

Linda Willis **Anne Carpenter** Dementia Support Manager



Dementia 2014 The Hidden voice of Loneliness

Dementia Awareness Week™ 18-25 May 2014



- Two thirds of people with dementia are women
- One in three people over 65 will develop dementia



Defining Dementia

- The term dementia describes a set of symptoms including memory loss, mood changes, and problems with communicating and reasoning.
- Dementia is not part of growing old. It is caused by diseases of the brain, the most common being Alzheimer's.



Employment and Dementia

As many as 18% of people diagnosed with dementia under the age of 65 continue to work after a diagnosis of dementia.

27% of carers of people with dementia also continue to work.



Facts and Figures

There are 800,000 people with dementia in the UK, with numbers set to rise to over 1 million by 2021. Dementia can affect people of any age, but it is more common in older people so many people have already retired when they are diagnosed with dementia. At least 17,000 people in the UK are living with early onset dementia that develops before the age of 65 and they may still be working when they are diagnosed. Despite the physical and mental impact of dementia many people with dementia are able to continue working, particularly in the early stages of their condition, and would choose to do so. Many people will have financial commitments, such as mortgages, or dependent children, so will need to stay in paid employment for as long as they are able.



Unpaid Carers

Unpaid carers provide a major part of the support to people with dementia. There are estimated to be 670,000 people in the UK



Equality Act 2010

The Equality Act 2010 (England and Wales) protects anyone who has a disability, including people with dementia. Under the Equality Act employers must make reasonable adjustments for employees with a disability so that they are not disadvantaged at work.

Carers have the right to request flexible working, and the right to request time off to look after dependents in an emergency.



Ability to work and reasonable adjustments

People with dementia can continue to work, particularly in the early stages of their condition. Employers must be aware of their duties to their employees and how they can support people with dementia. Job centres and careers advisors must also be equipped to support people with dementia to find work or access out-of-work benefits.



Diagnosis

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



Dementia Friendly Communities

Alzheimer's Society is attempting to tackle this stigma through the creation of dementia friendly communities. This programme of work focuses on improving inclusion and quality of life for people with dementia so that people with dementia are more able to remain independent and have choice and control over their lives.



Financial Impact

The financial impact of giving up work particularly affects people with early onset dementia who are more likely to have financial commitments, such as a mortgage to pay, or to have dependent children. Those with early onset dementia may not be able to access their pensions early and may experience delays in accessing payments from insurance policies. This makes access to out-of-work benefits and careers advice particularly important for them.



Welfare

Alzheimer's Society hears many examples of people struggling to access Personal Independence Payments and out-of-work benefits such as Employment and Support Allowance.

The assessment process for benefits needs to be designed so that it can adequately measure the impact of dementia on a person's daily life and accurately assess a person's ability to work.



Carers and Employment

Caring for someone with dementia can be emotionally and physically exhausting. Some carers decide to give up work to provide care, others continue to work. However, combining work and caring for someone with dementia can be challenging. An Alzheimer's Society survey (2010) of people with dementia and their carers found that:

- •53% of carers said that their work had been negatively affected due to their caring responsibilities.
- •27% were worried that caring might have an impact on their capacity to work in the future.
 - •23% said that they had changed their work pattern and 19% had reduced their working hours.
 - •48% said they had flexible working arrangements at work.
 - •Only 19% of carers indicated that their employer offered a specific policy for carers.



The Alzheimer's Society campaigns for:

The government to raise public awareness of employment rights and to increase employers awareness of the Equality Act and its relevance for employees with dementia • Employers to adopt good employment practices that support people with dementia and carers to remain in work if they choose, but also recognise dementia as grounds for early retirement and protect a person's entitlement to pension rights and other benefits • GPs to have the relevant skills, training and support to recognise the symptoms of dementia in all age groups. This will facilitate early diagnosis of dementia and prevent problems arising at work • Greater access to and uptake of dementia awareness training, for employers and staff working for Jobcentre Plus.



- •A public awareness campaign to raise awareness of dementia and reduce stigma and discrimination so that people can openly discuss their diagnosis of dementia at work and be supported by their colleagues.
 - The development of evidence about how best to support people with dementia to remain in work and the sharing of best practice.
- The creation of dementia friendly communities in England and Northern Ireland and dementia supportive communities in Wales.



Dementia Friends

www.dementiafriends.org.uk

Thank you do you have any questions?



National Telephone Helpline No.

0300 222 1122

Monday to Friday 9am – 5pm

Weekends 10am - 4pm