

People with dementia and the right to independent life

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Tuija Alava, an expert by experience for Pohjois-Savon Muisti, was diagnosed with Alzheimer's disease while still in working life. Alava lives alone and copes well in her everyday life, but she also receives regular assistance from home care services. Credit: Raija Törrönen/University of Eastern Finland

Experiences of people with dementia and their family members show

researchers how a progressive illness affects the realization of the fundamental rights, and how the status of people with dementia can be improved.

"I had a lot of stress, both in my personal life and at work. As a result, I started to have severe symptoms of delirium and was admitted to a psychiatric hospital. At first, doctors suspected that I have bipolar disorder, and I was treated in various hospitals. My life began to find a balance only after a right medication was found. It took a long time to get a diagnosis of Alzheimer's disease, and being diagnosed really startled me," says Tuija Alava, talking about her dementia.

Alava's symptoms started to occur when she was in her 60s. When she was first diagnosed, she needed a lot of support both from home care services and from her family. Now, it's been seven years since her diagnosis, and Alava is doing well—better than in years. She lives alone in her own home in Kuopio and copes well in her everyday life, but she also receives regular assistance from home care services.

"I've been running my household by myself for four years. I also get help from home care services. On Mondays, a nurse comes for a home visit, and I also have a drug-dispensing robot. Alzheimer's disease does not prevent me from coping with everyday life yet, but it requires being prepared for the future. This is a merciful disease in that it doesn't involve a feeling of illness, and symptoms are also individual," Alava says.

Tuija Alava talks about her life openly and in an accustomed manner. She works as an expert by experience for Pohjois-Savon Muisti, a regional association of the Alzheimer Society of Finland. The society's Memory Pilots, i.e., centers for memory-related expertise and support, provide people with dementia and their families with guidance and support.

"I happened to notice the association's office by chance when I was on a walk. I stepped in and told them that I'd be interested in becoming involved. That's when it started. Now I'm an expert by experience in a group of women who have dementia and are of the same age. Most of them have a spouse, and that gives a strong sense of security. I think I'm the only one living alone. Fortunately, I'm still in good shape and have support around me, three children and siblings."

Experiences of dementia as material for science and art

Tuija Alava is one of the many Finns who are diagnosed with dementia while still in working life. The number is estimated to be around 10,000, and the total number of Finns with neurodegenerative dementia is estimated at 200,000. Every year, slightly under 15,000 new dementia diagnoses are made.

Because dementia affects such a large number of people and society at large, it is also the subject of a lot of research. At the University of Eastern Finland, dementia is at the heart of the multidisciplinary Neuroscience Research Community, NEURO RC. NEURO RC consists of 17 research groups and combines clinical neuroscience with data science, and neuro-innovation with law.

One of the most recent research projects, *Varjoja paratiisissa?* ("Shadows in Paradise?"), examines how the rights of people with dementia are realized in the welfare society. Funded by Kone Foundation, the project is led by Professor of Law and Society Kaijus Ervasti at the Law School.

"It is not enough for legislation to safeguard the rights of people with dementia, but their rights must also be realized in practice. We don't

fully understand how these rights are perceived to be realized, and this is why we are collecting information from people with dementia and their family members. We want to know where they experience problems and we try to improve their status," Ervasti says.

Researchers ask people with dementia and their families to share their experiences of legal problems, assistance seeking, and problem-solving. The project also uses methods of art, and the material will serve as background for a novel by Minna Lindgren.

"A novelist is able to express the experiences of people with dementia and their families in a way that is different from a researcher, whose work is rather clinical. This is why art-based methods are valuable to us," Ervasti points out.

Who decides and who gets access to services?

Despite having an illness, every human being has the right to a good and dignified life. The key issues related to the realization of the rights of people with dementia are related to the right to self-determination, and equality.

"The right to self-determination and the realization of autonomy have been of key importance for years. We really should get past the idea that dementia prevents a person from making decisions about their life. Often, a person with dementia is capable of making decisions either independently or with support," says Professor of Law and Aging Anna Mäki-Petäjä-Leinonen. She leads the Institute of Law and Welfare at the University of Eastern Finland.

In Finnish legislation, the status of people with dementia is governed by, e.g., the Act on Disability Services and Assistance, the Act on Care Services for Older People, and the Act on the Status and Rights of

Patients. According to Mäki-Petäjä-Leinonen, national legislation is on a fairly good level, with the exception of the Act on Self-determination, which has been under preparation for a long time.

In everyday situations, social welfare and [health care professionals](#) assess whether a person is capable of adequately understanding what they are doing in a decision-making situation. If a court of law has to assess the capability of someone with dementia to decide on their own affairs, the assessment often relies on medical evaluations. According to Ervasti, professionals have to weigh situations on a case-by-case basis, balancing between self-determination and protecting the person.

"Health care professionals are required to comply with the principles of law in their work. Can a person be allowed to make a decision in a particular situation, or should they be protected instead? Family members often also play a role, and many would like to do everything they can to protect their loved one. The issues at hand are very diverse," Ervasti and Mäki-Petäjä-Leinonen say.

At the early stages of the disease, a person with dementia may give a continuing power of attorney or make an advance directive. If no advance directive can be found, the presumed wishes of the patient are interpreted on the basis of how they used to make decisions when things were normal.

Services for people with dementia are interpreted in different directions

The realization of the rights of people with dementia is also closely linked to equality. The services available to someone with dementia is affected by, e.g., whether the services are interpreted to be part of disability services or services for the elderly. If the interpretation is that

the services are granted on the basis of disability, a person with dementia will have a better access to transport services under the Act on Disability Services and Assistance than an elderly person under the Social Welfare Act.

The need for support of working-age people with dementia may be very different from those of older people with dementia. Yet, it is still common to draw a parallel between people with dementia and elderly people, because 70% those diagnosed with dementia are over 65 years old.

"Among those with dementia, older people and people who are lonely are the most vulnerable. Even for those who have an aging spouse at their side, it is worth asking whether they can use digital services and whether they can cope with informal care," says Mäki-Petäjä-Leinonen, highlighting the realization of support in informal care.

"Many family members giving informal care deal with the matters of their spouse, father or mother without support. They either don't know how to seek support or they don't want to, or they are denied it. If a person knows how to seek support for informal care, they usually know how to seek access to other services as well. Then there are informal carers who slip through the cracks of the support system and get overburdened by the burden of care."

The status and situation of informal caregivers vary depending on the problems faced by the person they are caring for. Some face difficult and complex situations. Dementia also affects people in different ways: some become easy-going, others become aggressive and challenging.

"The earlier the diagnosis is made, the sooner it is possible to prepare for what's ahead, and to get guidance and counseling. But who should give the necessary guidance and counseling, that's a good question," Mäki-

Petäjä-Leinonen says.

In addition to social welfare and health care professionals and memory nurses, organizations such as the Alzheimer Society of Finland play an important role in the counseling and guidance of people with dementia.

Alzheimer Society's local associations set things in motion and offer peer support

The Alzheimer Society of Finland is a national umbrella organization for people with dementia and their family members, and the society has some 14,500 members. The local associations of the Alzheimer Society of Finland work with customers and do advocacy work locally, and they also communicate on service and development needs from the regional to the national level.

Tuija Alava works as an expert by experience in Pohjois-Savon Muisti, one of the Alzheimer Society's local associations. Experts by experience are in high demand when people want to share and hear experiences of what it is like to have dementia, and what it feels like for a family member.

"People look for a peer experience and find it important. People who are in the same group and have the same condition have the need to interact with one another," says Eija Rytönen, Executive Director of Pohjois-Savon Muisti.

Last year, the association received more than 3,500 calls and emails from customers. The work with customers often involves listening, guiding people to relevant sources of information, and encouraging them to seize the moment.

"Nowadays, people with dementia are more functional and aware of things than before. We get a lot of questions about what it means to be diagnosed with dementia. Often, the first reaction is shock because dementia is often seen as a disease of the elderly. For a sixty-something, the diagnosis can be scary, and they may feel like it's the end of the world," Rytönen says.

Rytönen emphasizes customer-oriented and comprehensive review of the patient's situation as soon as the disease is diagnosed. In progressive dementia, being prepared for the future emerges as an important factor.

"Matters relating to advance decision, guardianship and safety should be discussed openly as soon as someone is diagnosed with dementia."

For people working in the association, it is evident that there is a great need for services both among people with dementia, and their [family members](#). However, the association does not provide statutory services, which are the responsibility of the public sector.

"We get contacted a lot, and the role of associations is being highlighted. However, the role of associations in what kind of service they provide, and which matters are handled by the public sector, should be emphasized in counseling."

Work to help people with dementia is ongoing on many fronts: social welfare and health care professionals and organizations provide support and advice, science develops ways to treat and prevent dementia, and the rights and treatment of people with dementia are governed by legislation and sanctions.

"In addition, improving the status of people with dementia is largely dependent on the attitudes and values of modern society," Rytönen says. When there's a will, there's a way.

"We need to change our attitude towards dementia and to remove stigma. People should be provided with information about what [dementia](#) really is like."

Provided by University of Eastern Finland

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