

Thoughts of people with younger onset memory disease about INCLUSION

Younger onset memory diseases are often associated with various types of loss: the diagnosis may drive away your friends or cause you to retire from work or lose your driving license. However, the majority of people with younger onset memory disease feel that the life they are leading is as much about their personal interests and passions as it was before the onset of the memory disease.

The results of this presentation are based on a survey conducted by the Alzheimer Society of Finland about feelings of inclusion of people with younger onset memory disease. Due to the small number of respondents, the survey results are only indicative, but they tell of genuine everyday experiences and bring forward the voice of people diagnosed with memory disease.

Things that PROMOTE INCLUSION



- possibility to decide on matters related to your own well-being and everyday life
- maintaining your own role in the family
- hobbies
- friends
- support and services, such as transport service and support persons
- peer support groups and counselling provided by memory associations

Things that HINDER INCLUSION



- retiring from work
- decreasing social connections
- increased need for assistance, dependency on family members
- giving up driving
- monitoring your own behaviour
- persons close to you not understanding what you are going through
- giving up on handling financial matters and paperwork
- changes related to your own coping

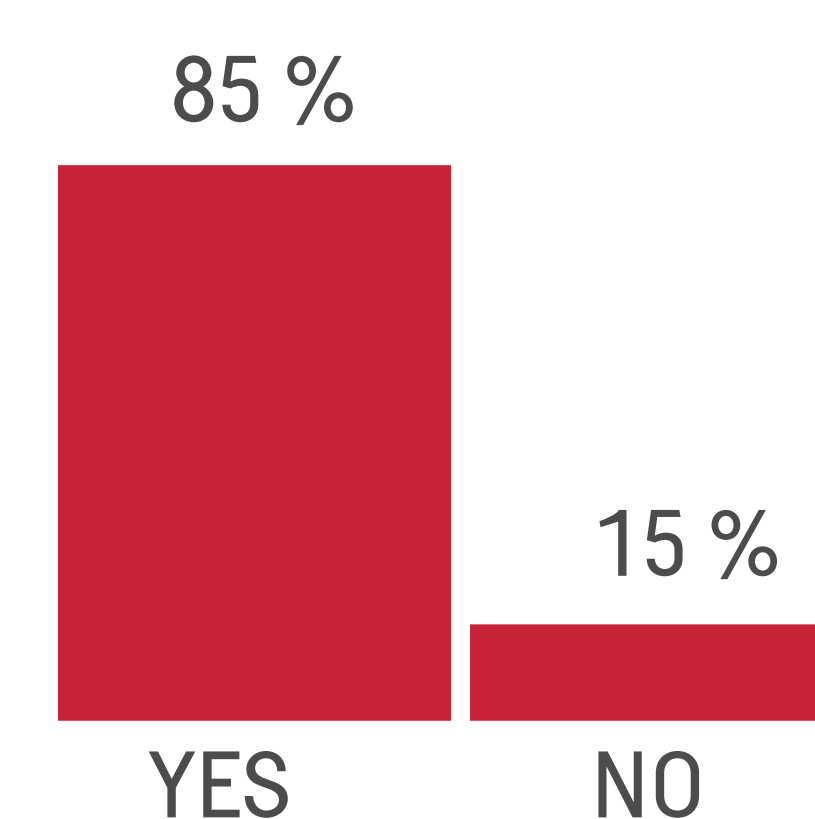
THE ENFORCEMENT OF RIGHTS OF PEOPLE WITH MEMORY DISEASE CAN BE PROMOTED BY...

- highlighting the special situation that people with younger onset memory disease are in
- letting them tell of their own experiences
- involving them in decision-making
- drawing up a living will
- participating in activities organized by the Alzheimer Society of Finland and its memory associations
- raising awareness about the possibility to continue working
- speeding up diagnosing

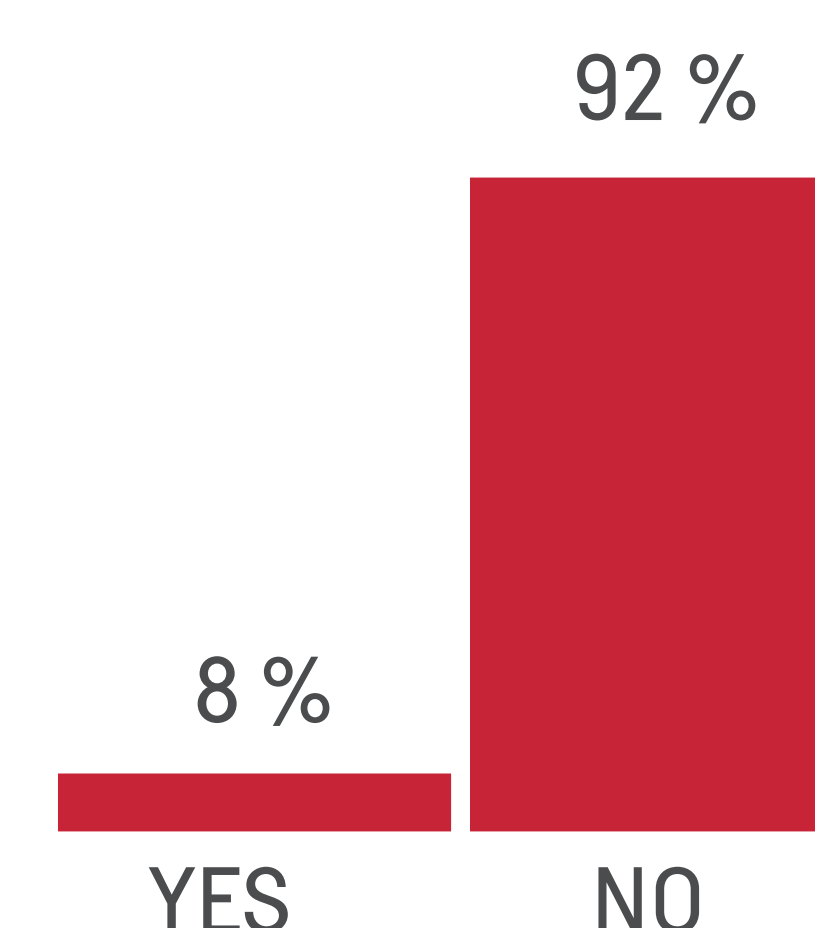
ATTITUDES CAN BE CHANGED BY...

- providing correct information to the general population about the diseases and their diversity
- reminding people that memory diseases are neurological diseases and like so many others
- emphasizing that life goes on also after a diagnosis of memory disease
- understanding that people with memory diseases need to be helped, not laughed at

Have you been able to lead your life your own way despite the memory disease? (n= 48)



Have you been able to continue working? (n= 48)



The survey was conducted during the spring of 2016 as an online questionnaire. It investigated the views and thoughts of people with younger onset memory disease (under 65 years old) regarding inclusion. The survey was based on ten different themes, utilizing both yes/no questions and open questions. It was possible to answer the survey either alone or together with another person.

50 people answered the survey. More than half of the respondents were 60 years of age or older and 60% of them were women. Almost half of the respondents said that they were diagnosed with memory disease in 2014 or later.

It is estimated that there are 7,000 working-age adults with memory disease in Finland.