



Alzheimer Nederland



Alzheimer Cafés in the Netherlands

Growth, support and structure

**Marco Blom, a Director of 'Alzheimer Nederland'
May, 14 2010**

For 'Alzheimer Café UK' conference, Ascot

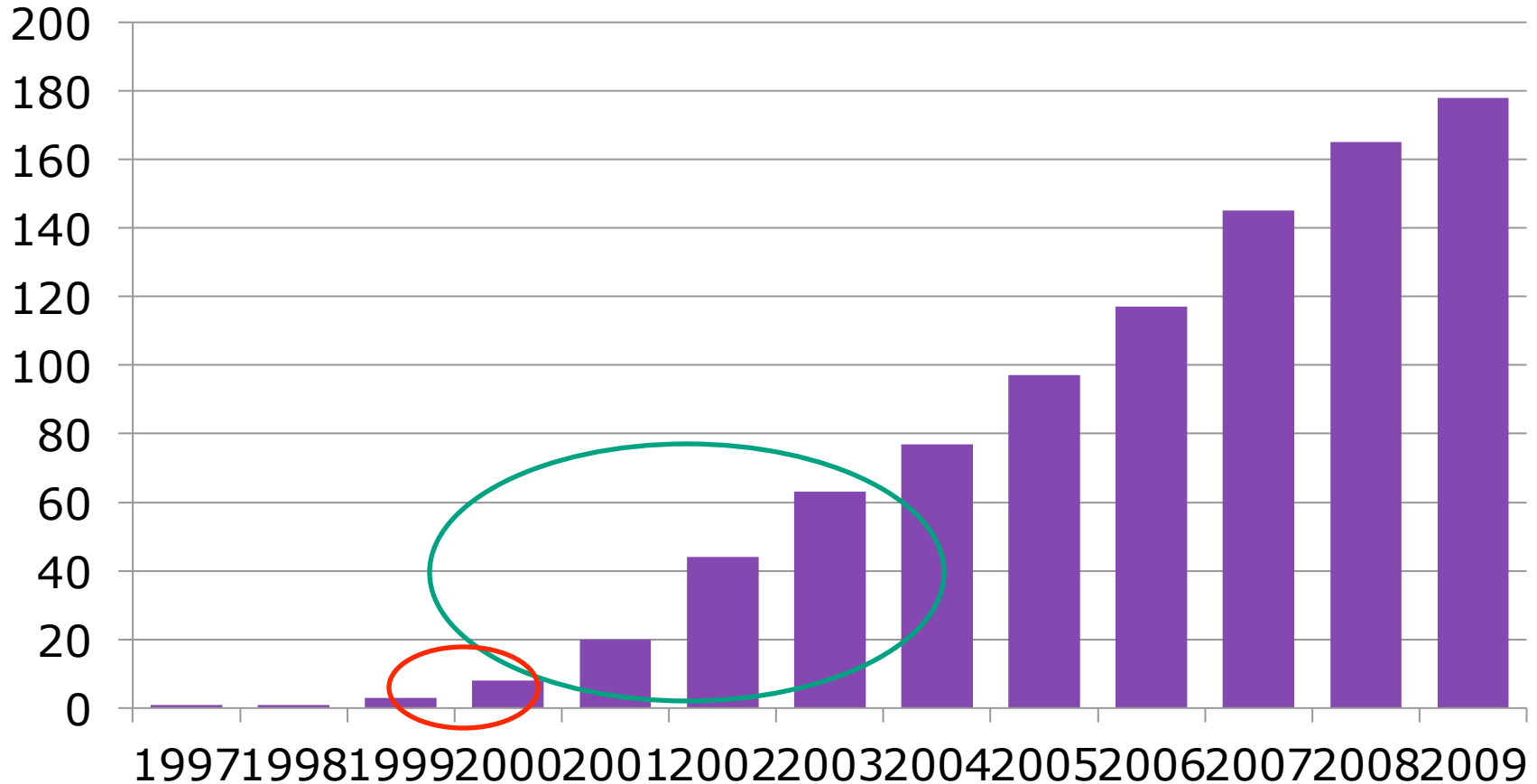


Topics

- ☀ Start and growth of the Alzheimer Cafés
- ☀ Effectiveness of the Alzheimer Cafés
- ☀ Back office (strategy, support and standards)
- ☀ Quality as a key issue
- ☀ International development



Alzheimer Cafés: start and growth





Alzheimer Cafés: start and growth

- ☀ TV-documentary 'Living with dementia'

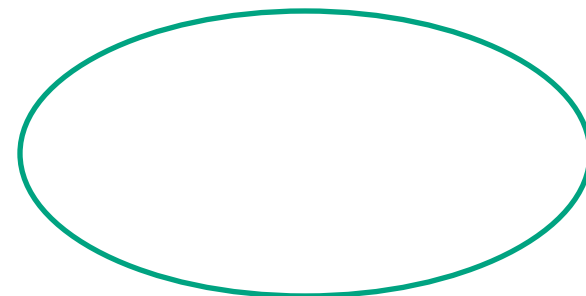
- ☀ Alzheimer Café: location and structure

- ☀ Manual for setting up Alzheimer Café

- ☀ Special symposium and workshops

- ☀ Development of training for leaders

- ☀ Supportive material





Alzheimer Nederland

Dr. Bère Miesen: receiving 'Dementia Award 2010' for his Alzheimer Café idea





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Alzheimer Cafés: effectiveness

- ✿ Growth as a sign of success
- ✿ Number of patients and family carers attending
- ✿ Majority of people 'stamgasten' (core guests)
- ✿ Anecdotal information (satisfaction is high)

- ✿ No scientific proof
- ✿ Recommended as good practice by 'Interdem'



Alzheimer Cafés: indirect effects

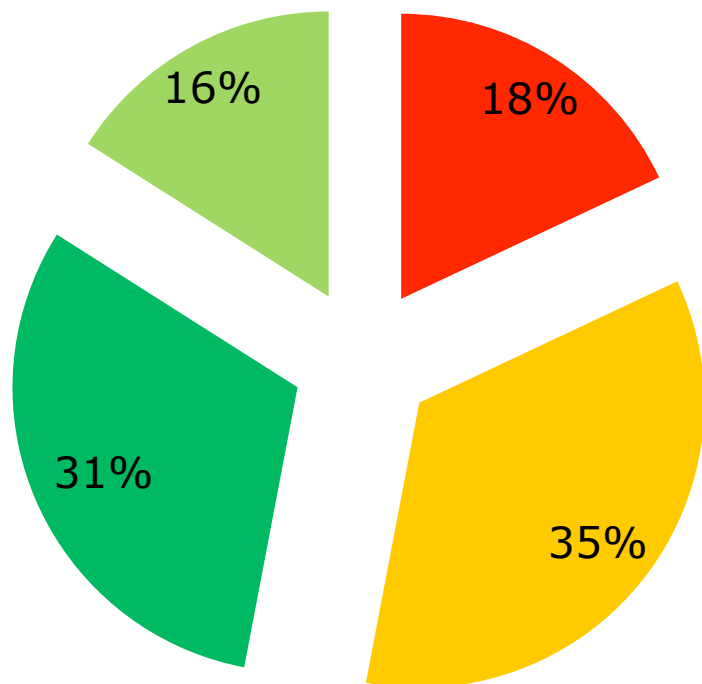
- ✿ Gives a face to the illness
- ✿ Less taboo
- ✿ Empowering people with dementia and families
- ✿ Balancing the emphasis on medical 'treatment'

- ✿ Platform for advocacy and lobbying
- ✿ Free publicity in local newspapers
- ✿ Educate professionals and other visitors (politicians)



Average number of visitors

■ < 20 ■ 20 - 40 ■ 40 - 60 ■ > 60

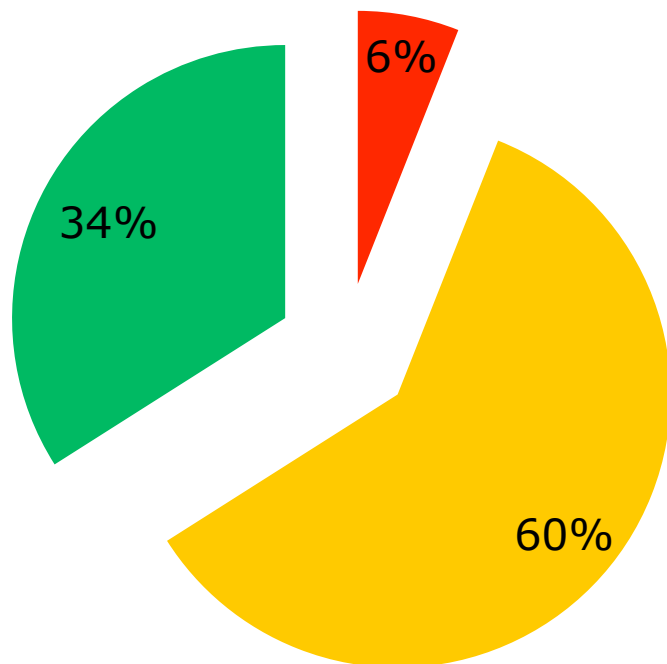


| | Number of AC's |
|---------|----------------|
| < 20 | 32 |
| 20 - 40 | 63 |
| 40 - 60 | 56 |
| > 60 | 29 |



People with dementia attending

■ None ■ 5 -10 % ■ > 10 %

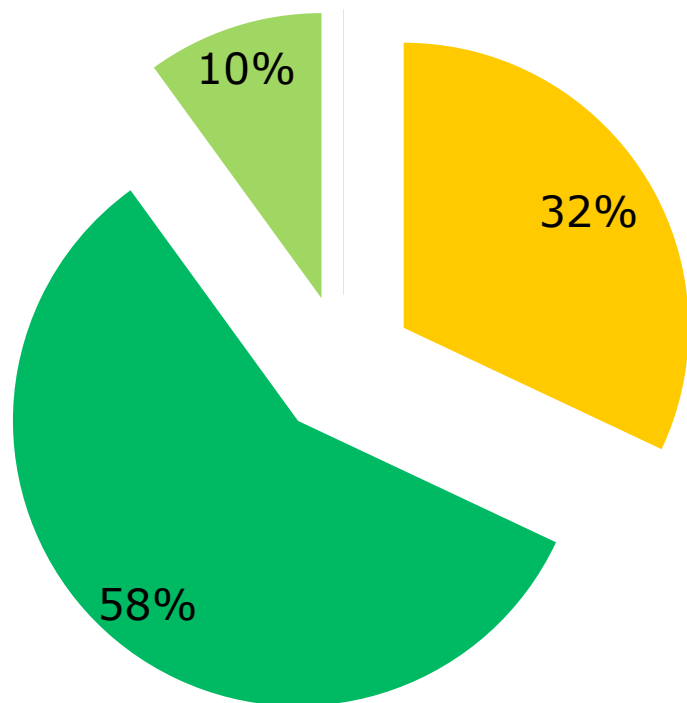


| | Number of AC's |
|---------|----------------|
| None | 11 |
| 5 -10 % | 108 |
| > 10 % | 61 |



Family carers attending

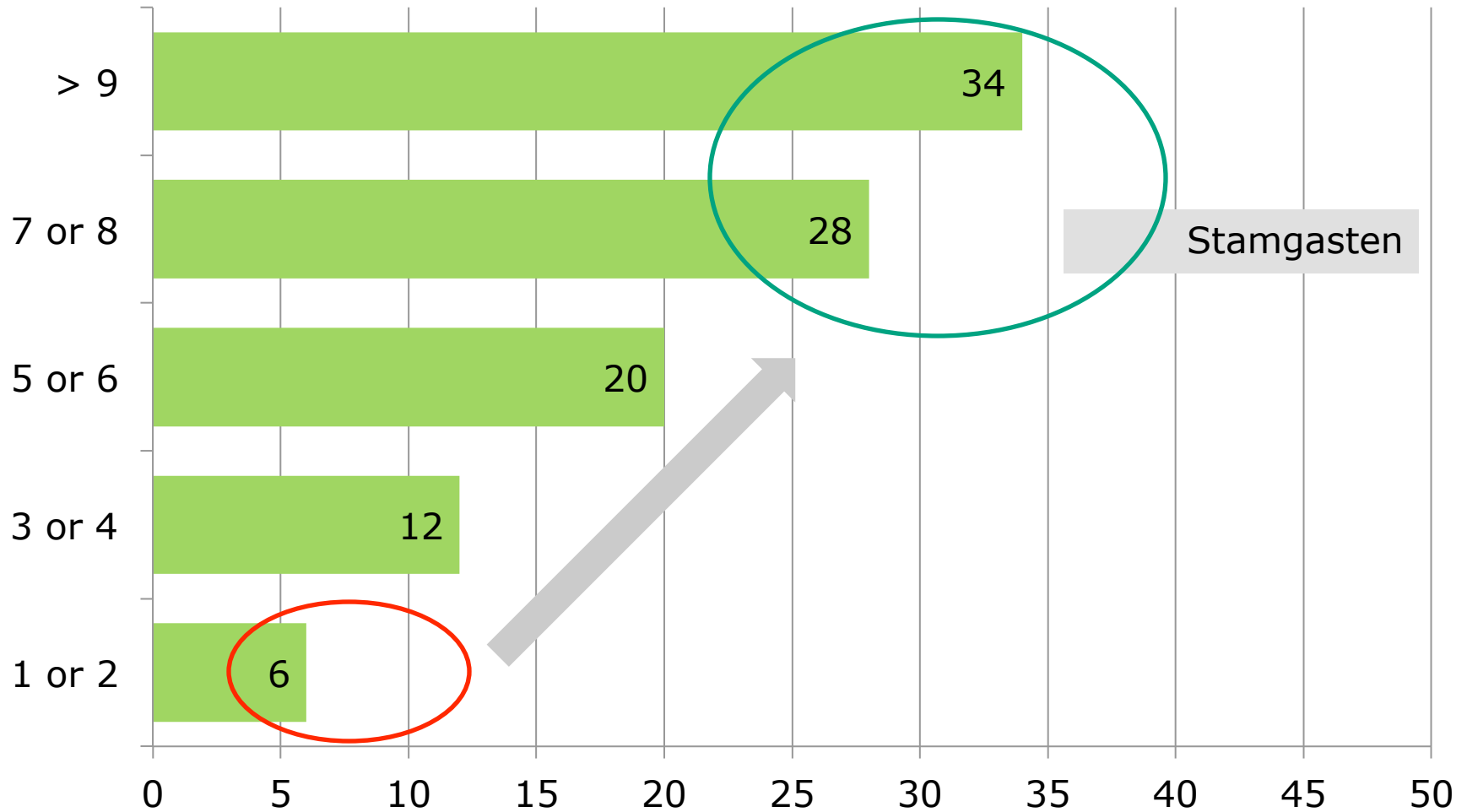
■ 30 - 50 % ■ 50 - 70 % ■ > 70 %



| | Number of AC' s |
|-----------|-----------------|
| < 30% | 0 |
| 30 - 50 % | 58 |
| 50 - 70 % | 104 |
| > 70 % | 18 |



Average number of visits per year





Alzheimer Cafés: in numbers

Every month:

- ☀ Number of visitors > 7,000
- ☀ Number of people with dementia > 600
- ☀ Number of family carers > 4.000

Every year:

- ☀ Number of unique visitors in a year: ± 35,000
- ☀ 'Core guests' are the majority, people with dementia and family carers. Some professionals as well.
- ☀ Number of people with dementia we reach: ± 2,000
- ☀ Number of family carers we reach : ± 15,000



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- ☀ Quality as a key issue
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Back office: support (2000 – 2005)

- ☀ Manual with practical guidelines
- ☀ Information materials (flyers, posters)
- ☀ Workshop held on annual national 'Volunteers Day'
- ☀ National meetings for regional branches
- ☀ National training for 'discussion leaders' by Bère Miesen



Back office: support (2006 – 2010)

- ☀ Manual with practical guidelines
 - ☀ Information materials (flyers, posters)
 - ☀ Workshop at annual national Volunteers Day
 - ☀ National meetings for regional branches
 - ☀ National training for discussion leaders
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- ☀ Manual with practical guidelines
 - ☀ Information materials (flyers, posters)
 - ☀ Regional meetings for volunteers in Cafés
 - ☀ Regional training for discussion leaders
 - ☀ 'Train-the-trainers' programme by Bère Miesen



Back office: standards

- ☀ Alzheimer Café , registered by a European trademark
- ☀ Development of a set of quality criteria
- ☀ Bi-annual survey amongst Alzheimer Cafés

- ☀ Regular contact with working group
- ☀ Volunteer of the regional branch as contact person
- ☀ Alzheimer Nederland 'owns' information table

- ☀ Alzheimer Café is part of the 'Dementia' guidelines (drawn by Ministry of Health, National body of Health Insurance companies and Alzheimer Nederland)



Topics

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- ☀ Back office (strategy, support and standards)
- ☀ **Quality as a key issue**
- ☀ International development



Some quality criteria

- ☀ Non-profit; free admission, [free or] normal prices for drinks
- ☀ Monthly / At least ten times a year
- ☀ Avoid cancelling two meetings in a row

- ☀ 'Year programme' should cover whole range [of themes]
- ☀ Emphasis on emotional and psychosocial aspects
- ☀ Information preferably by means of an interview

- ☀ A variety of professionals play an active role
- ☀ Involvement of regional branch of Alzheimer Nederland
- ☀ If there are no people with dementia, it is not a 'real' Alzheimer Café



[Dutch] Trained discussion leaders

- ☀ Experienced in supporting patients/family carers
- ☀ Multidisciplinary knowledge about dementia
- ☀ Therapeutic / Counselling and group work [background]
- ☀ Plays an exemplary role in communicating
- ☀ Emphasis on openness versus avoidance
- ☀ Responsibility and continuity



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International development

- ☀ Belgium
- ☀ United Kingdom
- ☀ Denmark
- ☀ Germany
- ☀ Finland
- ☀ Italy
- ☀ Spain
- ☀ Greece
- ☀ Malta
- ☀ Cyprus
- ☀ United States
- ☀ Canada
- ☀ Australia
- ☀ Aruba
- ☀ Curaçao



International development: proposal

- ☀ Support other countries in founding and running Alzheimer Cafes according to the original model
- ☀ Draw up international criteria and guidelines for Alzheimer Cafes to improve the quality of life
- ☀ Enhancing and controlling the quality of the Alzheimer Cafes by a tailor-made programme
- ☀ Self-evaluation method for Alzheimer Cafes throughout the world
- ☀ International research on the effectiveness of Alzheimer Cafes in several countries
- ☀ Working together and setting the agenda



Alzheimer Nederland

International Conference of IPA

☀ The Hague, 2011

Special workshop planned
For this conference, called:
'Alzheimer University'

6-9 SEPTEMBER 2011
THE WORLD FORUM
THE HAGUE, THE NETHERLANDS

CALL FOR ABSTRACTS OPENS 1 NOVEMBER 2010
CALL FOR ABSTRACTS CLOSES 4 FEBRUARY 2011
JUNIOR RESEARCH AWARD SUBMISSION DEADLINE 29 APRIL 2011

IPA

Collaborating Organizations

- European Alzheimer's Disease Consortium (EADC)
- European Association of Geriatric Psychiatry (EAGP)
- INTERDEM (Early Detection & Timely INTERvention in DEMentia)
- Netherlands Institute of Psychologists, Section of Psychologists in the Care for the Elderly
- Netherlands Psychiatric Association, Department of Old Age Psychiatry





As in the words of

- ☀ 'Tragedy is not deep and sharp if it can be shared with friends.' *Shalamov*

- ☀ 'Friendship is not deep and sharp if it cannot be shared in times of tragedy.'