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Society

Leading the  
fight against  
dementia



# Creating a dementia- friendly workplace

A practical guide for employers

**Document purpose:** This guide for employers is designed to help them provide support for staff members with dementia. It may also be a useful resource for people living with, or affected by, dementia in the workplace. The guide includes practical tips and examples of situations that managers can use to ensure best practice as well as to review existing approaches to supporting people living with dementia in the workplace.

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**Contact:** Alzheimer’s Society Dementia Friendly Communities Programme team at [dementiafriendlycommunities@alzheimers.org.uk](mailto:dementiafriendlycommunities@alzheimers.org.uk)

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**Web:** [alzheimers.org.uk/dementiafriendlycommunities](http://alzheimers.org.uk/dementiafriendlycommunities)

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# Foreword

**For too long, Alzheimer's disease and other types of dementia have been mistakenly perceived as an 'old person's disease' and 'a natural part of ageing'. Frequently, people hear the word dementia and picture an older person in care, unable to live well – and certainly unable to work. But we know that 40,000 of the 850,000 people in the UK living with dementia are under the age of 65. With the UK statutory retirement age rising, and the number of people with dementia expected to increase to 1 million by 2021, we will see many more people developing dementia while still in employment.**

Although a hidden issue in many workplaces, dementia is not something organisations can continue to ignore. The Equality Act (2010) requires employers to avoid discrimination and make reasonable adjustments to ensure people with dementia and their carers are not disadvantaged in the workplace.

A widespread lack of awareness and understanding of dementia often stops people from talking openly about the condition. However, nationwide awareness-raising initiatives such as Dementia Friends, and a greater focus on diagnosis by GPs, has led to more people being diagnosed with dementia at an earlier stage.

With a timely diagnosis, and the right support, many people with dementia are able to continue working and choose to do so. In addition, some, especially those with early onset dementia, have financial commitments, such as mortgages or family dependants, and need to stay in paid employment for as long as they are able.

Given the scale of the challenge, society must come together to protect the rights of people with dementia to inclusion. Spearheading this movement is Alzheimer's Society's Dementia Friendly Communities programme – regions, cities, towns and villages that are doing as much as possible to support people with dementia, tackle stigma and improve inclusion.

When the Prime Minister launched the government's Challenge on Dementia in 2012, he urged both individuals and businesses to work towards becoming dementia friendly by engaging and supporting people with dementia in their local communities.

The response to the programme has so far been impressive, with a significant number of communities across England already signed up to the national Dementia Friendly Communities recognition process. A number of leading national employers are also involved. Many have adjusted their work practices as well as encouraging colleagues to play their part individually, for example by becoming Dementia Friends.

We recognise that organisations and businesses of all sizes face challenges when supporting employees living with dementia, putting into practice the legal obligations of the Equality Act and working in partnership with the person with dementia to make reasonable adjustments. We have produced this practical guide for managers and HR teams to support employers to become truly dementia friendly.



**Jeremy Hughes**

Chief Executive, Alzheimer's Society

# 1 Introduction

**As the workforce ages and the number of people retiring at a later age increases, the number of people living with dementia while they are in work is set to rise. This has implications for employers, who are beginning to recognise that dementia is becoming an increasingly big issue for their organisation and their staff.**

We hope managers will use this guide as a tool to review existing approaches to supporting people living with dementia in the workplace. We also hope it will be a catalyst to help your organisation think differently about how to support colleagues living with dementia and their carers in the future.

A dementia diagnosis doesn't necessarily mean a person can no longer do their job. However, dementia is a progressive condition and over time it will increasingly impair a person's ability to work. As this happens, they may need support to help them remain at work. Eventually, they may need information from their employer about leaving work. This might include discussing retirement options and access to financial advice.

Similarly, support will be needed for those who decide they no longer want to work following a diagnosis of dementia. Finally, some employers will specifically wish to recruit and employ people with experience of living with, or caring for someone with dementia, for example as peer support workers.

This practical guide is for all UK employers – across all sectors and of all sizes – to help them provide this type of support for the people with dementia and the carers they employ. It may also be a useful resource for people living with or affected by dementia in the workplace. In the following sections you'll find:

- information about dementia, its symptoms and common issues faced by people with dementia
- information about your legal responsibilities in relation to the protection of people with dementia from discrimination
- ideas to help you develop awareness of dementia in your workplace
- step-by-step tips to help you support a member of staff who is affected by dementia at different stages of their dementia journey, covering a number of common workplace scenarios
- information and guidance on making reasonable adjustments to ensure people with dementia are not disadvantaged in the workplace
- a list of organisations that can give further advice and support to you as a manager, and to employees who either have dementia or care for someone with the illness.

There is no one-size-fits-all approach to supporting staff living with dementia. However, this guide aims to give you the tools you need to begin your organisation's journey to becoming a dementia-friendly employer.

## Dementia in the workplace

The following statistics indicate the scale of dementia as an issue facing society as a whole. They also reveal the impact on the UK working environment:

- There are 850,000 people with dementia in the UK.
  - The cost of dementia to the UK is £26 billion a year (based on 2013 cost data).
  - The number of people with dementia in the UK is forecast to increase to over 1 million by 2025 and over 2 million by 2051.
  - There are over 40,000 people with dementia under the age of 65 in the UK.
  - Currently, 18 per cent of people diagnosed with dementia under the age of 65 continue to work after a diagnosis of dementia.
  - Dementia is an issue that disproportionately affects women. Two-thirds of the people living with dementia in the UK are women and most family carers, as well as those paid to care for people with dementia, are women.
- In a recent survey of employers, 89 per cent of respondents recognised that dementia was a growing issue for their organisation and their staff.
  - A survey of 888 HR decision makers in small, medium and large businesses carried out by the Centre for Economics and Business Research found one in 10 businesses had employed someone living with dementia.
  - The Centre for Economics and Business estimates that the average person diagnosed with dementia while still at work, will have been in their current job for at least nine years. The early retirement of those diagnosed with dementia costs English businesses £627 million a year.

Figures from: Dementia UK: second edition (Alzheimer's Society 2014; Alzheimer's Society 2010) and Supporting employees who are caring for someone with dementia (Employers for Carers/Carers UK 2014).

# 2 Becoming a dementia-friendly employer

## What does being ‘dementia friendly’ mean?

**People with dementia can face challenges if they want to continue working after a diagnosis of dementia. While wider changes are needed to help them remain in the workplace, such as improvements in diagnosis rates, better access to support and greater awareness of dementia and its symptoms, there is also much that employers can do. Employees also have rights that must be respected.**

Becoming a dementia-friendly employer is about creating an environment in which:

- everyone is aware of and understands dementia
- people with dementia and their carers feel able to seek help and support
- policies are in place that will support the needs and rights of people with dementia
- people with dementia feel included, have choice and control over their lives
- people with dementia are able to continue – as far as possible – to contribute their skills and experience to the organisation.

Being a dementia-friendly employer needn't be onerous. It is about raising awareness of the challenges faced by those living and working with dementia, thinking flexibly about how you can support and enable staff affected by dementia who choose to continue to work, and developing a culture that values everyone.

‘It’s about what you can do and making it work in everyone’s best interests. When considering your staff living with dementia, it is vital to understand what that means to the person and to your organisation. The first thing is to consider what the employee can bring to your organisation, not what they may have difficulty with, either now or in the future. This guidance gives employers the information they need to understand the situation and treat each employee on a case-by-case basis.’

Ron Cullen, Director, UK Renal Registry

## Why become a dementia-friendly employer?

Becoming dementia friendly will not only make a huge difference to staff who are affected by dementia; it may have benefits for the whole organisation and it makes good business sense too.

### **It’s the right thing to do**

A dementia-friendly working environment gives staff members with dementia and carers the opportunity to continue to play an active part in the workforce and clearly signals your commitment to creating an inclusive workplace. By becoming dementia friendly, you will further develop a culture that understands and supports all staff and enables them to work in a way that suits them and meets the organisation’s needs.

### **It will help you to retain staff**

Loyal and hardworking staff are an extremely valuable resource. Creating a working environment in which people know they will be supported if they develop dementia will help you to retain their advanced skill set and historical knowledge of the company for as long as possible.

### **You will become an employer of choice**

Evidence suggests that people look to work in organisations with policies and cultures that are inclusive and empowering. By working towards becoming a dementia-friendly employer, you will demonstrate that you understand and value the contribution made by all staff and attract the best recruits.

### **You will provide a more inclusive service**

It is estimated that by 2025 there will be over 1 million people in the UK living with dementia. Your understanding of, and support for, their needs will help you demonstrate that you provide a more inclusive service.

### **It will future-proof your organisation**

By investing in awareness raising and rethinking your approach to dementia now, you will have robust approaches in place to support staff who either have dementia or are carers, before dementia becomes a business-critical issue.

### **It will contribute to increased productivity**

Evidence suggests that productivity and quality of service delivery are enhanced when staff work in a culture that is inclusive and that values everyone's contributions.

### **You will be fulfilling your legal responsibilities**

The Equality Act 2010 (England and Wales) protects anyone who has a disability – generally this will include people living with dementia. The Act defines disability as 'a mental or physical impairment that has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities'. 'Long-term' typically means 12 months or more. 'Substantial' is defined in the Act as 'anything more than minor or trivial'.

Under the Act, employers have a duty to make reasonable adjustments for employees with a disability so that they are not disadvantaged at work. (See page 17 for more information about making reasonable adjustments.) The Act covers all aspects of employment, including the recruitment process – terms, conditions and benefits, as well as treatment compared to other workers, such as discrimination, harassment and victimisation.

It also protects people who experience discrimination because they are associated with someone who has a disability – such as their carer, from direct discrimination and harassment. Carers have the right to request flexible working, and the right to request time off to look after dependants in an emergency.



# 3 What is dementia?

**Dementia describes a set of symptoms that may include memory loss, mood changes and problems with communicating and reasoning. These symptoms occur when the brain is damaged by certain diseases. Alzheimer's disease is the most common form of dementia, but there are more than 100 other types including vascular dementia and dementia with Lewy bodies.**

Dementia affects people in different ways, depending on the disease as well as the person. It is one of the main causes of disability in later life, ahead of cancer, cardiovascular disease and stroke.

## Common signs and symptoms of dementia

**Memory loss** – for example, a person may:

- have problems recalling things that happened recently (although some people easily remember things from a long time ago)
- repeat themselves or ask the same question continually over again.

**Difficulty thinking things through and planning** – for example, a person may:

- have problems concentrating, following a series of steps, grasping new ideas or solving problems
- struggle with familiar daily tasks, such as following a recipe or using a debit or credit card.

**Problems communicating** – for example, a person may:

- have difficulty finding the right word
- struggle to follow a conversation or misinterpret things.

**Being confused about time or place** –

for example, a person may:

- lose track of what time, date or season it is
- not know where they are, even in a place they know well.

**Problems with sight and visual perception** –

for example, a person may:

- have difficulty judging distances (for example, on stairs)
- misinterpret patterns or reflections in mirrors.

**Mood changes or difficulties controlling emotions** – for example, a person may:

- become unusually sad, frightened, angry or easily upset
- lose interest in things and become withdrawn
- lack self-confidence.

## Some common issues that affect people living with dementia

**Difficulty getting a diagnosis**

Early assessment and diagnosis of dementia is key to preventing problems at work and enabling people to continue to work for as long as possible after their diagnosis. However, currently only 48 per cent of people with dementia in the UK are diagnosed. People with early onset dementia can face particular delays receiving a diagnosis.

Symptoms of dementia in people under 65 years of age are often put down to stress or depression and, in some cases, it can be years before people receive a confirmed diagnosis. By this stage they may have already had to stop working. Once someone has a diagnosis of dementia they can plan for the future and this includes their working life plans. Early diagnosis can also help employers

to provide support and seek specialist advice about how best to support individuals and plan for the future.

### **Financial issues**

The financial impact of giving up work may particularly affect people with early onset dementia, who are more likely to have financial commitments, such as a mortgage to pay or dependent children. They may not be able to access their pensions early and may experience delays in receiving payments from insurance policies. This makes access to advice about benefits and careers particularly important for them, as well as information about Lasting Powers of Attorney and making a will.

### **Stigma**

There is a widespread lack of awareness of dementia and lack of understanding of how it affects people. People with dementia and their carers often refer to the stigmatising effects of diagnosis, the attitudes they encounter towards dementia and the profound effect this has on them and their families.

Many people who develop dementia while in work report that they feared the reactions of colleagues and employers. They were worried that they might not be supported to continue at work or would be discriminated against if they looked for a new job. Others reported negative reactions from colleagues when they disclosed their diagnosis, including being bullied at work.

### **Gavin, aged 63, Warehouse Operative, Bunzl Healthcare**

Gavin has worked at Bunzl Healthcare in Manchester for the past 10 years, picking and packing products for distribution. Gavin was diagnosed with dementia by his GP three years ago, after others noticed changes in his behaviour. He told colleagues about his diagnosis two years later when they began to notice that he was finding it difficult to carry out his daily responsibilities. After sharing his diagnosis, Gavin says that his colleagues were extremely supportive and were on hand to help him when dealing with large orders.

Initially, Gavin didn't need any modifications to his role. However, his role has changed over time to accommodate his situation. He now works on the packing benches as he began to become confused with product codes and locations while picking and sorting items to be packed. He has also moved to a four-day week to give him a longer rest period between working days.

Gavin knew Bunzl Healthcare would support him after his diagnosis although he wasn't aware how they would do this. Because of this experience, he believes they now have a better understanding of how to help others with dementia in their workforce.

# 4 Creating a dementia-friendly working environment – some practical tips

**Being dementia friendly is about supporting individuals with dementia and carers. But it is also important to create an environment in which every employee understands dementia and feels able to talk about it. If you provide public-facing services, you might also consider how you can make them more accessible to customers or users who have dementia.**

Below are some ways you can help your organisation start its journey towards becoming dementia friendly.

- Encourage open dialogue and create an environment in which staff feel they can talk about dementia. One way to do this is by running awareness-raising activities in the workplace. For example, you could work with local Dementia Friends Champions to deliver Dementia Friends sessions during lunch-breaks.
- Conduct a staff survey to find out how many people are affected by dementia, including those who care for someone with the disease.
- Include information about dementia in newsletters, on your staff intranet, in communal staff areas, on noticeboards and in reading areas.
- Work with the Alzheimer's Society representative in your area to make staff aware of local services for people affected by dementia.
- Think about your premises, including any customer-facing environments, from a dementia-friendly perspective. If possible, work with local people living with dementia to seek their views. Simple, low-cost changes, such as clear signage and better acoustics, can make your premises or services more inclusive of people living with dementia.
- Circulate this guide to ensure that all managers in the organisation are aware of dementia in the workplace and how it might affect their staff.
- Consider dementia issues when making future plans or revising your organisation's HR policies and procedures. For example, you could introduce dementia awareness to the diversity and inclusion, and customer service elements of induction for new staff.
- Be careful about the terminology that is used within the organisation. Words such as 'dementia sufferer', 'demented' or 'burden' can be offensive and disempowering.

## **Working towards becoming dementia friendly: Joseph Rowntree Foundation (JRF) and Joseph Rowntree Housing Trust (JRHT)**

JRF and JRHT are working towards becoming an organisation that recognises and addresses the impact of dementia on all of us.

Our action plan shows the practical ways in which we have begun to make changes within the organisation.

### **What we aim to do**

#### **Involve people living with dementia and/or others directly affected by dementia in determining how we become more dementia friendly**

People with dementia have been actively involved in several projects across JRHT. People who regularly meet in our community centre provided their perspectives on how to improve the building during a £300,000 refurbishment programme. Another group provided training for a film production company commissioned by JRF to make a series of films about life with dementia.

#### **Engage with our staff and challenge our perceptions and understanding of the experience of living with dementia**

In autumn 2013, the 'Conversations about dementia' roadshow visited 17 JRHT and JRF sites and spoke to 250 staff face-to-face, answering questions, collecting perspectives and building staff engagement on the topic of dementia. During Dementia Awareness Week 2014 a myth-busting poster campaign challenged

readers to think differently about life with dementia. Staff and residents have also been invited to sessions about the importance of Lasting Power of Attorney.

#### **Support individual staff who are directly affected by dementia themselves, in their families or in their communities**

Dementia information boxes – created by a team of staff volunteers – have been distributed to each JRF and JRHT workplace and put into canteens, staff rooms etc. The boxes provide easy-to-access, free information for staff to take away and share with friends and family.

#### **Use our understanding of dementia to have a practical and permanent influence on all the services we provide and the way we provide them**

Staff from the planning and construction team have received bespoke training from the Stirling Dementia Services Development Centre and have incorporated dementia-friendly design principles in the commissioning of architects and planners for a new building development in New Earswick, York.

#### **Explain the benefits of being dementia friendly to individual staff members**

A full-time internship position was created to deliver Dementia Friends information sessions to all staff across JRF and JRHT during autumn/winter 2014.

# 5 Supporting people with dementia in the workplace

**As a manager, what would you do if a member of staff told you that they had dementia? Or if you noticed that someone was having problems at work that could indicate dementia?**

This section will help you handle situations like these and give ongoing support for the person with dementia. It is divided into three phases:

- **Phase 1:** Supporting employees in the early stages of dementia
- **Phase 2:** Ongoing support and management
- **Phase 3:** Leaving work

Remember that this is a guide and not a comprehensive list. It is important to consider each individual on a case-by-case basis. Depending on the circumstances, you may wish to take legal advice.

The guide also refers to human resources (HR) and occupational health as sources of support and advice. If you do not have an HR team or access to occupational health services, you may be able to get additional support from the organisations listed on page 26.

## Phase 1: Supporting employees in the early stages of dementia

There are a number of ways in which you might find out that a staff member is having problems with their memory or showing other symptoms of dementia. Remember that, although diagnosis is important, early signs of dementia may be apparent before a diagnosis can be made.

## Communication

Part of the support you provide will be facilitating good communication. It can help people with dementia if you follow the following tips:

- Find a suitable place to speak, with minimal background noise.
- Get their full attention before you start to communicate.
- Be patient and allow them plenty of time, as it may take them longer to process information.
- Check with the person that you have understood correctly what they have said.
- Make sure the person can see you clearly and maintain good eye contact to help them focus on you.
- Listen carefully to what the person has said. If they have difficulty finding the right word or finishing a sentence, ask them to explain it in a different way.
- Remember that people with dementia can become frustrated if they are unable to find the answer. They may respond with irritation or even aggression in extreme circumstances.

## Examples of workplace scenarios

The following situations show suggested responses to problems or issues that you observe or with which you are presented. Remember to consider each individual instance carefully according to the specific circumstances involved.

## Situation A

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You notice changes in an employee's behaviour. For example, they might:

- struggle to remember recent events
- find it hard to follow conversations
- forget the names of colleagues/clients
- be unable recall things, such as written communications or conversations
- repeat themselves or lose the thread of what they are saying
- have problems thinking and reasoning
- appear anxious, depressed or angry about their forgetfulness
- seem confused even when in a familiar environment.

## Ways to respond

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There are many sources of information and support available (see page 26). Do take advice.

The best initial response is caution. Do not jump to any conclusions about your employee's health – dementia is one of a wide range of causes of these types of behaviour. Having said that, you do need to start to communicate with the person about your concerns. Encourage dialogue and a culture of honesty.

Remember that, although dementia is likely to affect a person's ability to do certain tasks, many skills and abilities are retained, often for a considerable period of time. Your overriding message should be supportive. In addition, consider the following practical steps:

- Check your organisation's policy. If you do not have a policy on dementia, you may find the information you need in a range of other policy documents.
- Seek advice from HR or occupational health professionals. If you don't have access to HR advice within your organisation, see page 26 for other sources of support.
- Arrange a conversation with the person about the changes in behaviour that you have noticed and prepare for it carefully using the points identified below. This is not a 'formal' meeting but you should have some specific examples you can refer to. A general 'feeling' that there is a problem is not a sufficient basis for a conversation. Consider the following tips:
  - A good starting point for the conversation might be to ask whether the person has noticed any changes themselves.
  - Think about your own non-verbal behaviour, for example staying positive and confident, maintaining eye contact, being patient, not speaking too fast and listening carefully.
  - After the conversation you might agree to arrange a referral to occupational health to establish the best way forward.
- Keep notes of your discussions and any plans.

## Situation B

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You notice that a staff member's ability to do their job is impaired.

Signs of this might be:

- a reduction in performance levels, for example missing deadlines or producing incomplete work
- attendance issues, for example arriving late for work or leaving early, or occasional unexplained absences during the working day
- apparent conduct issues, for example displays of anger or emotional outbursts at work.

## Ways to respond

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In the interests of the business/service and of the person involved, it is important that you respond to these issues quickly by starting the careful communication process outlined above.

Usually, poor performance at work due to capability, conduct (disciplinary) or attendance could trigger the start of a performance management procedure. However, if dementia is a possible cause of the person's problems, you should be careful to avoid moving into formal proceedings. Seek advice from HR/occupational health if you are in doubt about the cause of the change in behaviour.

Take advice on your organisation's policy and procedure.

## Situation C

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You find out that staff are hiding issues in the workplace in order to 'protect' a colleague with memory problems/dementia.

## Ways to respond

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It is important to create an inclusive employment environment where staff recognise that openness and honesty is in everyone's best interests.

Practical steps to address this type of issue include raising your concerns with trusted team members (confidentially), or discussing the organisation's policy approach at team meetings.

## Situation D

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An employee comes to you because they have received a diagnosis of dementia or because they are worried about their memory.

### Ways to respond

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Approaching you will have taken a lot of courage, so recognise and value this when you talk to the person by:

- making sure the person knows that their skills and experience are still valued
- reassuring the person that the organisation will support them where it can
- developing a written plan that is flexible and based on open communication and trust.

The plan could include:

- the wishes of the staff member
- the needs of the employer
- definitions of short, medium and long-term actions
- the names of people most likely to be involved in ongoing 'case management'
- the frequency of future meetings and reviews
- any agreed adjustments to the role. Adjustments might include changes to the person's working arrangements, such as a change in their working hours, skills requirements or their level of accountability/responsibility (see page 17 for more information about adjustments)
- any other support that has been agreed, such as the use of special equipment or technology, external contacts (for example, family members), appropriate re-training opportunities, arrangements for emotional support, the link between primary health support, such as the person's GP, and internal occupational health support, a mentor/buddy/support worker
- any arrangements you have agreed with the person about informing colleagues of the diagnosis.



## **Situation E**

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A family member or colleague gets in touch to report their concerns about a staff member.

### **Ways to respond**

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Listen carefully to what is being said. An appropriate response will balance confidentiality and any internal requirements or procedures, and the outcome would usually be to:

- express thanks for bringing the issue to your attention
- explain that you are not in a position to discuss the case in detail
- offer reassurance that you will address the issues appropriately.

Encourage the family or team member to get in touch with you again if they have any concerns in future.

If appropriate, raise the issue with the staff member involved – see Situation A on page 12 for more guidance.

## **Situation F**

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A customer reports concerns about an employee.

### **Ways to respond**

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Listen carefully to what is being said. An appropriate response will probably balance confidentiality and the requirements of your organisation's compliments and complaints procedure, and the outcome would usually be to:

- thank the customer for bringing the issue to your attention
- reassure them that you will address the issues appropriately.

If appropriate, raise the issue with the staff member involved – see Situation A on page 12 for more guidance.

## Phase 2: Ongoing support and management

Dementia is a progressive condition and a person's symptoms will change over time. It is therefore important to continue to meet regularly to monitor and review the situation.

This section covers the following considerations:

- Ongoing support of the person in the workplace
- The role of an occupational health service
- Liaison with the person's GP/primary care team
- The response and management of the wider team
- Addressing negative responses

### Ongoing support for the person with dementia

- Remember that getting a diagnosis can be traumatic, confusing and isolating. Be aware that people may need time to adjust.
- Recognise that supporting people may take more time and resources – people may need practical and emotional support.
- Undertake risk assessments that focus on supporting the person to remain at work if they choose to.
- Continue to work with the employee to agree reasonable adjustments that will help them continue to do their job. Remember that you may be able to get financial support to help with this. See the section on reasonable adjustments (page 17) for more information about potential funding for adjustments.
- Undertake regular structured reviews. The adjustments required may change over time as the person's dementia progresses. A flexible and responsive approach is most likely to be successful.

- Be honest about what is achievable.
- Continue to take advice from HR and occupational health professionals. If you don't have access to this type of advice within your organisation, see page 26 for other sources of support.

### The role of an occupational health service

If you have an occupational health team or service available to you, talk to the person with dementia about referring them to occupational health for an assessment. The success of an occupational health referral will depend on the quality of questions put to the medical experts. In relation to a member of staff with possible dementia, an occupational health referral could include the following questions:

- What aspects of their role can the person do now?
- What aspects of their role could be affected by their dementia?
- What can the person do that is not part of their current role?
- What is the likely next step in the development of the condition?

### Liaison with the person's GP/primary care team

Whether or not you have access to occupational health, it is important to stay in touch with the person's GP or primary care team. This should be part of the plan you agree with the person with dementia (see Situation D page 14). As a manager, you might take on the liaison role, or your occupational health team could do this, if you have one.

## The response and management of the wider team

Although confidentiality is critical, at some point it may be appropriate to have a wider discussion within the team about the person's dementia. It is essential that such a discussion takes place with the permission of the person living with dementia and in a way with which they are comfortable.

If the person chooses to lead the discussion, give them the support they need to do so. However, they may prefer you to take the lead, or you could talk to your HR, occupational health or learning and development team to arrange an external facilitator.

The agenda might include:

- determining how best to respond in different situations
- information sharing to increase team awareness about dementia (on a general or individual basis)
- letting the team know about adjustments to the person's role
- a discussion about the impact on other roles in the team
- an opportunity to raise any issues of concern or worries
- next steps.

## Addressing negative responses

Because of the stigma that still surrounds dementia, there is a risk that someone who is concerned about dementia may be unwilling to talk to their employer about it, or that their colleagues may respond in a negative way.

By becoming a dementia-friendly organisation, you will hopefully increase awareness of dementia and reduce the stigma attached to it. This will enable staff to acknowledge and discuss any problems that they might have at work because of their dementia.

However, as a manager it is important to be aware of the potential for negative responses and the possibility of problems such as bullying. Your role is to encourage openness but also to set a standard of behaviour and use the relevant procedures to address any inappropriate behaviour robustly.

## Making reasonable adjustments

As a person's dementia progresses, the symptoms can increasingly affect their ability to work. For example, people who access Alzheimer's Society's services have described getting lost when travelling for work, not remembering the details of instructions or tasks they have been given, forgetting meetings or being unable to complete a routine task.

Under the Equality Act 2010, employers are required to make reasonable adjustments for people with disabilities, including people with dementia, to ensure they are not disadvantaged at work. There are various ways to do this, for example by reallocating a task to another employee, moving the person's desk to a quieter area or agreeing a change of working hours.

The reasonable adjustments might apply to the physical features of the buildings, fittings or equipment. All aspects of employment should be considered when thinking about adjustments, including recruitment and selection, promotion, professional development review, transfers, training, career development and retention.

This section includes:

- Planning and agreeing reasonable adjustments
- Things to bear in mind when considering a request for a reasonable adjustment
- Funding for reasonable adjustments
- Reviewing reasonable adjustments

- Redeployment
- Examples of reasonable adjustments
- Two case studies showing how different employers made adjustments in their workplace for people with dementia.

### **Planning and agreeing reasonable adjustments**

As a manager it is your responsibility – together with your staff member and, where appropriate, an HR officer – to make decisions about making reasonable adjustments. The symptoms of dementia affect people in different ways, so you will need to assess each case on an individual basis.

Doctors, employers or occupational health advisers cannot make decisions on what constitutes a reasonable adjustment for someone with dementia. It is only possible to agree reasonable adjustments by consulting with the person about the barriers they are experiencing in the workplace.

Although decisions about reasonable adjustments are managerial rather than medical, you should take any relevant medical information and/or expert opinion on board as well as information from the member of staff.

If you are finding it difficult to identify a suitable reasonable adjustment, or if you need specialist advice or assessment, seek further advice from your HR or occupational health team. If you don't have this type of support within your organisation, see page 26 for sources of advice. Employers must not use a diagnosis of dementia to force someone to leave work, or to automatically exclude them from being recruited.

The effect of an impairment depends on the individual and their circumstances. To accommodate this requires some flexibility. Some employers may wish to consider developing a disability leave policy. Disability

leave is one of a range of possible reasonable adjustments, as well as working from home and flexible working.

### **Things to bear in mind when considering a request for a reasonable adjustment**

- What disadvantage is the person with dementia facing in the workplace, and what is the nature of the adjustment being requested?
- Has expert advice been sought, for example from HR, occupational health, a GP or other specialist, or an Access to Work adviser (See section 'Funding for reasonable adjustments' on page 19 for more information about Access to Work.)
- How effective will the adjustment be in supporting the person with dementia to do their job and prevent them being disadvantaged?
- How practical is it to make the adjustment, for example how long will it take to implement and will additional training be needed for the person with dementia or anyone else?
- What are the financial costs, if any? When assessing whether the cost is 'reasonable', take into account relevant experts' recommendations and the financial and other resources of the employer.
- Is financial or other assistance available to help make an adjustment, such as through Access to Work?
- What, if any, disruption will be caused by making the adjustment?
- What effect, if any, will the adjustment have on other members of staff?
- Would making the particular adjustment result in unacceptable risks to the health and safety of any member of staff (including the member of staff who has dementia)?

- Would making the adjustment reduce a health and safety risk for the member of staff with dementia and/or other staff?

### **Funding for reasonable adjustments**

If there is a cost attached to making a particular adjustment, you could talk to the staff member about applying for funds from Access to Work. Access to Work is a scheme run by Jobcentre Plus that offers assistance to disabled people and those with long-term health problems who are in paid employment or are starting a job.

It provides practical support and funding to meet additional costs associated with overcoming work-related obstacles resulting from a disability or health problem. The member of staff (rather than the organisation) must make the application to Access to Work for assistance.

### **Reviewing reasonable adjustments**

It is important to review reasonable adjustments regularly to make sure that the adjustment is still effective in helping the staff member to carry out their role.

Agree review dates with the member of staff and, where possible, document the meetings. The frequency of these reviews will vary depending upon individual circumstances.

As well as the agreed review dates, you may find that additional reviews are needed in response to a change in the person's circumstances. For example, you may need to review things:

- following a change in the person's role or responsibilities
- following a transfer, promotion or specialist post-selection process
- to access a training event/course
- for probationary performance assessments
- for performance and development reviews

- if the person wants to/is required to participate in a career development scheme, or go to a regional meeting or seminar
- following a change in the individual's condition
- following a period of absence
- following an intense period of rehabilitation or treatment
- if new working practices or technology are implemented in the workplace
- if an aspect of the role or workplace is making the person's condition worse
- during the use of the grievance or disciplinary procedure
- to alleviate the impact of a period of potential stress, for example a restructure
- as a result of an office move or change in the working environment.

### **Redeployment**

You might consider redeployment (moving the person to a new role) if adjustments to their existing role are not possible, or if any adjustments that already been made have been unsuccessful.

When you talk to a member of staff about redeployment, discuss whether any adjustments need to be made to help them carry out the new role. Don't assume that adjustments required by the person for one role will necessarily be required for an alternative role.

## Examples of reasonable adjustments

### Working environment

#### This might include:

- installing soundproofing or visual barriers to minimise distractions
- clear signage to enable the person to find their way around the building
- reorganising the workspace to create a quiet area
- adopting a clear labelling system to help the person organise their work
- planning dementia-friendly meeting spaces.

### Role/working pattern

#### Review the person's current job specification and consider:

- allocating some duties to another person
- transferring the person with dementia to an existing vacant role that they can carry out more easily
- changing the person's working hours. This might include:
  - agreeing a flexible working pattern
  - scheduling duties around the effects of their medication
  - agreeing working hours to accommodate travel requirements
  - altering their working hours to accommodate their symptoms, which might be worse in the mornings or evenings.
- giving the staff member time off during working or training hours for rehabilitation, assessment or treatment.

## Training

### Think about the following ways of ensuring training is accessible:

- allowing additional time for e-learning packages and tailoring training techniques to suit individual needs
- providing extra support during induction training
- providing refresher training if someone is returning to work after a long absence
- ensuring external trainers are flexible and able to accommodate the person's needs
- ensuring that venues, resources, materials, visual aids and mode of delivery are accessible
- acquiring or modifying equipment.
- modifying instructions or reference materials
- modifying procedures for testing or assessment
- providing a reader or interpreter.

## Supervision or other support

### This might involve:

- allocating a mentor for a member of staff whose dementia leads to uncertainty or lack of confidence in the workplace
- holding regular meetings to ensure that reasonable adjustments are still meeting the individual's needs and that colleagues are being supportive
- providing additional support by repeating instructions or providing them in writing
- making the staff member aware of the support available from trade unions, staff associations, occupational health and counselling services, disability support networks and other internal support networks
- holding an awareness session on dementia for colleagues (only with the individual's consent)
- providing additional guidance and supervision, particularly in the short term, if the person is returning to work following a period of absence.

### **Paul, aged 57, Coffee Shop Assistant, Sainsbury's**

Paul has worked at a Sainsbury's coffee shop for the past two years, having gained years of experience in catering when he was younger. He first visited his GP about his symptoms at the end of 2012 and again in March 2013. He was given an MRI scan, consultation, blood tests and various memory tests before receiving a formal diagnosis of dementia in July 2013. Paul kept his employer informed of the situation and also told close colleagues so that they understood why he was making mistakes and taking a long time to learn new things.

'There were occasions when some colleagues would get very impatient or annoyed because I was always asking questions, sometimes the same ones over and over, because I couldn't grasp or remember what they had told me.'

Things improved once his colleagues knew about his diagnosis and Paul feels that he has their support and understanding.

He now carries out basic duties that he can perform confidently, such as washing-up, clearing tables and serving meals. His hours have been changed to fit with his partner's shifts as he is no longer able to drive. He has regular meetings with management to make sure he doesn't have issues and feels his work is recognised.

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

'I feel very fortunate that I have an employer that responds quickly and sympathetically to my situation while balancing the needs of the business – but there is a lot to be done to ensure that employers generally know the steps they should be taking to support their workforce living with dementia.'



**Hilary, aged 55, Head of Business Development and Support, UK Renal Registry**

Hilary has worked at the UK Renal Registry for nearly 11 years, following years of experience in senior management positions. She first noticed symptoms of dementia 15 years ago. Hilary didn't visit the GP until seven years ago and only received a diagnosis of dementia in the last two years after returning to the GP for the third time.

Hilary told her manager about her diagnosis the day after receiving it, although she knew there was no specific HR policy in place to support her intention to remain at work.

'I had been having more noticeable problems at work and I knew he would be supportive, so told him straight away. I was also glad to be able to explain why I was not functioning as well as I had been before.'

As well as informing the staff that she managed, Hilary also told the organisation's trustees. This was to ensure that they were aware of any associated risks, as her role involves HR and finance responsibilities. She wanted the rest of the organisation to be informed a year after her diagnosis.

Apart from stepping back from some line management responsibilities, no further amendments to Hilary's role have been made or needed yet, although she knows that this will change as her dementia progresses. She hopes that policy will be implemented 'that lays the ground rules and framework for continued employment and recognises what it means financially to a person working with dementia.'

**Transition to phase 3**

At some stage, a discussion will begin about the person with dementia leaving work. This could be their choice, or it could be that you are no longer able to make adjustments to keep the person at work. This may be a difficult time, but being honest about options during ongoing management and review will mean the person is better prepared when this stage comes.

You may need to give the person information about where to find advice on their finances and alternative income sources.

Make sure you take advice from HR/ occupational health at every stage if retirement or dismissal due to ill health is likely.

### **Phase 3: Leaving work**

When it becomes clear that a member of staff is no longer able to fulfil their role, support the person to agree a dignified exit package and strategy. The example scenarios at the end of this section may help you to consider suitable responses in this type of situation. You should seek to avoid using capability and disciplinary procedures at this time.

### **Post-employment support**

People with dementia often feel let down by society. People with dementia may find that plans they made for retirement are no longer possible and options are limited.

Find out whether your organisation has opportunities for volunteers that fit with the person's skill set. The person may find it enjoyable and therapeutic to return to aspects of the work and maintain contact with their colleagues in a familiar environment.

If your organisation has a retirement club or retirement activities, encourage them to be as dementia friendly as possible.

## Situation G

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The employee decides to leave.

### Ways to respond

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- Consider discussing a gradual reduction in hours if this is an option, but check whether this will have any pension implications.
- Apply the provisions of an ill health retirement process if appropriate.
- If the person wants one, arrange a leaving celebration.

## Situation H

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You determine that the person's continued employment is not sustainable.

### Ways to respond

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It could be that you are no longer able to make the adjustments that are needed to enable the person to work. This could be a difficult time; honesty about options over a long period of time will ease some of the difficulty.

It is essential to follow your organisation's policies and procedures carefully. Take advice from HR.

## Situation I

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The employee is unfit for work and is unable to make the decision to leave, but their family members are intervening.

### Ways to respond

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If it is apparent that the person has had a rapid decline and you are in touch with family members:

- Identify a key contact in the family and agree a reliable communication process with that person.
- Arrange an occupational health referral.
- Maintain contact with the family and the employee.
- Ensure that the usual welfare arrangements/home visits continue.

If a leaving celebration is inappropriate, send a letter of thanks to the person at their home address to recognise formally their contribution to the business/service.

# 6 Where to find out more

## Useful organisations

The following organisations can offer guidance or resources for you as a manager. You can also use this list to direct a staff member with dementia, or who cares for someone with dementia, towards sources of support and advice.

### ACAS

[www.acas.org.uk](http://www.acas.org.uk)

### Age UK

[www.ageuk.org.uk](http://www.ageuk.org.uk)

### Alzheimer's Scotland

[www.alzscot.org](http://www.alzscot.org)

### Alzheimer Society

[alzheimers.org.uk](http://alzheimers.org.uk)

### Business Disability Forum

[www.businessdisabilityforum.org.uk](http://www.businessdisabilityforum.org.uk)

### Carers Trust

[www.carers.org](http://www.carers.org)

### Carers UK/Employers for Carers

[www.carersuk.org](http://www.carersuk.org)

### CIPD (Chartered Institute of Personnel and Development)

[www.cipd.co.uk](http://www.cipd.co.uk)

### Citizens Advice Bureau

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

### Dementia Action Alliance

[www.dementiaaction.org.uk](http://www.dementiaaction.org.uk)

### Dementia Friends

[www.dementiafriends.org.uk](http://www.dementiafriends.org.uk)

### Dementia Services Development Centre

[www.dementia.stir.ac.uk](http://www.dementia.stir.ac.uk)

### Dementia UK

[www.dementiauk.org](http://www.dementiauk.org)

### Department for Work and Pensions

[www.gov.uk/government/organisations/department-for-work-pensions](http://www.gov.uk/government/organisations/department-for-work-pensions)

### Frontotemporal Dementia Support Group

[www.ftdsg.org](http://www.ftdsg.org)

### Inclusive Employers

[www.inclusiveemployers.co.uk](http://www.inclusiveemployers.co.uk)

### Lewy Body Society

[www.lewybody.org](http://www.lewybody.org)

### Local Government Association

[www.local.gov.uk](http://www.local.gov.uk)

### Public Health England

[www.gov.uk/government/organisations/public-health-england](http://www.gov.uk/government/organisations/public-health-england)

### Young Dementia UK

[www.youngdementiauk.org](http://www.youngdementiauk.org)

## Useful resources

Dementia Engagement and Empowerment Project (DEEP) produces a series of guides for organisations and communities who want to work well with people with dementia and support their involvement. These include titles such as Dementia-friendly tips for employers, Choosing a dementia-friendly meeting space and Involving people with dementia at conferences and events.

They are available from DEEP at  
**[www.dementiavoices.org.uk/  
resources/deep-guides/](http://www.dementiavoices.org.uk/resources/deep-guides/)**





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

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

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

T [020 7423 3500](tel:02074233500)  
E [info@alzheimers.org.uk](mailto:info@alzheimers.org.uk)  
[alzheimers.org.uk](http://alzheimers.org.uk)

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