Tips for employers who want to be more dementia friendly

Key messages

- Many people are now working until later in life. Age is the main risk factor for dementia.
- People are being diagnosed at a much earlier stage in their dementia, while they may still be in employment and coping at work.
- Many employers want to do the right thing if people who work for them develop dementia.

People are being diagnosed with dementia at a much earlier stage, when they are relatively young. Many people with a very early diagnosis may still be functioning well and will be able to cope at work with relatively few changes. But they will need more support as their condition develops.

The Equalities Act 2010 should safeguard those diagnosed with dementia against unfair treatment at work. Employers must demonstrate they have made reasonable adjustments to enable people who develop dementia to continue to work.

This document discusses some of the issues related to employment and dementia and highlights ways in which employers can become more dementia friendly.

Openness about dementia

The stigma associated with dementia often stops people from talking or thinking about the condition.
People may be afraid to tell work colleagues or managers what they are experiencing.

People may fear that the response from their employers will be entirely negative and unsupportive.

People may want to try to carry on as normal.

Sometimes, colleagues may realise something is wrong and cover for the person. However, even then, the stigma surrounding dementia often means that they do not discuss what’s going on with the person involved.

How employers can help:

• Consider running awareness-raising activities on dementia in the workplace.

• Create an environment where staff can talk about dementia.

• Make sure staff know who to turn to for advice and support inside and outside the organisation.

• Include dementia-related information on staff noticeboards, in staff newsletters and in reading areas.

Getting a diagnosis

Because dementia is more typically associated with older age, many people who are working will not immediately associate the symptoms they are experiencing with dementia. Doctors also may not immediately test for dementia in younger people.

People who develop dementia while working, irrespective of their age, often fear going to their GP to get a diagnosis because they feel they have everything to lose.

Even after someone has approached their doctor, getting a diagnosis of dementia can be a long and complicated process.

People may not want to discuss the possibility of a diagnosis of dementia with their employer while they are going through this process.

How employers can help:

• Have clear and open policies about how your organisation will support people who develop dementia.
• Tell the person with dementia about any organisational requirements or procedures they need to follow.

• Encourage staff to be aware of the symptoms of dementia and how they might affect their work.

• Be flexible, understanding and compassionate about employees needing to attend medical appointments.

Adjusting to dementia

Getting a diagnosis of dementia can be a traumatic, confusing and isolating experience for those affected and for their families and friends.

People will need time to adjust to the diagnosis. Their lives will be changing in many ways.

Dementia is likely to affect the person’s ability to do certain tasks – and this may increase over time. However, many skills and abilities are retained, often for a considerable time.

How employers can help:

• Be flexible and use the skills of the individuals involved – adjust certain parts of the job where necessary.

• Make sure the person knows that their skills and experience are still valued.

• Encourage dialogue and a culture of honesty.

• Reassure staff that the organisation will support them where they can.

• Work with others, such as occupational health services or local memory services, to develop ways of supporting staff members affected by dementia.

• Carry out risk assessments that focus on supporting the person to stay in work in the short term.

• Acknowledge that supporting people may take time and resources – people may need practical and emotional support.

• Review the situation frequently with the staff member.

• Be honest about your concerns and the adjustments you can reasonably make.
Retirement

Dementia is a progressive condition. In many situations, it may not be not be possible or desirable for people with dementia to continue in employment.

However, retirement can be a daunting prospect for those who are not prepared for it.

*How employers can help:*

• Support people to retire in a gradual way – perhaps by reducing hours at work over a period of time.

Support after retirement

People with dementia often feel as if society has left them on the ‘scrapheap’.

Going from a busy working life to not working is even more difficult with a diagnosis of dementia.

Retirement when you have dementia may mean that plans do not happen and options are limited.

*How employers can help:*

• Encourage retirement clubs and activities supported by the organisation to be as dementia friendly as possible.

• Offer or signpost to specific advice on living with dementia.