We demand rehabilitation!
The voices of the people for the Finnish Memory Program

ADI conference 20.4.2013 Taipei

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Alzheimer Society of Finland

• Established in 1988
• A non-profit organization
• Central Society for 42 member associations
  - 11’000 members
  - 140 employees
• ~130 000 persons with memory illnesses
  - 13 000 new diagnosis yearly
The status of national dementia strategies in Europe

- Countries with national dementia strategy in place
- Countries with government commitment to developing a dementia strategy
- Countries with other political support for developing of dementia strategy
- Countries with no political support for developing of dementia strategy
National Memory Programme 2012-2020

CREATING A "MEMORY-FRIENDLY" FINLAND

MINISTRY OF SOCIAL AFFAIRS AND HEALTH

Helsinki, Finland 2013
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
    - The commissioner of National Memory Surveys → existing services and service gaps
Four main areas of activity and promotion:

1. Lifelong brain health and the prevention of memory illnesses
2. Positive attitudes towards people with memory illnesses
3. Good care and rehabilitation is essential
4. High quality research and competence of professionals
What is rehabilitation?

- We cannot cure or stop these diseases → focus on *maintaining* the current situation
- Promoting and supporting a meaningful life and the continuing of life as it was before the diagnosis
  - Not only on the final stages of the disease
- Rehabilitation is also a strong message: diagnosis is not the end of the world!
- The attitudes are significant
  - As long as we see memory-related diseases primarily as death sentences, we cannot provide rehabilitation that supports the quality of life for people with the diseases and their families
THE MODEL OF REHABILITATION — A PERSON’S RIGHT TO A GOOD LIFE

REHABILITATION PLAN

Counselling, guidance, assigned support person
Rehabilitative treatment at home

Prevention
Ways of life healthy to one’s brains, being aware of the risks and recognizing the early symptoms of the dementing illnesses

DIAGNOSIS of a dementing illness

First hand information

Adaptation training

Day rehabilitation

Round-the-clock rehabilitation in short or long term care

Individual therapies and psychological support

PEER SUPPORT

THE PERSON WITH A DEMENTING ILLNESS AND HIS / HER FAMILY
- everyday life according to one’s own habits
- social relationships
- cultural interests, physical exercise etc.
- medical treatment of the dementing illness
- prevention and treatment of other illnesses
- technological device and other support of the environment
National forums for people w/ memory illness

- October 2010
  - The conclusion of the forum: There is no rehabilitation

- May 2012
  - The need for rehabilitation was documented in the Finnish Memory Program

- September 2012
  - The demands of the forum: Rehabilitation plans, peer support, adaptation training and more diverse day rehabilitation
  - “People with memory illness were not heard”
  - An official announcement was made and presented to policy-makers
The participants of the forum and the Alzheimer Society of Finland as their representative demanded that the voices of the people have to be strongly taken into account.
“Rehabilitation is needed when you still have your ability to function. It’s not possible to maintain or get back something you’ve already lost.”

- Care partner
So what have we done wrong?
- A working group of *professionals* for *ppl*
  - Old-fashioned way of thinking

And how to correct it?
Finnish National Memory Programme
- what happens now?

• An ongoing working group of people with memory illness
  – Working tightly with us
  – The Aim: The Society does not just represent, but really walks side by side

• A lot of work with attitudes

• The execution plan for the Memory Programme
Getting involved, having a say, taking action is an important part the rehabilitation process!

It empowers you, keeps you in charge of your own life

So I encourage all of you to ASK, to LISTEN, to HEAR, and to WALK BESIDE or rather BEHIND the ppl w/ memory illness rather than lead
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