Why is employment important?
Having a job is good for a person (and their family), as it not only meets their financial needs but can also provide purpose, daily routine, personal satisfaction and a sense of teamwork. In addition a person can gain self-esteem and a sense of value and benefit from the professional and personal relationships they form at work. Employment can have a significant effect on a person’s well-being.

What is young onset dementia?
Dementia is frequently categorised as late onset (being diagnosed when over 65 years of age) or young onset (under 65 years of age). People who have young onset dementia are more likely to be in employment at the time of diagnosis and are more likely to have a partner who also works.

Young onset dementia tends to take longer to diagnose than dementia in people aged over 65. On average, a person usually has symptoms for four - five years before getting a diagnosis. This can be because doctors are less likely to suspect dementia in a younger person, as well as their lack of recognition of the symptoms of young onset dementia, which may include progressive changes in: personality, cognitive ability, social functioning, communication, mood or behaviour.

How might the early signs of young onset dementia be recognised in the workplace?
Someone with the early signs of young onset dementia may notice that their concentration is not as good as before, and they make uncharacteristic mistakes while at work. They may also start to have a problem with communication, due to struggling to find the right word. Some people who have young onset dementia describe how they found simple work tasks more difficult than before and this caused them to lose confidence and feel distressed.

Dementia is classified as a disability in the Equality Act 2010, which means that a person with this diagnosis has a legal protection from discrimination.
Work colleagues may be the first people to recognise the early changes associated with young onset dementia, but they might attribute them to another cause such as stress, tiredness, relationship issues or physical or mental ill health. Often employers may wrongly assume that a change in personality, social functioning or behaviour of an employee is intentional or controllable – and they may start a performance management process, and in some cases, even terminate their employment.

This lack of recognition of the early signs of young onset dementia may lead to a delay in diagnosis, which in turn can lead to a delay in giving the person the appropriate support.

What is the potential impact of a diagnosis of young onset dementia?

When a younger person gets a diagnosis of dementia they are more likely than someone with late onset dementia to have:

- a significant delay in receiving an accurate diagnosis
- a rare or genetic form of dementia
- types of dementia that affect behaviour and social functioning
- a job/career, and a partner who is also in employment
- a heavy financial commitment such as a mortgage, and/or dependent children

If, in addition to the diagnosis, they are also facing the prospect of losing their job, it can add considerable distress for the person and their family.

People who have a diagnosis of young onset dementia and have had to leave their employment report a reduction in their confidence and self-esteem. They also describe experiencing multiple losses, including their social status, the opportunity to perform different roles, independence and social network, as well as a significant reduction in finances.

Often, people decide to leave their job after a diagnosis, because they begin to find the work too challenging or overwhelming. But some people displaying early signs of dementia have their employment terminated, because of a general lack of understanding about the condition.

Employment rights and young onset dementia

Dementia is classified as a disability in the Equality Act 2010, which means that a person with this diagnosis has a legal protection from discrimination or from being encouraged to take early retirement or face formal dismissal due to their diagnosis.

Once a person is diagnosed with dementia they are advised to speak with their employer as soon as possible. The employer should then refer the diagnosed person to an Occupational Health service to receive specialist advice and support. The diagnosed person should be open and honest about how dementia affects their work so they receive the most appropriate advice and support.
The Occupational Health service should then devise an employment action plan fully involving the person who has been diagnosed. This should include an examination of their current workload, taking into consideration how dementia affects their abilities. Occupational Health should then advise reasonable adjustments to the job such as:

- Allocating tasks individually rather than all at once
- Giving advice on simplifying routines
- Providing a quieter work space with fewer distractions
- Offering regular breaks during the day to limit the effects of tiredness
- Providing assistive technology e.g. alerts, reminders
- Setting up a buddy scheme and regular support sessions
- A reduction in hours or move to a lower grade post (if needed or requested)

It can be helpful for the person with the diagnosis to tell their immediate colleagues, as this may lead to more understanding and assistance, as well as promoting awareness about young onset dementia.

There are some occupations with a legal requirement that a person with dementia informs them of their diagnosis, such as the armed forces, health professionals and people operating dangerous machinery. If you are unsure about this, read your contract. You could speak to the HR team in your organisation.

**Employment while caring for someone with dementia**

The Flexible Working Regulations 2014 require employers to consider requests from carers for flexible working practices, where these can be accommodated within the organisation. The employee must:

- have been working for the employer for at least 26 weeks
- submit the request in writing
- state whether there has been a previous application for flexible working, and if so, when
- date the application

Unfortunately, the partners or relatives of a person diagnosed with young onset dementia often leave their job, due to worries about leaving the person at home, and the lack of specialist services and support available to them. This can leave families with financial problems. But there is support for families (please see ‘What help and support is available’ at the end of this leaflet).

**Alternative occupations and meaningful activities**

It is important for a person’s well-being to feel a sense of belonging, self-worth and purpose. Finding an alternative occupation or meaningful activity that the person can enjoy, that provides a sense of purpose and routine, and lifts their mood and energy levels, is important.
The alternative occupation and meaningful activity should be one that the person wants to do and can find fulfilment in. The person with the diagnosis will be the best guide of what kind of activity this could be. You could ask them if there is something they have always wanted to get involved with but haven’t found the time. This could involve:

- part-time employment either in the same organisation or in an alternative one that uses the person’s knowledge and skills
- volunteering
- hobbies or creative activities e.g. art, photography, sports, pottery
- further study or classes at local venues
- social media
- campaigning
- research
- keep fit and swimming
- walking groups
- table tennis
- travel and exploring
- singing and music

The important thing is that the plan should be tailored to what the person would want to try and do – not just attending what is currently on offer in their local area!

The benefits of a tailored plan is that it offers:
- enjoyment
- pleasure
- happiness
- increase in energy and mood levels
- sense of purpose
- ongoing value
- routine
- stimulation

What help and support is available?

Helpline support

If you have any questions or concerns about dementia, please call the specialist dementia nurses on the Admiral Nurse Dementia Helpline, open **Monday to Friday, 9am-9pm, and 9am-5pm at weekends**, on 0800 888 6678 or helpline@dementiauk.org

Activity and support groups
- The Dementia Engagement and Empowerment Project (DEEP): www.dementiavoices.org.uk
- Dementia Adventures: www.dementiaadventure.co.uk
- Young Dementia UK (Young Dementia Network): www.youngdementiauk.org/young-dementia-network

Financial support

Benefits calculator: www.gov.uk/benefits-calculators
- Carers Allowance: www.gov.uk/carers-allowance
- Council Tax reduction: www.gov.uk/apply-council-tax-reduction
- Employment and Support Allowance: www.gov.uk/employment-support-allowance
- Personal Independence Payment: www.gov.uk/pip
- Personal Health Budget: talk to the local NHS team who help you most often with your care
- Personal Budget: you can request information about a personal budget by contacting your social services department and asking for a Needs Assessment
The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit www.dementiauk.org/donate or call 0300 365 5500.

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If you’re caring for someone with dementia or if you have any other concerns or questions, call or email our nurses for specialist support and advice.

Call 0800 888 6678 or email helpline@dementiauk.org

Open Monday – Friday, 9am – 9pm
Saturday and Sunday, 9am – 5pm

www.dementiauk.org • info@dementiauk.org

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