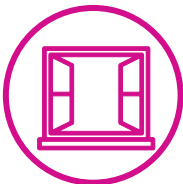
Creating a dementia-inclusive environment

Creating an accessible and welcoming environment for people with dementia involves designing spaces that are safe, comfortable and supportive of their cognitive, emotional, and physical needs. Here are some elements to consider.



Safety and accessibility

- Fit non-slip flooring to prevent falls
- Install handrails and grab bars in key places
- Keep pathways clear
- Ensure toilets are well maintained and well signed
- Make sure steps are clearly marked and provide a ramp if possible
- Avoid making changes to the layout unless necessary (eg changing the location of products in a shop)



Lighting

- Natural light helps visibility
- Keep lighting consistent and even to avoid shadows and glare



Colour and contrast

- Use contrasting colours for walls, floors, furniture and signs to enhance visibility
- Use soothing colours like soft blues and greens
- Avoid complex patterns: stick to solid colours
- Avoid shiny surfaces like highly polished wood/lino that may appear wet or slippery



Noise

- Use sound-absorbing materials like carpets, curtains, and acoustic panels
- Where possible, create quiet areas where customers can retreat from overstimulation



Signage

- Place signs at eye level and at a consistent height
- Use simple, straightforward wording
- Choose a font that is large, bold and easy to read, and use the same font on all signs
- Use pictures or symbols to reinforce the wording on the sign; keep to universally recognised icons (eg emergency exit sign, disabled sign)
- Ensure a high contrast between text and background (eg black on white) and keep to the same colours throughout
- Place signs at key decision points (eg junctions, doorways)
- Signs for toilets and exits are particularly important

Supporting people with dementia to use remote services

People with dementia may have difficulty using the internet, which could have implications if your business trades solely online. [AbilityNet](#) provides useful information and services to help you make your online platforms accessible for disabled and older people.

People with dementia may also lack the confidence or communication skills to speak on the phone and may need a family member, friend or other representative to make phone calls on their behalf. Many people find face-to-face services more helpful than telephone or online chat, so it is worth considering whether some form of in-person support can be offered, for example, offering face-to-face appointments at a time and place that suits the customer.



The Sunflower lanyard and other forms of ID

The [Sunflower lanyard](#), provided by Hidden Disabilities, is worn by many people with invisible conditions to indicate that they may need extra time, space, support and understanding in public places. It is a good idea to make staff aware of what the lanyard signifies so they can support their customers and clients.

To show their support for the Sunflower scheme, organisations can become a member and access training, webinars, inclusion tips and more. Members also qualify for a discount on sunflower lanyards and other products, which you may wish to make available to your customers.

Some people with dementia also carry other forms of ID to make people aware of their condition, such as a card with details of their diagnosis that they can discreetly show to staff if they need support.

How we can support you

Dementia UK has a wealth of free resources on its website to help organisations understand more about dementia so they can better support customers and clients who use their services. Please visit dementiauk.org/information-and-support

The Dementia at Work Team at Dementia UK can also support you with raising awareness, upskilling staff and developing customer service policies that specifically address the needs of customers with dementia. Please visit

dementiauk.org or email dementia.work@dementiauk.org

Sources of support

Dementia UK's Dementia at Work Programme

Our Dementia at Work Programme provides organisations with a range of services to increase their understanding and awareness of dementia and improve support for employees and customers affected by the condition. To find out how we can support you, for example with information, masterclasses and bespoke training, please contact [▶ dementia.work@dementiauk.org](mailto:dementia.work@dementiauk.org)

Dementia UK support for people living with dementia and their carers

Dementia UK's specialist Admiral Nurses support people living with dementia, their families and carers with any aspect of the condition. If you have employees with dementia or staff who care for someone with the diagnosis, please encourage them to contact us.

Helpline: call free on 0800 888 6678 (Monday-Friday 9am-9pm; Saturday, Sunday and bank holidays 9am-5pm except 25th December) or email

▶ helpline@dementiauk.org

Virtual clinic appointments: to pre-book a free phone or video appointment with an Admiral Nurse, visit [▶ dementiauk.org/book](https://dementiauk.org/book)



Dementia UK resources

On Dementia UK's website, you will find a wide range of information and advice on all aspects of dementia, including leaflets to read online, download or order. Please visit dementiauk.org/information-and-support

As an employer, you may find these resources particularly helpful:

- **Driving and dementia**
- **Employment and young onset dementia**
- **Living aids and assistive technology**
- **Stigma and discrimination**
- **Supporting customers affected by dementia**
- **Supporting staff affected by dementia**
- **Tips for communicating with a person with dementia**
- **Understanding young onset dementia**
- **Young onset dementia: different symptoms**

Employment rights

- **Accessibility of shops and businesses for disabled people**
- **Disability Discrimination Act 1995 (Northern Ireland)**
- **Employment Relations (Flexible Working) Act 2003 (England, Scotland, Wales)**
- **Equality Act 2010 (England, Scotland, Wales)**
- **Flexible Working Regulations (Northern Ireland) 2015**
- **Reasonable adjustments for workers with disabilities or health conditions**
- **Time off for family and dependants (England, Scotland, Wales)**
- **Time off for dependants (Northern Ireland)**
- **Unpaid carer's leave**

Other resources

- **AbilityNet**
Specialist services and support to create a digital world accessible to all
- **Acas (the Advisory, Conciliation and Arbitration Service)**
Free advice on employment law, HR processes and good practice at work
- **Access to Work scheme**
- **Carer Passport scheme**
- **Carers UK**
Information, advice and support for unpaid carers
- **CIPD report: 'Supporting working carers'**
- **Citizens Advice**
Free, confidential advice and support, including on work, benefits, debt and money
- **DEEP (Dementia Engagement and Empowerment Project): Tips for employers who want to be more dementia-friendly**
- **Early retirement, pensions and benefits**
- **Employing disabled people and people with health conditions**
- **Equality Advisory and Support Service**
Advice on equality and human rights across England, Scotland and Wales
- **Gov.uk benefits section**
- **Health Adjustment Passport**
- **Hidden Disabilities Sunflower scheme**
- **MoneyHelper Pension Wise service**
- **NHS-approved occupational therapy providers**

**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



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