

## Service Provision in Young-onset dementia: Towards an integrative approach in caregiving



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### Introduction

- Currently an estimated 35.6 million people are affected by dementia and this number will double by 2030 and even triple by 2050 (WHO, 2012)
- An estimated 6-9% of people affected by dementia before the age of 65 (WHO, 2012)
- Increasing incidence of YOD with the increase of known risk factors for dementia such as obesity, diabetes and cardiovascular disease in developed countries? (Kivipelto et al, 2005; Hayden et al, 2006; Razay et al, 2006)
- Mainstream dementia services are unlikely to be familiar with the needs and wants of these younger people and their families and have less resources to meet their needs (Luscombe et al, 1998)



### National Taskforce Young-onset Dementia

- Care organizations & Alzheimer's Association Netherlands
- Aim:
  - (1) National care program young-onset dementia
  - (2) Appropriate funding
  - (3) Best practice > evidence based care in YOD



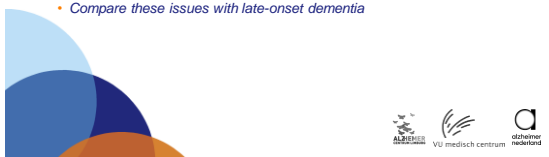
### The Needs in Young-onset Dementia (NeedYD) Study

- Alzheimer centres and Florence care group.
- Multicentre study, two year follow-up
- 215 people with YOD and their caregivers
  - 100 attending memory clinics
  - 115 via national taskforce organizations
- Comparison group, 199 people with LOD



### The Needs in Young onset Dementia (NeedYD) study

- Investigate the course of young-onset dementia (i.e. cognitive functioning, problem behaviour, caregiver functioning)
- Explore care needs of people with young onset dementia and their caregivers
- Explore what factors are related to the use of (in)formal care, caregiver burden and the time to institutionalization in community dwelling people with young-onset dementia
- Compare these issues with late-onset dementia

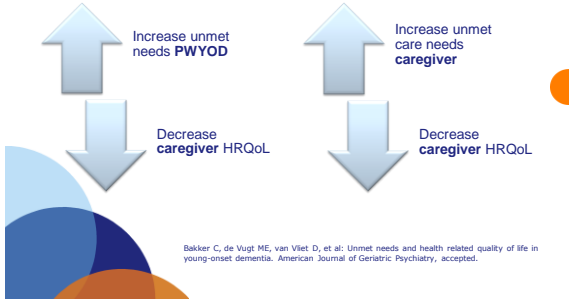


### Unmet needs in YOD

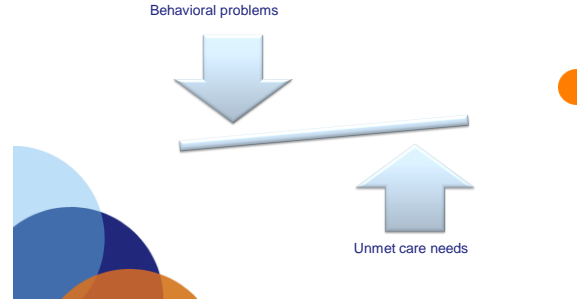
- 24% of needs unmet!
- Most often unmet needs regarding:
  - Meaningful daytime activities (46%)
  - Social company (37%)
  - Eyesight and hearing (37%)
  - Information (23%)
  - Psychological distress (18%)
  - Etc.



### Unmet care needs and health related QOL



### Unmet care needs and behavioral problems



van Vliet D, de Vugt ME, Bakker C, et al: Time to diagnosis in young-onset dementia as compared with late-onset dementia. *Psychol Med* 2012; 1-10

### Dealing with a lack of knowledge and understanding **RAISING AWARENESS**

### Raising awareness among the general public

- Periodic interviews or editorials in local newspapers
- Media coverage of events
- STIP-JD (Information and initial support through telephone or email)
- Interviews at "Alzheimer Cafe" meetings



### Education of health care professionals

- YOD in the curriculum of elderly care physician education program
- YOD in the curriculum of general practitioner education program
- Training program occupational physicians and insurance company doctors
- In-company training program for those working with people with young-onset dementia
  - Base program: 8 sessions on main YOD topics
  - Advanced modules: tailored to individual needs of the professional

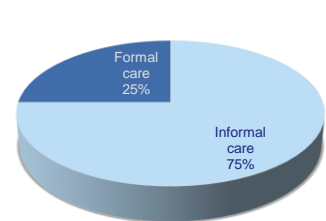
The need for an integrated approach in YOD caregiving

## MANAGEMENT OF YOD

### Florence YOD Care Program



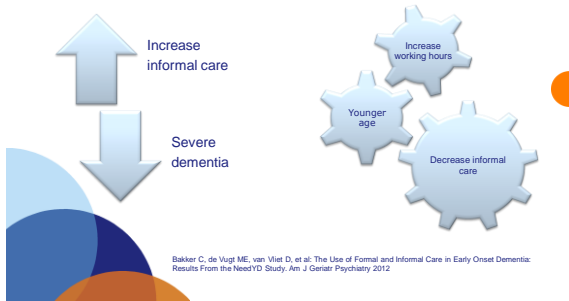
### Formal – informal care ratio



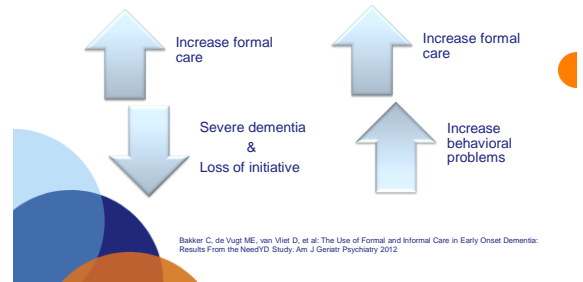
- One caregiver
- Usually a spouse
- Sometimes a child

Bakker C, de Vugt ME, van Vliet D, et al: The Use of Formal and Informal Care in Early Onset Dementia: Results From the NeedYD Study. Am J Geriatr Psychiatry 2012

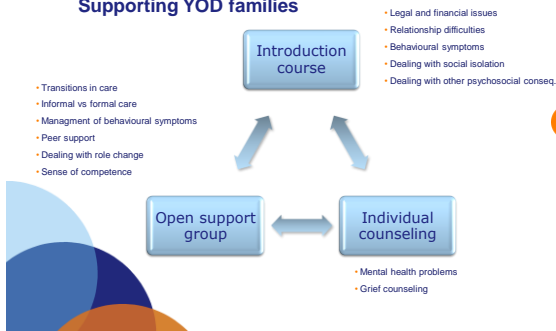
### Predictors of informal care use



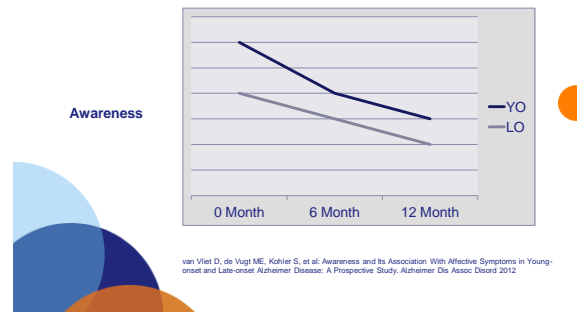
### Predictors of formal care use



### Supporting YOD families



### Awareness in young-onset AD



### Support groups

- Meet with other people with YOD
- Share experiences
- Treatment of mild depressive symptoms
- Deal with changes as they occur
- Lower threshold for day care



### Themes

- Loss of identity and sense of self (Harris et al., 2002)
- Social aspects (Werner et al., 2009)
- Information about the disease and care options
- Mobility
- Intimacy
- Social company
- Communication (Bakker et al., submitted)





### Social events

- Meet other YOD families
- Meet YOD professionals
- Non-demanding environment



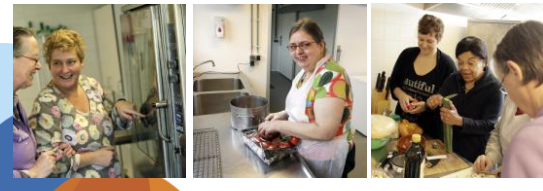
Supporting YOD families during the caregiving trajectory

## COMMUNITY SUPPORT



### Day care centre

- Flexible operating hours
- Highly trained staff
- Program fitting the needs of people with YOD



### Physical exercise

- Enhance physical health
- Improve cognitive functioning
- Reduce behavioral problems
- Retain mobility as long as possible



### Art Therapy



- Non-verbal
- Reduce behavioral problems
- Improve sense of self



### Musical Therapy

- Non-verbal
- Reduce behavioral problems
- Effective also in advanced dementia



### Overnight and weekend stay service

- Respite
- Observation behavioral symptoms
- Acute intervention



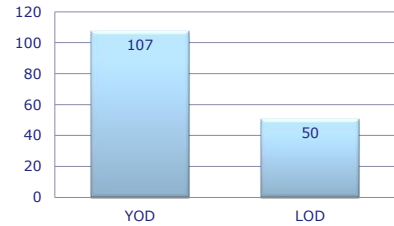
### Integrating care with diagnostic services

- Collaboration with department of neurology, Haga Clinic
- Second opinion regarding dementia diagnosis
- Etiology of behavioral problems and treatment options
- Consults, such as psychiatrist, internist, clinical geneticist



### When community care options have run out **RESIDENTIAL CARE**

### Time to institutionalization (Months)



Bakker C, de Vugt ME, van Vliet D, et al: Predictors of the Time to Institutionalization in Young-Versus Late-Onset Dementia: Results From the Needs in Young Onset Dementia (NeedYD) Study. J Am Med Dir Assoc 2012

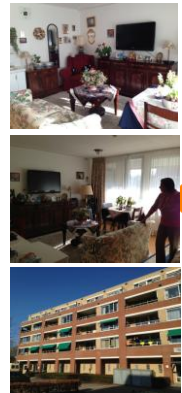
### Predictors for institutionalization in YOD



Bakker C, de Vugt ME, van Vliet D, et al: Predictors of the Time to Institutionalization in Young-Versus Late-Onset Dementia: Results From the Needs in Young Onset Dementia (NeedYD) Study. J Am Med Dir Assoc 2012

### Sheltered living

- Alternative for long term residential care
- Small scale
- Focus on creating a home
- Expert care is nearby



### Long term care

- Small scale living in a large scale facility
- Mean duration of stay 3+ years
- Care program continues
- Creating a 'home' within an institution
- Caregiver participation
- Low usage of psychotropic drugs
- No restraints used



Thank you for your attention

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