

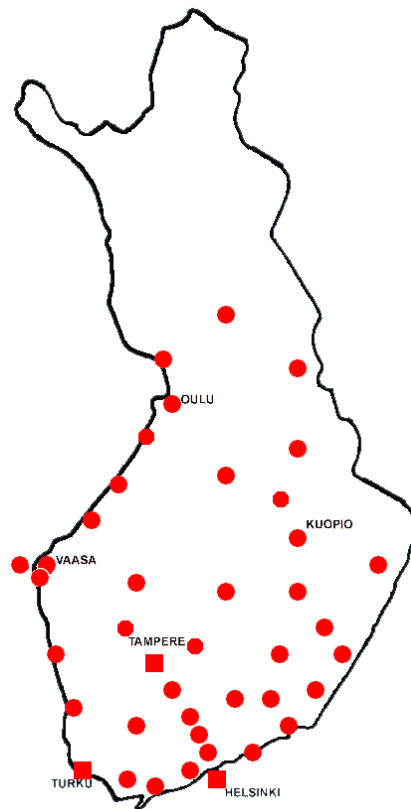


Giving voice to person with dementia and voluntary work

14.3.2019

The Alzheimer Society of Finland

- Established in 1988
- A non-profit organization
- Central Society for 44 member associations
 - 14'500 members
 - Member associations have 38 local branches.
- Mainly funded by the STEA (Funding Centre for Social Welfare and Health Organisations).



Memory diseases in Finland

- Approximately 193 000 persons with memory diseases
 - 93 000 with the moderate or severe stage of the disease
- 14 500 new diagnosis every year
- 7 000 persons with younger-onset memory diseases (under 65)

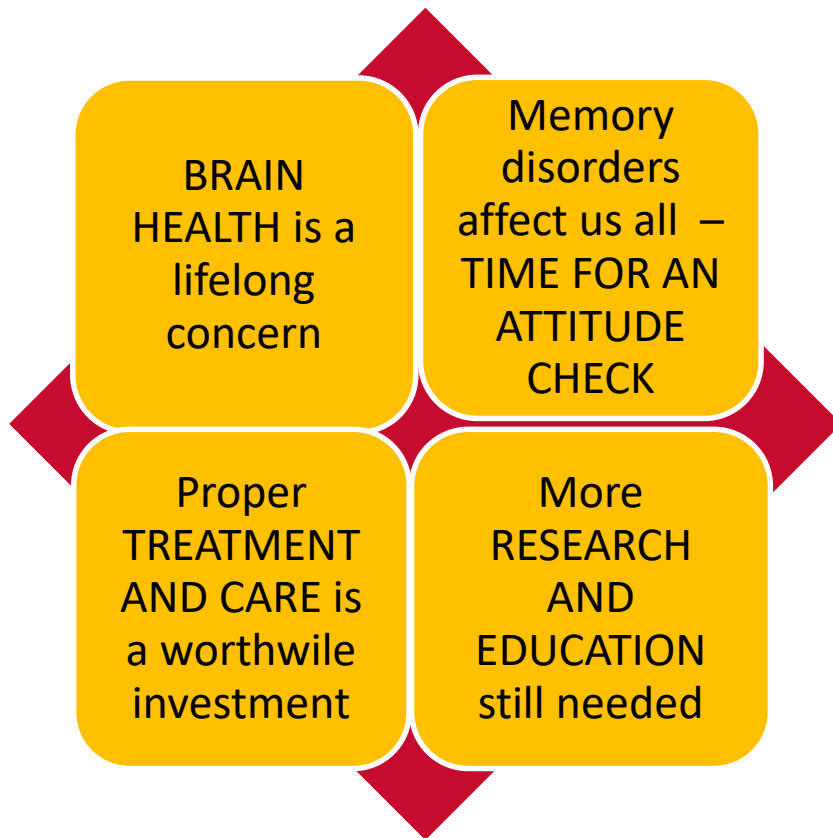
The Alzheimer Society of Finland works nationwide to achieve the following goals:

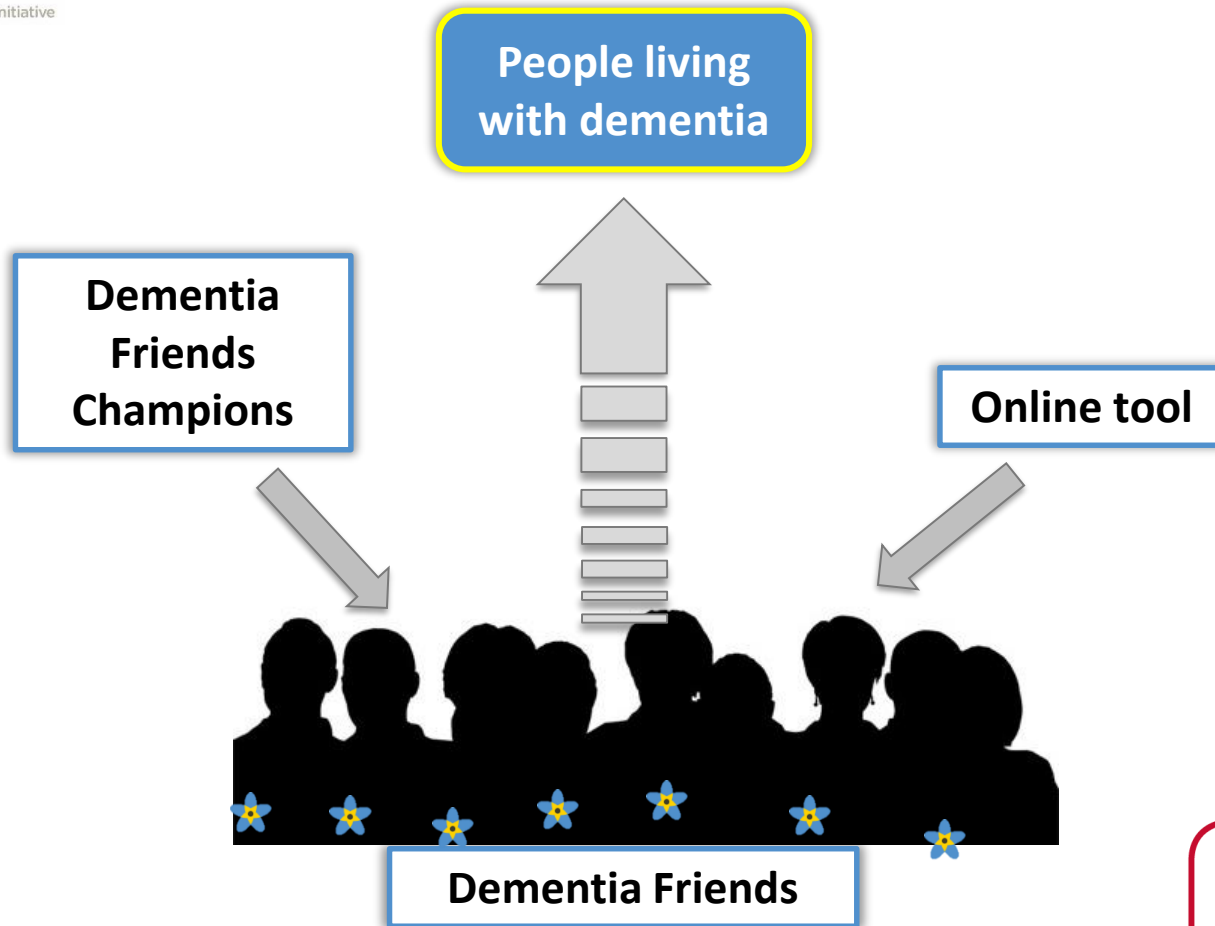
- Improve the quality of life of people with memory diseases and their caregivers
- Promote the legal, economical and social rights of people suffering from memory diseases
- Develop the support system of people with Alzheimer's disease and their caregivers
- Educate the professionals in health care
- Influence the attitudes towards people with memory diseases
- Influence the political decision making process

National memory programme 2012-2020 in Finland

- Launched on May 2012
- Prepared by the Ministry of Social Affairs and Health along with other organizations
 - Alzheimer Society of Finland has been a key supporter of the Memory Plan for many years
 - Part of the working group since the planning started
 - Now responsible for third sector implementation of the programme and one of the secretaries in the steering group

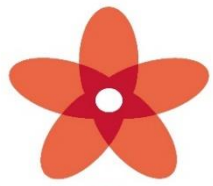
The Finnish National Memory Programme





Dementia Friends Champions...

- Are **volunteers** who are passionate about raising awareness of dementia
- Run Dementia Friends **information sessions** in their community e.g. in their workplace, to family and friends, to clubs they are part of, public sessions in the community



Muistikummi

Global Dementia friends movement

- Dementia-friendly initiatives have power to change the way we think, act and talk about dementia on a global scale.
- Finnish version is called "Muistikummit"
- Launched in Finland in September 2018.



-5000 dementia friends in
Finland at the moment (03/19)

-Webinars

-Co-work with students

-Next plan is to create an internet version

-News letters

-social media





Voluntary Brain Health Champions

Voluntary Brain health champions

- Promotes brain health through lectures and events
- Guides group sessions on issues related to brain health
- Volunteers go through a one-day training
- Most of the volunteers have a background of working in the social and healthcare sector.
- Local memory associations can train Brain Health Champions for their area.



Memory activists

THE ACTIVISTS BEHIND DISEASE

The Finnish model of participation

KUUSTERÄ Kirsti (The Alzheimer Society of Finland, Helsinki, Finland),
YLITOLONEN Juha and KATTAOUI Taru (Memory Association of
Oulu Region, Oulu, Finland and Memory Activists)



The need for new models of participation

In recent years, the Alzheimer Society of Finland and the 44 local memory associations have developed methods to enhance participation of people with memory diseases. They are involved in the decision making in less than half of Finnish memory associations.

Active involvement to the decision making in local memory associations



Questionnaire to local associations 2015, n=39



Memory Activists – the national model

The national working group of people with memory diseases and their family members has supported the work of the Alzheimer Society of Finland since 2013.

- meets four times a year
- gives feedback to strategies, plans and projects of the Alzheimer Society of Finland
- takes stand in issues crucial to the people with memory diseases
- encourages people to talk about memory diseases

Local Memory Activist groups

As the work of the national Memory Activists have been established and the need of a uniform participatory model identified, The Alzheimer Society of Finland has been building a model and offering support for local Memory Activist groups.

The aim is to have a group in each 18 regions of Finland by 2018. The local Memory Activists will uphold the work of the local associations and discuss the situation of people with memory diseases at the region.

The guiding principles:

- genuine influence
- promoting and supporting active participation of all members

SUPPORT TO LOCAL MEMORY ACTIVIST GROUPS

- All groups are organized by regional expert and support centres coordinated by The Alzheimer Society of Finland
- Basic principles and good practices are collected into a brief manual
- Experiences are changed by mail and in meetings
- Communication channels of the Alzheimer Society of Finland are in use

Positive experiences

The Memory Activists groups give people with memory diseases and their family members new opportunities to have a say to the work of memory associations and the wider society.

“The activity and work moral of the Memory Activists is high. We participate and work with our whole hearts.”

Questionnaire to Memory Activists 2016

“We have been faces to the cause. We have changed the image and the concept of memory diseases. We are networking at home and abroad. We've shared information between local associations and the Society. We have provided tips on the service unit for younger onset disease and we were really listened to! We have been well-represented in the media.”

“In this group the people with diagnosis are in the forefront. We know what we are talking about. We also need support from the social environment to aid a person with the disease to cope. The best experts in that are the family and friends. They have their own, real vision and experience to share.”



Said by Memory activists...

- ” We have been faces to the cause. We have changed the image and the concept of memory diseases.”
- “We are networking at home and abroad. “
- “We’ve shared information between local associations and the Society. “
- “We have provided tips on the service unit for younger onset disease and we were really listened to! “
- “We have been well-represented in media.”

What other tasks there are where people with dementia are involved?

- Steering groups
- Expert by experience
- Quality of Life and Care Guidelines
- Peer groups
- Different types of voluntary work

Memory-friendly environment

- **The Alzheimer Association of Finland has published information leaflet about memory-friendly environments.**
- The “Quick-guide to the memory friendly environment” raises awareness and gives practical ideas how to design easily accessible and clear environments. Memory friendliness helps people with cognitive impairment or memory diseases to live independently as long as possible.
- The leaflet highlights ways to make environments more memory friendly: for example, good lightning, clear signs, a quiet sound environment and logical and familiar ways to design spaces. On the other hand, people with memory diseases might need more time and support from us all. Memory friendly environments are based on understanding and acceptance of diversity.



Kiitos! Thank you!

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