



Dementia and the workplace

A guide for employers
in Scotland



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This information has been prepared by the Early Stage Dementia project, which is funded by the Life Changes Trust to support the charity in raising awareness of early stage dementia and promoting the impact healthy active ageing can have on reducing the risk of dementia.

This guide contains general advice only which we hope will be of use to you. Nothing in this guide should be construed as the giving of specific advice and should not be relied on as a basis for any decision or action. Age Scotland does not accept any liability arising from its use.

We aim to ensure that the information is as up to date and accurate as possible, but please be aware that certain areas are subject to change from time to time. Please note that the inclusion of named agencies, companies, products, services or publications in this guide does not constitute a recommendation or endorsement by Age Scotland.

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Introduction

Dementia is the umbrella term for a group of illnesses that cause damage to the brain and its functions; including thinking, memory and communication. Around 90,000 people in Scotland today are living with dementia, and its incidence is rising steeply as the population ages.

Dementia is a workplace issue.

It is often thought of as something which affects people who have retired. However with state pension age rising and abolition of the default retirement age people will increasingly experience the first symptoms of dementia while at work. Also, many employees juggle work with caring for a family member or friend who has dementia.

Surveys show that people would often be reluctant to tell their employer if they were diagnosed with dementia. They are also far less likely to seek medical advice for problems with thinking, memory and communication than for physical symptoms. It is possible to live well, and work well, with dementia – but both employers and employees need to acknowledge the issue, and approach it in the right way, for that to happen.

This guide explains how dementia can affect the workplace and what employers can do to minimise the risk of dementia adversely affecting their workforce and business. It also sets out what they must and should do with regard to an employee who is living with dementia, or who is caring for someone with dementia.

Dementia is a workplace issue: the case in numbers

12%

^{*1} Proportion of people with
dementia in the UK who are

UNDER AGE 70

18%

^{*2} People under age 65 with
dementia in the UK who

**CONTINUE
IN WORK**

after receiving
a diagnosis

93%

^{*4} **WORKING
CARERS**

in the UK who report that
looking after someone with

**DEMENTIA
has affected their
CAPACITY
TO WORK**

£22.7BN

^{*5} **PREDICTED
SPENDING
POWER**

of households affected by
dementia in the UK by 2030



Adults in Scotland
who have given

**REGULAR CARE
TO SOMEONE
WITH DEMENTIA**

19% ^{*3}

39% ^{*3}

People in Scotland who

**WOULD NOT WANT
THEIR EMPLOYER
TO KNOW**

if they were diagnosed
with dementia.

90,000 ^{*6}
**PEOPLE IN
SCOTLAND
WITH DEMENTIA**

X2 ^{*7} 
Predicted increase in
**DEMENTIA
IN SCOTLAND
BETWEEN
2011 & 2031**



Five facts workplaces should know about dementia



Memory loss is not always the first sign of dementia

There are around 100 types of dementia. Memory loss is a symptom common to the early stages of many. But with some the first signs are different, for example changes in behaviour.

Compulsiveness
Forgetfulness **Losing thread**
Hard to plan or decide
Misjudging depth and distance
Appetite changes
Alertness fluctuations
Slower movement
Apathy **Poor balance** **Mood swings**
Less fluent speech **Sleep problems**



What looks like dementia may be something else

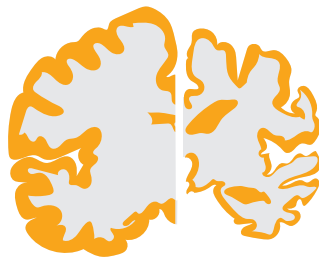
Early stage dementia has symptoms in common with other conditions, including stress and depression. Many causes of problems with memory, communication and thinking can be treated very effectively, and sometimes reversed.

Depression
Menopause **Anxiety**
Stroke **Medications**
Lack of sleep
Nutritional deficiencies
Epilepsy **Dementia**
Head injury
Stress related illness
Infections **Underactive thyroid**



Dementia is not a natural part of ageing

As brains age there is inevitably some change in thinking abilities. Dementia is far more severe, gets progressively worse, and is ultimately terminal.



Healthy

Alzheimer's



Diagnosing dementia can be a slow process

Other possible causes of symptoms need to be ruled out. Typically a GP will refer to specialists for further tests. It can take months, sometimes years, to confirm a diagnosis. The diagnosis rate in Scotland is estimated to be 65 percent.



A dementia diagnosis is worth getting

A timely diagnosis allows for early treatment and support that can enable someone to live well, and work well, with dementia: potentially for years to come. In Scotland there is an entitlement to at least one year of support after diagnosis coordinated by a dementia link worker or Community Psychiatric Nurse.

“[Getting a diagnosis] was a relief ... with all the ‘not remembering’ I knew there was something wrong.”

Myra, office manager

*8

Dementia and the law

The main legislation that applies where dementia affects a workplace is the Equality Act 2010.

The Act sets out nine ‘protected characteristics.’ Unfairly discriminating against an employee on the basis of one or more of these is unlawful.

Disability is a protected characteristic. It is defined as a ‘physical or mental impairment that has a substantial and long-term adverse effect on someone’s ability to carry out normal day-to-day activities.’ Dementia matches the disability definition. Because it’s a progressive disability the Act treats it as having a substantial adverse affect as soon as it has some impact on a person’s ability to carry out normal day to day activities.

There is no limit to compensation that can be claimed under the Act. It applies to organisations of every kind and every size.

The Act also protects against discrimination that takes place because of who someone thinks you are, or because of someone you’re associated with. So, for example, unfair discrimination against an employee because they are caring for someone with dementia will be unlawful.

Protection from discrimination extends to agency workers, casual workers, zero hours workers and, in some situations, self-employed workers. It doesn’t depend on the existence of a written contract. It applies so long as someone has agreed to personally do work for an employer in exchange for pay. Where one worker is discriminatory toward another because of a disability, the employer can be liable under the Act.

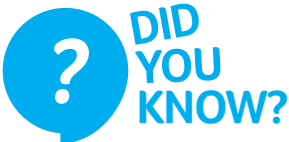


○ TYPES OF DISCRIMINATION

- **DIRECT:** Where a person is treated differently and worse than someone else without justification.
- **INDIRECT:** Where a practice, policy or rule is applied equally, but because someone has a protected characteristic it has a different, and worse, effect on them. However if an employer can prove there's a good reason for the practice, policy or rule they will not be liable
- **ARISING FROM DISABILITY:** Where someone is treated unfairly because of something connected to a disability, rather than the disability itself.
- **HARASSMENT:** Where unwanted behaviour offends someone or makes them feel intimidated or humiliated.
- **VICTIMISATION:** Where someone is treated badly because they complain about discrimination or help someone who has been discriminated against.

○ EQUALITY ACT 2010 PROTECTED CHARACTERISTICS

- AGE ■ RACE ■ SEX ■ SEXUAL ORIENTATION
- DISABILITY ■ RELIGION OR BELIEF
- GENDER REASSIGNMENT ■ PREGNANCY OR NEW BABY
- MARRIAGE OR CIVIL PARTNERSHIP



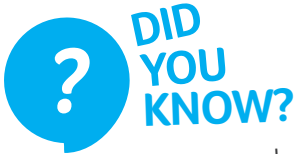
Under the Equality Act 2010 being unaware of an employee's disability does not necessarily excuse an employer. A tribunal may take a view that they could have been reasonably expected to know, in which case they may be held liable for unfair discrimination.

Steps to make your organisation dementia ready

1. Foster an open and supportive working culture

So that should an employee experience problems with memory, thinking or communication, they are likely to both tell you and seek medical advice.

Dementia shouldn't be taboo. Encourage conversation about it so that myths and stigma can be dispelled. Send a clear message that anyone with a problem related to dementia will be shown compassion, not the door.



In general employees are not obliged to tell their employer if they are diagnosed with dementia. The exception is if they are in the armed forces, or work on a plane or a ship, in which case the law requires that they tell their employer if they receive a dementia diagnosis.

49% ^{*9}

People who feared they would be considered mad if they had dementia.

**“I received
no counselling,
no transition from
work to retirement
due to disabilities.
No leaving party.”**

Agnes Houston,
Campaigner



2. Encourage healthy working lifestyles

Many of the risk factors associated with dementia are related to lifestyle. These include: lack of exercise, type 2 diabetes, smoking, alcohol misuse, high blood pressure and obesity.

Look at what you, as an employer, can do to support your employees to adopt and enjoy lifestyles – within and outside of work – that minimise the risk.

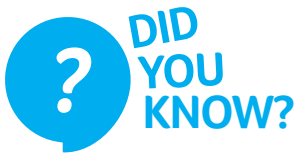
WEEKLY EXERCISE RECOMMENDATIONS (AGE 19 TO 64) *10

150 MINS: fast walking / moderate aerobic activity

OR 75 MINS: running / other vigorous aerobic activity

OR 90 MINS: one vigorous AND two moderate 30 minute bouts of activity

AND 2 DAYS: minimum on which you do activities that strengthen major muscle groups (lifting, gardening, dancing, yoga, weights)



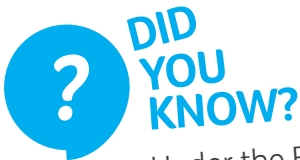
Research suggests being seated for long periods increases your risk of bad health, including dementia. Experts recommend getting up and moving for a couple of minutes every 30-45 minutes. The damage of a sedentary working day isn't undone by exercising before or after work.

3. Become a ‘carer friendly’ employer

Employees who are caring for someone who is living with dementia will need, and are entitled to, flexibility and support - and an appreciation, by you, that the demands on them will increase as the dementia progresses.

○ WHAT WORKING CARERS WANT ²⁴

- FLEXIBLE AND SPECIAL ARRANGEMENTS FOR CARING LEAVE
- PUBLICITY ABOUT AND RECOGNITION OF CARERS IN THE WORKPLACE SO THAT THEY WOULD FEEL ABLE TO ASK FOR HELP
- MORE FLEXIBLE ARRANGEMENTS FOR WORKING HOURS AND PATTERNS, INCLUDING REMOTE WORKING
- INFORMATION ABOUT SUPPORT AVAILABLE TO DEMENTIA CARERS
- OPPORTUNITIES TO LINK WITH OTHER EMPLOYEES IN A SIMILAR SITUATION
- EMERGENCY OR BACK-UP CARE OR SUPPORT ARRANGED BY THEIR EMPLOYER
- SUPPORT FOR REDUCING STRESS AND IMPROVING THEIR OWN WELLBEING



Under the Equality Act 2010 employees living with, or caring for someone who has, dementia have the right to request flexible working from their first day in post, and as many times as they need to each year.



Employers for Carers
www.employersforcarers.org

Carer Positive
www.carerpositive.org

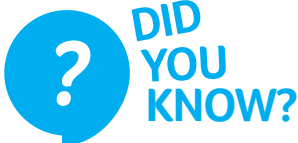


4. Make preparatory changes for people living with dementia

Things that can be helpful for an employee with early stage dementia, for example well structured, clear and jargon-free internal communications, often benefit everyone. If you introduce dementia aware practices now your organisation won't be caught off-guard as and when dementia becomes a live issue. Such improvements often require forethought or a change in habits rather than money.

For people with dementia the physical environment can either enable or further disable them. Design features which help them make sense of the world are not necessarily expensive, particularly where part of an initial build or scheduled refurbishment. These can include: good lighting; features that reduce noise such as carpets; and use of floor layout, signage and decor to make routes and facilities obvious.

This approach can be applied to changes to assist customers with dementia. Pricing, for example, could be kept simple to minimise potential for difficulty with handling money.



Under the Equality Act 2010 providers of goods and services to the public are required to anticipate and make reasonable adjustments for disabled customers.



**WHO
CAN
HELP?**

Dementia Services Development Centre

Consultancy and training on making buildings and spaces dementia friendly.

www.dementia.stir.ac.uk

5. Apply HR good practice to everyone

An employer that ensures all staff have regular supervision and an annual appraisal will be better placed to identify difficulties a staff member is experiencing because of early stage dementia, or any other form of cognitive impairment.

However one survey found that less than half of workers aged over 65 received formal performance appraisals as compared to almost two thirds of all employees. [*11]



CIPD

(Chartered Institute of Personnel and Development)

The professional body for HR and people development.

www.cipd.co.uk

**I started
recognising that I
wasn't quite as sparky
as I once was. That's all I
put it down to – just a
dulling of the senses.**

John, journalist

*8



Spotting the signs, taking the right action

Intervening

Deciding how and when to intervene when an employee shows signs that could be dementia can be complex. Move with as much caution as the situation allows: although if there is a health and safety risk that should be as soon as possible.

When the time is right, have a one to one meeting with the employee. Show empathy. A person with early stage dementia may not be aware that there is a problem, so tact and sensitivity will be essential. If they are aware that could mean that they are anxious and worried.

GETTING READY FOR A MEETING

- ✓ **READ RELEVANT HR POLICIES**
- ✓ **SPEAK TO HR AND OCCUPATIONAL HEALTH COLLEAGUES (IF AVAILABLE)**
- ✓ **HAVE A CLEAR IDEA WHAT OUTCOME YOU WANT**
- ✓ **IDENTIFY A QUIET AND PRIVATE MEETING SPACE**
- ✓ **ALLOW TIME SO THE CONVERSATION ISN'T RUSHED**
- ✓ **START THE CONVERSATION WITH A FRIENDLY ENQUIRY, E.G. "HOW THINGS ARE WITH YOU?"**
- ✓ **CONSIDER HOW YOU WILL BROACH THE SUBJECT, E.G. "HAVE YOU NOTICED ANY CHANGES IN YOURSELF?"**



**WHO
CAN
HELP?**


Healthy Working Lives

www.healthyworkinglives.com

Fit for Work Scotland

www.FitforWorkScotland.scot

Don't put pressure on an employee to go on immediate sickness absence as this can undermine self-confidence and make it harder for them to continue in employment. It's not the place of a line manager to speculate as to diagnosis. However a good outcome might be that the employee agrees to see their GP or occupational health.



**DID
YOU
KNOW?**

Dementia can impair the ability to understand or express language. When communicating with someone who may have dementia speak slowly and clearly, listen carefully, be patient and be aware of what you are saying through your body language.

**I've
definitely noticed
a difference since he
went back to work. The
jumbling up of words isn't
so bad. He's a lot cheerier
and more talkative.**

Wife of Joe,
a handy-man

*8

Making adjustments

Employers have a duty under the Equality Act 2010 to make reasonable adjustments for an employee with dementia. These should address symptoms that disadvantage the employee in the workplace. What's 'reasonable' will depend on the size and resources of the organisation, and how practical and effective the adjustments would be.

If costs are incurred these can't be passed to the employee.

An employer may need to make changes to how things are done at work - its policies and procedures. Physical changes to the workplace may be necessary, for example to improve lighting and layout. It may need to provide extra aids or support.

The starting point for identifying adjustments is to talk to the employee. Look together at their job description. What can they still do, with or without support? Are there safety-critical, or people management aspects, that may need to stop? If changes to working hours, or their level of responsibility, are being considered there may be financial implications for the employee that should be discussed.

If he or she is finding it more difficult to learn new things moving to another job, even a less challenging one, could be counterproductive.

SOME ADJUSTMENT POSSIBILITIES

- Better lit environment
- Noise reduction
- Calendars, checklists, reminders
- Quality checking system
- Some duties reallocated
- Changes to start/finish times
- Reduction in hours
- Homeworking
- Time off for check-ups and treatment
- Extra or tailored briefings
- Support from a 'buddy'
- Mentoring or counselling support

Managing over time

Receiving a diagnosis for dementia can be very difficult emotionally. Be supportive and let the employee know that they are valued. Make a plan together that includes:

- What the employee wants
- Your needs as an employer
- Adjustments that you've agreed
- People involved in supporting him or her in work
- Any arrangements for informing colleagues of the diagnosis
- A schedule setting out when and how the situation will be reviewed

Research has suggested that whether or not someone is able to keep working after diagnosis depends on factors including: their stage of dementia, the level of insight they have into their own symptoms, and the strength of their support network in and outside of work. ^[*8] Consider what you as an employer can do to support the development of such a network.

Be aware that adjustments for an employee can sometimes have an impact on their co-workers. Supportive colleagues can be a huge asset for enabling someone to stay in employment.

However it's possible that some may, for example, be annoyed at having to take on additional duties. It may be necessary to look at their job descriptions, and whether some of the adjustments you are making could be learning or development opportunities for them.

Continuing in work is not always a realistic option. Even if it is now, eventually it won't be: dementia is progressive so an employee's capabilities will inevitably decline. When that time comes make your employee's leaving as positive as it can be.

He or she may need information about benefits and pensions, and support to complete any paperwork associated with these. They may be feeling anxious about loss of their work identity and work's social aspects. When they leave consider how you might recognise, and if appropriate celebrate, their contribution.



Access to Work

Grants for workplace disability adjustments.

www.gov.uk/access-to-work

Alzheimer's Scotland

Information on dementia including post-diagnosis support.

www.alzscot.org.uk

Age Scotland Helpline

Later life information and advice including benefits checks.

0800 12 44 222

Now & Next

Workshops to support employees in planning ahead in the later stages of their career.

www.nowandnext.scot

Healthy working lives

www.healthyworkinglives.com

Working Health Services Scotland

0800 019 2211

Fit for Work Scotland

www.FitforWorkScotland.scot

ACAS

www.acas.org.uk

Federation of Small Businesses

www.fsb.org.uk

**“Now we
have a Health
Passport, which means
they can't throw new
stuff at him and expect
him to do it.”**

Wife of employee
with dementia

*8

ACTION PLAN

The HR officer

Promote: Ensure all staff are aware of existing policies that benefit people with disabilities and carers.

Review: Check your policies and procedures to ensure they will enable you to respond to employees with dementia, and carers, effectively, fairly and legally.

Proof: When introducing or reviewing systems or processes think about whether these could potentially disadvantage a worker who has dementia, for example electronic pay slips.

Support: Be proactive in encouraging healthy working lives that reduce the risk of dementia. Support discussion of and information about dementia and carers in the workplace.





ACTION PLAN

The manager

Pre-empt: Instigate changes to working culture and practice that will be helpful should dementia become a live workplace issue, for example improving internal communications.

Develop: Look at how products and services could be made more accessible to people living with dementia. Areas to look at include premises, pricing, publications and staff training.

Respond: If a regular customer or client shows signs of dementia ensure as far as possible that they are served by the same member of staff each time.

ACTION PLAN

The customer-facing employee

Respect: You won't necessarily be able to tell who has dementia, so make 'dementia friendly' your default mode. Speak clearly and calmly, and be friendly and patient, with everyone.

Respond: If a customer seems forgetful or confused, ask how you can help. They might, for example, welcome:

- Some suggested options if they are struggling to choose
- Help with handling money
- Help to find their way around – with clear directions or even a simple map
- A quiet and well-lit environment where they can hear you properly and see your face clearly.



DID YOU KNOW?

Some people with dementia carry a help card so that they can discreetly ask for your understanding. It may simply say that they have a problem with their memory.



ACTION PLAN

Every staff member

Act: If you notice a colleague is struggling with thinking, memory or communication, speak in confidence to your manager or HR team. It may not be dementia. But if it is, ignoring, resenting or covering up declining performance won't help in the long run.

Talk: It's good to speak openly about dementia. When you do, think about words you use. Many people with dementia say that they feel stigmatised when referred to as 'suffering' or being in 'misery.'

Change: Look at your own lifestyle - is there anything you could change to reduce the risk of dementia?

Prepare: Take precautions, whatever your age. Make a will. Arrange a Power of Attorney - so that should you ever become unable to take important decisions, because of dementia or any other reason, someone you trust will be legally able to step in.



**WHO
CAN
HELP?**

Age Scotland Helpline

Later life information including
on Power of Attorney

0800 12 44 222

www.agescotland.org.uk/poa

Smokeline 0800 84 84 84

www.canstopsmoking.com

Drinkline 0300 123 1110

www.drinksarter.org

NHS Inform 0800 22 44 88

(fitness and diet advice)

Active Scotland

www.activescotland.org.uk

Take on life

www.takelifeon.co.uk

ACTION PLAN

The trade union representative

Spot: Be alert to the possibility of dementia when investigating capability and misconduct cases.

Support: Encourage members to seek medical advice when action is being taken against them, should they be showing uncharacteristic difficulty with thinking, communication or memory.

Collaborate: Work with employers and occupational health providers to develop strategies and policies that:

- Support adjustments for workers with dementia,
- Support staff who care for family members or friends living with dementia
- Make your workplace more dementia aware.



STUC (Scottish Trades Union Congress)

The STUC Disabled Workers' Committee carries out a range of work to tackle discrimination against disabled people in and out-with the workplace.

www.stuc.org.uk



ACTION PLAN

The Occupational Health professional

Know: Familiarise yourself with the signs, symptoms and progression of different types of dementia.

Connect: A range of health care professionals can contribute to vocational rehabilitation and supporting an employee with early stage dementia in work. These include Occupational Therapists and Speech and Language Therapists.



**WHO
CAN
HELP?**

Alzheimer's Scotland

Information on dementia including post-diagnosis support available in Scotland.

www.alzscot.org.uk

Alzheimer's Society

Information on dementia.

www.alzheimers.org.uk

Further information and support

Age Scotland

The Age Scotland helpline provides information, friendship and advice to older people, their relatives and carers.

Age Scotland helpline: 0800 12 44 222
www.agescotland.org.uk

Access to Work

Grants for practical support if an employee has a disability, health or mental health condition up to a maximum of £40,800 per year.

0345 268 8489
www.gov.uk/access-to-work

Advisory, Conciliation and Arbitration Service (ACAS)

Information, advice, training, conciliation and other services for employers and employees to help prevent or resolve workplace problems.

0300 123 1100
www.acas.org.uk

Alzheimer's Scotland

Information on dementia including post-diagnosis support.

0808 808 3000
www.alzscot.org

Alzheimer Scotland Centre for Policy and Practice at University of West of Scotland

A centre of excellence advancing dementia policy and practice.

01698283100
www.uws.ac.uk/ascpp



Carer Positive

An award recognising employers for support that they give to employees who are carers.

www.carerpositive.org

CIPD (Chartered Institute of Personnel and Development)

The professional body for HR and people development.

020 8612 6200

www.cipd.co.uk

Dementia Services Development Centre

An international centre of knowledge and expertise.

01786 467740

www.dementia.stir.ac.uk

Employers for Carers

A membership forum for employers committed to working carers. It offers resources, networking facilities, model policies, case studies, training and consultancy.

020 7378 4956

www.employersforcarers.org

Federation of Small Businesses

A membership body offering services including advice, financial expertise, support and a voice in government.

0808 20 20 888

www.fsb.org.uk

Fit for Work Scotland

Free, confidential and impartial advice to employees, employers, and GPs, to help people return to, and stay in, work after a period of sickness absence.

0800 019 2211

www.FitforWorkScotland.scot

Healthy Working Lives

Free occupational health and safety advice for employers in Scotland covering a range of health and safety issues.

0800 019 2211

www.healthyworkinglives.com

STUC

Scottish Trades Union Congress.

T. 0141 337 8100

W. www.stuc.org.uk

Working Health Services Scotland

An NHS service assisting the self-employed and employees of small enterprises (less than 50 staff) who experience injury or ill health and have difficulty remaining at work.

0800 019 2211

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0333 323 2400
info@agescotland.org.uk
www.agescotland.org.uk

Age Scotland helpline
0800 12 44 222

Age Scotland Enterprises
0800 456 1137 (Edinburgh)
0800 500 3159 (Glasgow)



www.facebook.com/agescotland



www.twitter.com/agescotland



www.youtube.com/agescotland