



Dementia in the Workplace

A Guide for Trade Union Reps

Trade union reps provide valuable support to disabled members facing difficulties in the workplace as a result of physical or mental impairment. On occasion an undiagnosed condition can be uncovered as a member is supported through sickness absence, performance improvement or disciplinary procedures.

This guide from the Disabled Workers' Committee aims to help raise trade union representative's awareness of dementia as a workplace issue including:

- Recognising early symptoms of dementia
- How to create dementia friendly workplaces
- How workers with early onset dementia can be supported in work
- How carers for family members or friends with dementia can be supported by employers
- Where trade union reps can access advice and support

The guide is not designed to make union reps experts in the condition, it aims to help them support members affected by dementia, either living with it directly, or as a carer for someone who has dementia.

Age Scotland is the largest charity in Scotland dedicated to enabling everyone to make the most of later life, and 'older people' is the section of society that is growing fastest. Increasingly people will continue working into their late sixties and beyond, as a result of removal of the default retirement age and a rising state pension age.

Dementia is an umbrella term for a number of chronic (long-lasting) and progressive (worsening) cognitive conditions. The term 'cognitive' relates to a person's mental processes, such as perception, memory, judgment, and reasoning. A certain amount of decline in cognitive ability is inevitable as part of the ageing process. With dementia the cognitive decline becomes severe and is, ultimately, terminal. It involves physical changes to the brain that cannot be reversed, although some symptoms may be alleviated with treatment. It is not a normal or inevitable part of the ageing process.

In its early stages the symptoms of dementia may be similar to other conditions such as depression or stress. As the risk of dementia increases significantly in later life, rising from one in 688 people under age 65 to one in 14 people over age 65, an early onset of dementia may well be overlooked.

Age Scotland and the STUC Disabled Workers' Committee strongly believe that workers with dementia and other cognitive conditions can, and deserve to, have the opportunity to continue in work. With the condition properly managed by medical professionals, and with support from their employer and occupational health providers, someone with dementia may be able to continue productively in work for some years.

Dementia signs, symptoms and diagnosis

Around 90,000 people in Scotland are living with dementia. Many live with the symptoms without seeking a medical diagnosis. Barriers to seeking a diagnosis include: stigma associated with the condition, anxiety about the diagnostic process, and justifiable concerns on the impact on their work and home life should the diagnosis be confirmed.

Memory loss is a symptom common to the early stages of many (but not all) forms of dementia. Where a worker seeks medical help for memory loss it can take months, and in some instances years, for a diagnosis to be confirmed. Before diagnosing dementia other possible causes of memory loss need to be ruled out, including: stress related illnesses, depression, anxiety, side effects of medications, nutritional deficiencies, infections and lack of sleep.

Early diagnosis is vital in providing the right kind of medical intervention and workplace support. Trade union reps handling casework should be aware of common dementia symptoms such as:

- Lapses in short term memory
- Language difficulty
- Difficulties in judging depth and/or distance
- Withdrawal from work or social activity
- Changes in mood and personality
- Worsening judgement
- Misplacing things or being unable to retrace steps
- Challenges in planning or solving problems
- Difficulty in completing tasks at home, work or leisure
- Confusion with time or place

Many of these symptoms, taken individually or collectively, are likely to have an impact on an individual's work performance. That could potentially expose them to sanctions by their employer as a result of failing to meet targets (often set unrealistically high for employees generally), increased sickness absence, or disciplinary action as a result of adverse behavioral traits caused by mood or personality changes.

Where a member displays any or all of these symptoms it does not necessarily mean they have dementia. Reps could however, when investigating cases, encourage members to seek medical advice when action is being taken against them should their member be displaying symptoms of ill health of any kind that are impacting on their work performance.

Trade unions and employers, along with occupational health providers, can work together to develop strategies and policies to support reasonable adjustments for workers with dementia, and for staff who care for family members or friends living with dementia, and to make Scottish workplaces more dementia aware.

Reasonable adjustments and dementia

Dementia fits the definition of disability in the Equality Act 2010, and as such workers who are living with dementia, or who are caring for someone with dementia, are protected from unfair discrimination under the Act. Under the Act it doesn't matter if a disability only has a minor effect at present. It can still be treated as a disability if it is having some effect on a person's daily life now, and is likely to have a substantial effect in the future.

Where a worker is at a substantial disadvantage because of their disability their employer has a duty to make 'reasonable adjustments' to enable them to remain in employment.

What are, and what are not, effective adjustments for workers with early stage dementia is less clear than for other disabilities, as it has only comparatively recently become a topic for research. As each type of dementia progresses differently, and as everyone who experiences dementia does so in a different way, adjustments will always need to be agreed with the worker. They will also need to be reviewed periodically to ensure they are and remain effective, particularly as symptoms may be becoming more severe.

Trade union reps wishing to find out more on dementia in the workplace should read the findings of research carried out by University of West of Scotland, Dementia in the Workplace – the potential for continued employment post diagnosis.¹

Areas to look at with regard to early stage dementia adjustments include:

1. Changes to the way things are done
 - Ensuring policies don't unfairly penalise someone who needs to take frequent short absences because of their condition or a caring responsibility
 - Allowing more flexible working and / or reduced hours
 - Changes to practices in the workplace to ensure they are inclusive of workers living with early stage dementia, for example communication to be made simpler and clearer
 - Re-allocation of some duties and / or reduction in some targets

2. Physical changes to an employee's working environment
 - Reducing distractions, for example noise
 - Changes to minimise risks associated with difficulties judging depth and distance, for example better lighting and improved flooring
 - More and clearer signage

¹ Tolson, D., Ritchie, L., Danson, M. and Banks, P. (2015) Dementia in the workplace: the potential for continued employment post diagnosis. Report to the funders.

https://www.researchgate.net/publication/303497370_Dementia_in_the_Workplace_Report_to_funders.

3. Extra aids or support

- A buddying system
- A supportive quality checking system
- Checklists, reminders, calendars
- Mentoring or counselling support

Other Considerations

In addition to becoming more familiar with the condition the main advice for reps would be to:

- Ensure your member is aware of their rights under the Equality Act 2010 and aware of their responsibility for their own health and safety and that of their co-workers. The member should also be made aware of their employers duty of care to all workers under the Health and Safety at Work Act (1974)
- If they have a diagnosis of dementia, to encourage them to inform their employer to ensure the employer is aware of their legal responsibilities. An employer does not have to make adjustments for a disability if they did not know, and could not be reasonably expected to know, that a worker had that disability
- Be aware that a worker who is living with dementia cannot continue in employment indefinitely. At some stage their condition will have progressed such that it is no longer possible to make reasonable adjustments to enable them to continue. Reps can support that process, and help members to access information and support so the experience is as positive for them as it can be. Leaving work, or reducing hours, prematurely because of a disability can also result in a substantial loss of income, reps can help members in that situation to access specialist benefits and money advice from sources such as local Citizen's Advice Bureau, Local Authority Welfare Rights Departments or Silver Line Scotland

- Support them to be fully supported by their medics and occupational health. This should include a risk assessment of their working environment
- Every person in Scotland who is diagnosed with dementia is entitled to a year post diagnostic support. In most areas, this is an Alzheimer Scotland Dementia Link Worker or a Community Psychiatric Nurse who will have a strong knowledge of local support groups or community activities which people who have recently been diagnosed with dementia may benefit from. Further details can be found on Alzheimer's Scotland's website
- Workers who are carers for a friend or family member with dementia will need increasing support and flexibility from employers as the condition progresses
- Become familiar with your employer's sickness absence policy, particularly relating to disability leave
- Check your own union for policy and guidance on disability issues

Resources and Further Reading

Age Scotland Telephone 0333 3232400

Age Scotland's Early Stage Dementia Project is funded by the Life Changes Trust to support the charity in raising awareness of early stage dementia and the signs and symptoms of the condition.

As part of this work Age Scotland, with support from the Life Changes Trust, has developed an early stage dementia workplace training package. This comprises two half-day courses. The first is titled '**Becoming a dementia aware workplace**', is suitable for staff at all levels, and encompasses:

- Dementia: what it is, and why it's relevant to the workplace
- The symptoms of dementia and how it can progress
- The risk factors for dementia and how risks can be reduced
- Communication with someone who is living with dementia

The second is titled '**Dementia, law and workplace good practice**', is suitable for staff with management or HR responsibilities, and encompasses:

- Employers' legal obligations when someone is living with dementia, or is a carer for someone who has dementia
- Ways in which someone who is living with dementia, or who is a carer for someone with dementia, may be supported to continue in employment
- Sources of support for employers and employees with regard to dementia

Further information is available from the Early Stage Dementia team:

ESDTeam@agescotland.org.uk

Access to work Telephone 0345 268 8489

An Access to Work grant can pay for practical support if an employee has a disability, health or mental health condition. The amount of the grant depends on the employee's circumstances, up to a maximum of £40,800 per year. The grant can pay for things like adaptations to the equipment, special equipment, fares to work if an employee can't use public transport, a support worker or job coach to help them in their workplace. Only the employee can claim, not their employer.

Alzheimer Research UK

Mental activity linked to slower cognitive decline - ARUK scientists link education, occupation and social engagement to better brain health later in life.

<http://www.alzheimersresearchuk.org/mental-activity-linked-to-slower-cognitive-decline-2/>

Alzheimer Scotland Telephone 0808 808 3000

Alzheimer Scotland provides a wide range of specialist services for people with dementia and their carers, and offer personalised support services, community activities, and information and advice at every stage of the dementia journey.

Carers Scotland Telephone 0808 808 7777

A source of information and advice for carers and professionals. It can also connect carers to local sources of support and peer-support opportunities.

Dementia Services Development Centre Telephone 01786 467740

An international centre of knowledge and expertise dedicated to improving the lives of people with dementia, including environmental design.

[Fit for Work Scotland](#) Telephone 0800 019 2211

Fit for Work Scotland provides 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. It offers:

- **Advice:** Access to health and work advice through a website and free-phone helpline for employees, employers, and GPs
- **Assessment:** Employees who have reached four weeks' sickness absence – or are expected to – can be referred by their GP or employer.

[Silver Line Scotland](#) Telephone 0800 4 70 80 90

A helpline service offering information and advice for older people, their families, friends and carers (Monday to Friday 9am to 5pm) and friendship to older people 24 hours a day. Silver Line Scotland is a partnership service of Age Scotland and The Silver Line. It can provide information and advice on matters including Powers of Attorney, pensions, benefits and money matters, and access to health, social care and housing services.

TUC

[Sickness Absence and Disability Discrimination, a trade union negotiator's guide to the law and good practice](#): includes advice on the law and disability, reasonable adjustments and disability leave agreements.

[Good Practice in Workplace Mental Health \(a Report on a TUC Seminar on Mental Health in the Workplace held in February 2015\)](#)