Support groups for children and youngsters living with a parent with dementia

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Alzheimer Europe 1 th of November 2016
Disposition

• "Time to be young" - a pilot project

• Knowledge about children and youngsters living with a parent with dementia

• Midterm evaluation results
The aim
To generate knowledge and experience on establishing support groups for children and youngsters with a parent with dementia

The vision
Building on this experience more support groups will be established in different regions of Denmark
The three groups

**Group 1**
- 9 participants
- 22-28 years
- Average age: 25 years
- 3 boys/6 girls

**Group 2**
- 9 participants
- 15-22 years
- Average age: 19 years
- 1 boy/8 girls

**Group 3**
- 6 participants
- 16-28 år
- Average age: 17 years
- 3 boys/3 girls

**The parents**
- 57 years on average
  - Alzheimer’s disease: 12
  - Frontotemporal: 5
  - Alzheimer’s + frontotemporal: 1

**The group moderators**
- 1 group moderator with knowledge and experience with dementia
- 1 psychotherapist

**The groups**
- Meets 11 times throughout 15 years
- 2½ hours
Knowledge about children and youngsters as caregivers

- Children, youngsters and dementia is an overlooked field of research
- Research so far is primarily qualitative studies focusing on how the everyday life of the child is affected
- No evidence based research
Grief, Loneliness, Responsibilities
I rarely feel lonesome now, because I know that I have the group, if I need to talk.
”When my parents need me, I help them and set aside my own needs”
Opening up

Can you talk to others about your parent's disease when you get sad, angry or worried?

I can talk to everyone about my parent's disease

I can talk to a few about my parent's disease

I can't talk to anyone about my parent's disease
"After I started in the project I dare to open more up in regards of my feelings about my mother’s disease. I have now opened up to the persons I feel that I might in the future need in order to talk to once in a while. I feel that I have developed a lot."
On a final note
Thank you for listening and a special thanks to VELUX FONDEN for the support of the project

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