Raising Awareness of Dementia in the Workplace ~ Employer Toolkit
WHAT IS DEMENTIA?

Dementia describes different brain disorders that trigger a loss of brain function. These conditions are all progressive and eventually severe.

- Alzheimer’s disease is the most common type of dementia, affecting 62% of those diagnosed.

- Other types of dementia include:
  - vascular dementia affecting 17% of those diagnosed
  - mixed dementia affecting 10% of those diagnosed
  - frontotemporal dementia is more common in younger adults aged under 65

- Dementia is one of the main causes of disability later in life, ahead of cancer, cardiovascular disease and stroke.

- Symptoms of dementia include memory loss, in particular short term; confusion and problems with speech and understanding.

Source: The Alzheimer’s Society

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Raising Awareness of Dementia in the Workplace

KEY ISSUES

- Employers have a duty to support staff under the Equality Act 2010, which recognises dementia as a disability.

- With the removal of the default retirement age and the changes in pension arrangements, many people are now working until later in life.

- Age is the main risk factor for dementia however it can affect anyone below the age of 65.

- People aged over 50 fear dementia far more than cancer or heart disease.

- Unhealthy lifestyles are associated with an increased risk of dementia.

- Most people are not aware of the association between healthier lifestyles and reduced risk of dementia.

- People are now being diagnosed at a much earlier stage of their illness, with many of these still in work across all employment sectors.

Source: The Alzheimer’s Society
Why is dementia important for all employers?

From the shop floor to boardrooms, dementia affects every workplace. Current dementia prevalence data estimates that 850,000 people in the UK will be living with dementia by 2015 and this number is expected to rise to 1 million by 2025 and 2 million by 2051. It is predicted that the cost of skills and experience lost from the workforce due to dementia will rise from £628 million to £1.16 billion in this timeframe. At the same time, dementia caring obligations will cost employers more that £3 billion by 2030, with the impact of dementia on workers reducing hours, changing work patterns, struggling with their own health or leaving their roles due to the demands of caring. The economic impact of dementia in the UK equates to £32,250 per person, a total cost of £26.3 billion.

Source – Alzheimer’s Society, Dementia UK Second Edition 2014

- 10% of the workforce is aged 65 plus and this number is growing
- 12% of people caring for someone with dementia give up work
- Of 550,000 carers of people with dementia, over 225,000 are at work

Source - Centre for Economics and Business Research, The Economic Cost of Dementia to English Businesses.

As our society ages, the fear of developing dementia is increasing. Recent research has shown that:-

- Older people are more fearful of developing dementia than they are of cancer.
- Two-thirds of people over the age of 50 fear that they will develop the condition while just one in ten said they were frightened about getting cancer.
- When 500 adults aged over 50 from across the UK were asked which condition they feared the most, 68% said dementia and 9.44% said cancer.

Source Saga Poll 2014

People are being diagnosed with dementia at a much earlier stage, when they are relatively young. Currently there are over 40,000 people under the age of 65 living with early onset dementia (Alzheimer’s Society Dementia UK Second Edition 2014). Many with a very early diagnosis may still be functioning well across a whole range of employment sectors and will be able to cope at work with relatively few changes. They will however need more support as their condition deteriorates.

Under the Equality Act 2010, employers have a duty to safeguard staff against unfair treatment at work. Employers must demonstrate that they have made reasonable adjustments to enable people who develop dementia to continue in work.

Two thirds of those with dementia live in the community and the value of the ‘dementia pound’, i.e. the spending power of households affected by dementia, is set to double to £22.7 billion by 2030 due to the rise in the numbers affected by the condition.

This toolkit has drawn on recent research and good practice to highlight ways in which employers can become more dementia friendly.
Information for employers/managers relating to staff that develop dementia

1. Being open about health, including dementia

Ensure that employee health and wellbeing is a recognised part of the organisational culture. Make this explicit by signing up to Government supported initiatives such as the Public Health Responsibility Deal, which helps employers to support staff to make informed, balanced choices that will help them lead healthier lives. For more information visit: https://responsibilitydeal.dh.gov.uk

Encourage all staff over the age of 40 to get an NHS Health Check – a free midlife MOT. For adults in England aged 40-74 without a pre-existing condition, it checks circulatory and vascular health and what the risk is of developing heart disease, stroke, type 2 diabetes, kidney disease and certain types of dementia. It also includes information and advice on risk reduction through:

- Maintaining a healthy weight
- Being physically active
- Eating a healthy and balanced diet
- Stopping smoking
- Cutting down on alcohol
- Being aware of family medical history

http://www.nhs.uk/Conditions/nhs-health-check

Encourage staff to request access to self-directed screening tools and checks as part of their monitoring of lifestyle and health conditions that may be available through their GP.

Be approachable and knowledgeable about health issues, including dementia, as people may be afraid to tell colleagues or line managers what they are experiencing as they may fear that the response will be negative and unsupportive. The staff member may want to carry on as normal. Equally colleagues may have realised and be supporting the person, however, often without discussion of what’s going on or any advice on how best to help them.

How you as the employer can help:

- Create an environment where staff can talk about their health, including dementia.
- Make sure that staff know how to seek advice from their GP in the first instance and are aware of other sources of information.
- Be aware of early warning signs of dementia i.e. forgetting instructions, tasks, appointments; decreased ability to plan and organise; unable to complete routine tasks; feeling stressed/overwhelmed.
- Consider encouraging staff to become a Dementia Friend by attending a free awareness raising session. They could then move onto becoming a Dementia Friends Champion which will equip them with the tools and resources to run an information session in your workplace. https://www.dementiafriends.org.uk/
- Include dementia information on staff intranets, notice boards, newsletters.
2. Getting a Diagnosis

Because dementia is typically associated with older age, many people who are in employment will not typically associate the symptoms they have with those of dementia. People may assume that their concentration and memory loss is the result of stress, anxiety and depression and they put off going to their doctor for fear of getting a diagnosis which will change their life. Health professionals such as GP’s may also not immediately recognise and test for dementia in younger people and getting a confirmed diagnosis can be a lengthy process.

Staff in this situation may not want to discuss their health condition whilst they are getting a confirmed diagnosis.

Be aware of and promote the advantages of an early diagnosis i.e. medication can be taken sooner to slow progress and maintain skills; the opportunity to plan and discuss wishes with family members whilst mentally capable; opportunity to learn how to cope whilst still able; time to adjust to the diagnosis.

How you as the employer can help:

- Have clear and accessible policies about how your organisation will support people who develop dementia.
- Inform the staff member about any organisational requirements of procedures that they need to follow.
- Encourage other staff to be aware of the symptoms and how they might affect work by attending Dementia Friends Training.
- Be flexible and understanding about the staff member’s need to attend medical appointments.

3. Adjusting to dementia

Getting a confirmed diagnosis can be a traumatic, confusing and isolating experience for those affected and for their families and friends. Everyone will need time to adjust to this diagnosis and the fact that their lives will be changing in many ways.

Dementia is likely to affect the staff member’s ability to do certain tasks and this may well increase over time. However, many skills and abilities are retained, often for a considerable time. People can be helped to adopt compensatory techniques to maintain their skills by using memory strategies and grading and adapting tasks. Financial support may also be available through the Government Access to Work scheme.
4. Moving towards retirement

Dementia is a progressive condition and in many situations, it may not be possible or desirable for people with dementia to continue in employment. However retirement can be a frightening prospect for staff members and their families if they are not prepared for it.

How you as the employer can help:

- Ensure that the employee knows what their rights at work are under the Equality Act 2010.
- Be flexible and continue to use the skills of the staff member by making reasonable adjustments – adjust certain parts of the job where necessary e.g. nominate a note taker; put requests in writing as opposed to verbal; put in place a buddy system; help with transport to/from work; change in role/workload; reduction in working hours.
- Carry out risk assessments that focus on supporting the staff member to stay in work in the short term.
- Make sure that the staff member knows that their skills and experience are of value and that the organisation will support them where they can.
- Encourage dialogue and honesty.
- Work with other support services such as Working Age/Young Onset Dementia Services, specialist health and work services, occupational therapists, occupational health services to assist both employees and managers to retain work skills for as long as practicable, adjusting the work environment.
- Encourage the staff member to contact Access to Work https://www.gov.uk/access-to-work/overview for possible financial help to pay for practical support to stay in work such as support workers/buddy system, transport to/from work, etc.
- Agree with the employee how a confirmed diagnosis is to be communicated.
- Recognise that supporting staff may take time and resources – people are likely to need practical and emotional support.
- Review how things are working frequently.
- Be honest about your concerns and the adjustments that you can reasonably make.
- Recognise that the staff member will be worried about their job security and financial position.
- Include information on local sources of financial advice such as Citizens Advice Bureau.
5. Support after retirement

Going from a busy working life to retirement is a challenge - with a diagnosis of dementia, this is even more difficult for the individual and their family/friends, with the consequent adjustments to individual plans.

How you as the employer can help:

- Make sure all communications are as clear as possible.
- Wherever possible, support staff to retire in a gradual way – reducing hours at work over an agreed period of time.
- Encourage staff to seek advice about retirement, including the financial and social impact.
- Consider offering pre-retirement courses for all individuals.

Support for staff that are carers for those with dementia

It is estimated that the number of people who will have left employment to care for people with dementia is set to rise from 50,000 in 2014 to 83,100 in 2030, with all of the consequent costs to their employers in terms of loss of skilled and experienced staff. Many continue to juggle their caring responsibilities alongside work roles. Employers have a duty to support these staff under the Equality Act 2010 and employees have a right to request Flexible Working. Practical measures that can be taken include:

- Changed working patterns
- Reduced working hours
- Changed job roles
- Remote working
- Time off to attend health appointments
- Flexible leave opportunity to fit with respite care

Practical tools to help employees manage stress and build personal resilience should also be made available in the workplace and be accessible from home.

More information can be found at: http://www.carersuk.org/ and at http://www.alzheimers.org.uk/
Dementia awareness for customer-facing staff

The value of the ‘dementia pound’ i.e. the spending power of households affected by dementia is set to double to £22.7 billion by 2030 due to the rise in the number of people affected by the condition.

Organisations that recognise and support people living with dementia can make a big difference to both them as customers and their carers.

By recognising symptoms and demonstrating an understanding to customers who may be having problems, organisations can improve their day-to-day life. Staff awareness and understanding can be developed by:

- Accessing Dementia Friends information available online which gives helpful tips on how to improve the customer experience of people living with dementia and their carers. [http://www.dementiafriends.org.uk/customers](http://www.dementiafriends.org.uk/customers)
- Appoint Dementia Friends/Champions in the workplace.
- Consider issues such as signage and public spaces – [http://www.dementiaaction.org.uk/resources/checklist](http://www.dementiaaction.org.uk/resources/checklist)

Join the Dementia Action Alliance

Organisations can join the Dementia Action Alliance and write a short action plan, outlining the actions the organisation will take to improve the lives of people with dementia. Once you have joined you can take part in your Local Dementia Action Alliance which is a group of organisations working together to make their community more dementia friendly.

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

This toolkit was created with the help of the following:-

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**Sources of Information** – The Alzheimer’s Society- Dementia UK Second Edition 2014; The Dementia Engagement and Empowerment Project; Dementia Action Alliance; Centre for Economics and Business Research – The Economic Cost of Dementia to English Businesses.

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