

THE ACTIVISTS BEHIND DISEASE

The Finnish model of participation

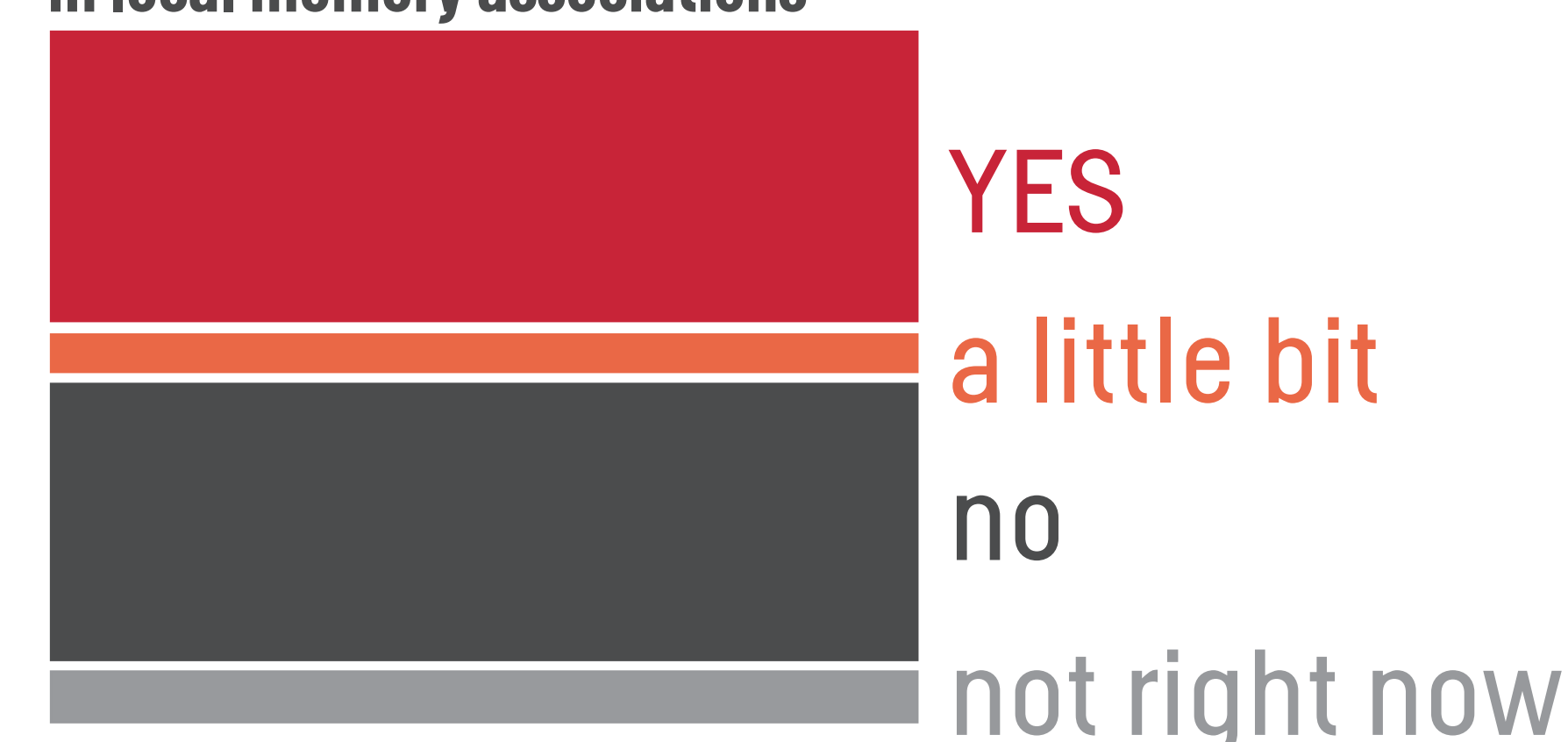
KUUSTERÄ Kirsti (The Alzheimer Society of Finland, Helsinki, Finland),
YLITOLONEN Juha and KATTAOUI Taru (Memory Association of
Oulu Region, Oulu, Finland and Memory Activists)



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 2017, n=38



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.