

# Working-age people living with dementia experience inadequate guidance and counselling

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The right of working-age people living with dementia to receive adequate and timely guidance and counseling is not realized properly, a

new study from the University of Eastern Finland shows. Study participants highlighted shortcomings in the continuity of guidance and counseling, as well as in equal access to guidance and counseling services. The study was published in *Ageing & Society*.

The study constitutes part of a multidisciplinary project exploring the experiences, life situations and realization of the rights of people with working-age [dementia](#) or mild cognitive impairment. Combining the perspectives of social psychology and law, the study was based on focus group discussions conducted with 12 adults (aged 54–65) who were diagnosed with dementia while still employed. Before getting their diagnosis, study participants had experienced a variety of challenges in their work, such as [memory problems](#), difficulties in managing new tasks, and stress caused by a hectic work pace. The challenges experienced at work caused feelings of anxiety and exhaustion. Before taking a [memory test](#) and getting their diagnosis, the challenges faced by study participants were sometimes interpreted as being caused by laziness, incompetence or alcoholism.

Nearly all study participants stopped working immediately after receiving their diagnosis of dementia. Most of them felt that it was a good solution considering the requirements of their work. In some cases, there was no discussion with the employer on the possibilities of adjusting the person's work. For employees wishing to continue working, retirement may have come as a surprise.

Retirement meant having to give up the routines and social contacts of the workplace. Some study participants also felt ashamed of their own disability. All study participants received [peer support](#) from local branches of the Alzheimer Society of Finland, and these branches also provided them with meaningful things to do. Peer support networks were considered valuable, as the social networks of people living with dementia may become smaller due to prejudice associated with the

disease.

The findings emphasize the importance of raising awareness of dementia among supervisors and employees. In addition, employers and professionals working in human resources and occupational health care should better understand the rights of people with early onset dementia, as well as practices that support their opportunities to influence. The researchers also consider it necessary to coordinate social and [health care services](#) and services provided by the third sector so that people with working-age dementia can receive adequate, timely and individual support.

**More information:** Mervi Issakainen et al, Experiences of influencing one's own life when living with working-age dementia, *Ageing and Society* (2021). [DOI: 10.1017/S0144686X21001525](https://doi.org/10.1017/S0144686X21001525)

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