DIAGNOSIS IS NOT THE END

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Alzheimer Society of Finland

• Established in 1988 to provide help and assistance for people with memory related illness and their family members and caregivers
• A non-profit organization which is mainly funded by the Finnish Slot Machine Association
• Finland has a total population of 5,4 million
  • 120 000 persons with memory illness
  • 13 000 new cases every year
The Society and the local associations

- Central Office in Helsinki, the capital city of Finland
- 2 District Offices
  - Northern Finland
  - Middle Finland
- Central Society for 42 member associations around the country
  - 11,000 members
  - approximately 140 employees
REPEAT study
Regular and structural support of memory patient

- The study was executed in 2010-2012
- 290 memory patient – caregiver pairs recruited at the time of the diagnosis by 60 geriatricians from all over Finland
- Comprehensive questionnaires for the patient and the caregiver were sent 1, 3, 6 and 12 months after the diagnosis
- The aim of the study was to examine first year after the diagnosis:
  - experiences of the diagnosis
  - need and availability of support and rehabilitation
  - how the disease influences the everyday life of the family
- Novartis Finland Oy has sponsored the collection and the analysis of data of this study
Conflicts of interest

- Novartis Finland has sponsored the collection and the analysis of the data of this study
- The researchers have not got any personal grants
- No other conflicts of interest
Characteristics of the study subjects
Gender

- People with memory illness (N=288)
- Caregivers (N=290)
The state of memory illness and the diagnosis (N=290)

- Early: 39
- Mild: 197
- Moderate: 52
- Severe: 3
- AD: 284
- PD: 7
Results
How much does the memory illness affect your life?

PEOPLE WITH MEMORY ILLNESS:

6 months from the diagnosis (N=157)

12 months from the diagnosis (N=149)

CAREGIVERS:

6 months from the diagnosis (N=175)

12 months from the diagnosis (N=162)

- Very much
- 2
- 3
- 4
- Not at all
What kind of expectations have you for the near future?

**PEOPLE WITH MEMORY ILLNESS:**

1 month from the diagnosis (N=205)

6 months from the diagnosis (N=165)

12 months from the diagnosis (N=153)

**CAREGIVERS:**

1 month from the diagnosis (N=233)

6 months from the diagnosis (N=178)

12 months from the diagnosis (N=161)

- Low expectations
- 2
- 3
- 4
- Hopeful expectations
How satisfied are you with your life at the moment?

**PEOPLE WITH MEMORY ILLNESS:**

- 3 months from the diagnosis (N=192)
- 6 months from the diagnosis (N=171)

**CAREGIVERS:**

- 3 months from the diagnosis (N=204)
- 6 months from the diagnosis (N=180)

Legend:
- Red: Unsatisfied or very unsatisfied
- Orange: Difficult to say
- Yellow: Satisfied or very satisfied
How do you feel at the moment?

- Optimistic and good
- Neutral
- Melancholic and sad
- Depressed

3 months from the diagnosis (N=194)
12 kk months from the diagnosis (N=153)
3 months from the diagnosis (N=207)
12 months from the diagnosis (N=162)

PEOPLE WITH MEMORY ILLNESS

CAREGIVERS
How much shame have you felt during the last month?

**PEOPLE WITH MEMORY ILLNESS:**

- 1 month from the diagnosis (N=156)
- 6 months from the diagnosis (N=143)
- 12 months from the diagnosis (N=129)

**CAREGIVERS:**

- 1 month from the diagnosis (N=184)
- 6 months from the diagnosis (N=158)
- 12 months from the diagnosis (N=140)
How much happiness have you felt during the last month?

**PEOPLE WITH MEMORY ILLNESS:**

1 month from the diagnosis (N=176)

6 months from the diagnosis (N=151)

12 months from the diagnosis (N=131)

**CAREGIVERS:**

1 month from the diagnosis (N=190)

6 months from the diagnosis (N=161)

12 months from the diagnosis (N=146)

- Not at all
- 2
- 3
- 4
- Very much
What would best support your / your near one's quality of life and functional capacity?
(1 month from the diagnosis)

- Domestic work
- Physical rehabilitation
- Memory aids
- Cultural activities
- Travelling
- Handicraft
- Meeting friends
- Peer support

People with memory illness (N=211)
Caregivers (N=227)
Conclusions

• In Finland both the patients and the caregivers seem to experience their first year after the diagnosis rather positively at least when the disease is diagnosed at an early state

• Feelings towards the future are confident

• Doing usual tasks of daily living, physical exercise and meeting friends support rehabilitation

→ Life does not end with a diagnosis
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