



# Young onset dementia: 'with the courage of an explorer'

Jurn Verschraegen, 18/09/2024



expertisecentrum  
dementie  
Vlaanderen

# Young onset dementia in Flanders + BXL

jongdementie			4.315	4.464	4.267	4.052	3.992	4.086	4.081	4.185	4.159	4.093	4.307
Mannen + vrouwen	per 100,000	conf.interval	2020	2025	2030	2035	2040	2045	2050	2055	2060	2065	2070
30-34	5,9	3,3-10,6	24	25	24	24	26	26	25	24	24	25	26
35-39	5,9	3,6-9,4	25	25	26	25	24	26	27	26	25	25	26
40-44	23,9	12,9-44,5	100	104	103	108	103	101	109	110	106	103	105
45-49	43,0	25,9-71,2	187	182	188	187	194	186	183	197	200	192	187
50-54	81,3	59,4-111,1	379	353	342	354	351	365	349	344	346	377	362
55-59	148,5	117,5-187,6	714	681	633	614	635	629	657	629	627	669	680
60-64	663,9	441,8-996,4	2.887	3.094	2.949	2.740	2.660	2.753	2.732	2.856	2.831	2.703	2.921
65-69			4.878	5.430	5.821	5.548	5.166	5.025	5.217	5.191	5.438	5.218	5.158
70-74			10.742	11.383	12.746	13.733	13.144	12.278	11.988	12.483	12.458	13.091	12.590
75-79			19.234	23.826	25.557	28.894	31.375	30.201	28.389	27.890	29.198	29.275	30.886
80-84			24.812	23.915	30.269	33.038	37.935	41.746	40.610	38.551	38.279	40.381	40.807
85-89			29.853	30.825	30.810	39.792	44.444	52.102	58.376	57.574	55.491	56.117	59.899
90-94			22.765	26.916	29.386	30.618	40.574	46.803	56.492	65.018	65.409	64.454	67.249
95+			5.895	6.985	9.121	10.568	11.678	15.562	18.934	23.633	28.351	29.904	30.480

# Mission

## Centres of Expertise on Dementia in Flanders

- We aim for a society that can cope with dementia
- So that every HUMAN affected by dementia, feels valued and supported.



# Mission

## HUMAN Together

- As a partner of the Flemish government, we improve the quality of life, housing and care of persons with dementia.
- We raise awareness about dementia in society and create a realistic image. We connect and strengthen persons active in the care sector. We develop and share our expertise through training, intervision, coaching and advice.



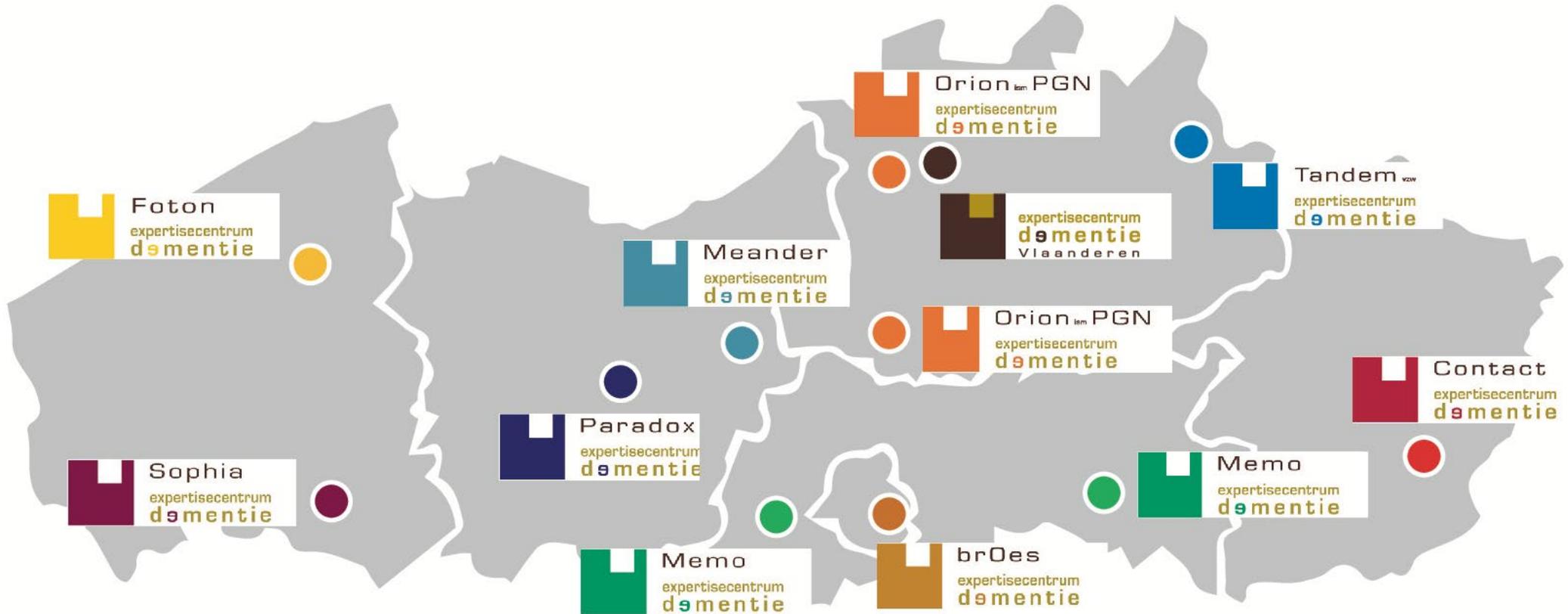
# Mission

## HUMAN Together

- We influence policy in function of good dementia care.
- We constantly keep our finger on the pulse and are innovative.
- We realise our mission in collaboration and co-creation with partners.



# Centres of Expertise on Dementia



# What we are doing

- Strengthening individuals active in the care sector
- Provide a good resource centre on dementia care for staff in the field and for those seeking good information and advice
- Connecting science and practice
- Raising awareness of the general public and society about dementia
- Informing and pointing out gaps to authorities (FLZ, municipalities)
- Keeping in touch with actual practice

# Strengthening individuals active in the care sector

- Dementia reference person
- Me, you, human together
- Dementia and you / now
- e-learnings and specific training offer through
- Dementia Consultant Physician



# Knowledge translation

- Provide a good resource centre on dementia care for staff in the field and for those seeking good information and advice. Connecting science and practice
- Example: prevention



# Dementia inclusive society

- Campaigns regarding a balanced approach on dementia
- Missing project with police services (cfr. Herbert Protocol (UK))
- Dementia friendly communities



# Digital tool YOD

- Specific demands rise
- Fragmented information
- Need for an accessible tool
- All target groups will have the same information

 dementie op jonge leeftijd

## Digitale ondersteuningstool voorstellings- en reflectiemoment



 Orion PGN  
expertisecentrum  
dementie

 expertisecentrum  
dementie  
Vlaanderen

 Vlaanderen  
is zorgzaam en  
gezond samenleven

 VLAIO - PIO statik

26 september 2024 | 13u30 tot 17u00

Marie-Elisabeth Belpairegebouw  
Simon Bolivarlaan 17, 1000 Brussel

→ Meer informatie? Neem contact op via [orion@dementie.be](mailto:orion@dementie.be)

# HR and YOD

- Document for occupational physicians
- Emphasise opportunities people still have
- Working = feeling yourself useful and of importance, daytime activities, social contact, financial security
- 'Being important' to oneself, but also to society



# HR and YOD

- General information, focus on young dementia and work
- Support for employee and family caregiver
- Support for employers
- Reference point for colleagues
- Inspiring examples, low-threshold tips



# Organisation of care for people with YOD

- Buddy work (voluntary work)
- Home care (cfr Familiezorg O-VI)
- Residential care (200 'beds' available, diagnostic bilan – 65 years)

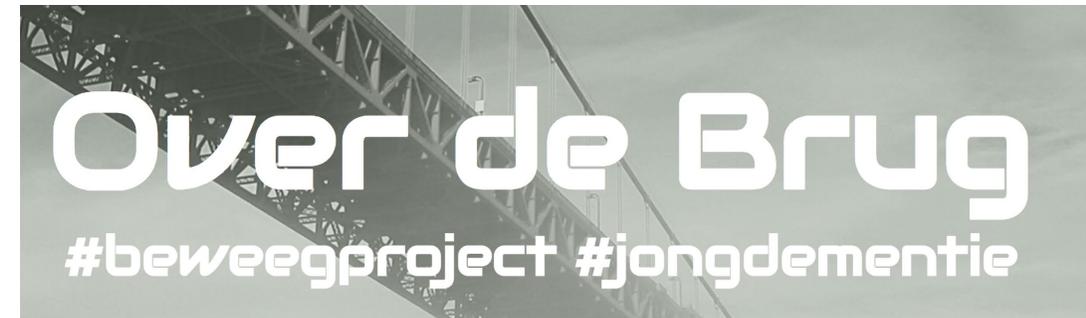


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# Buddy work





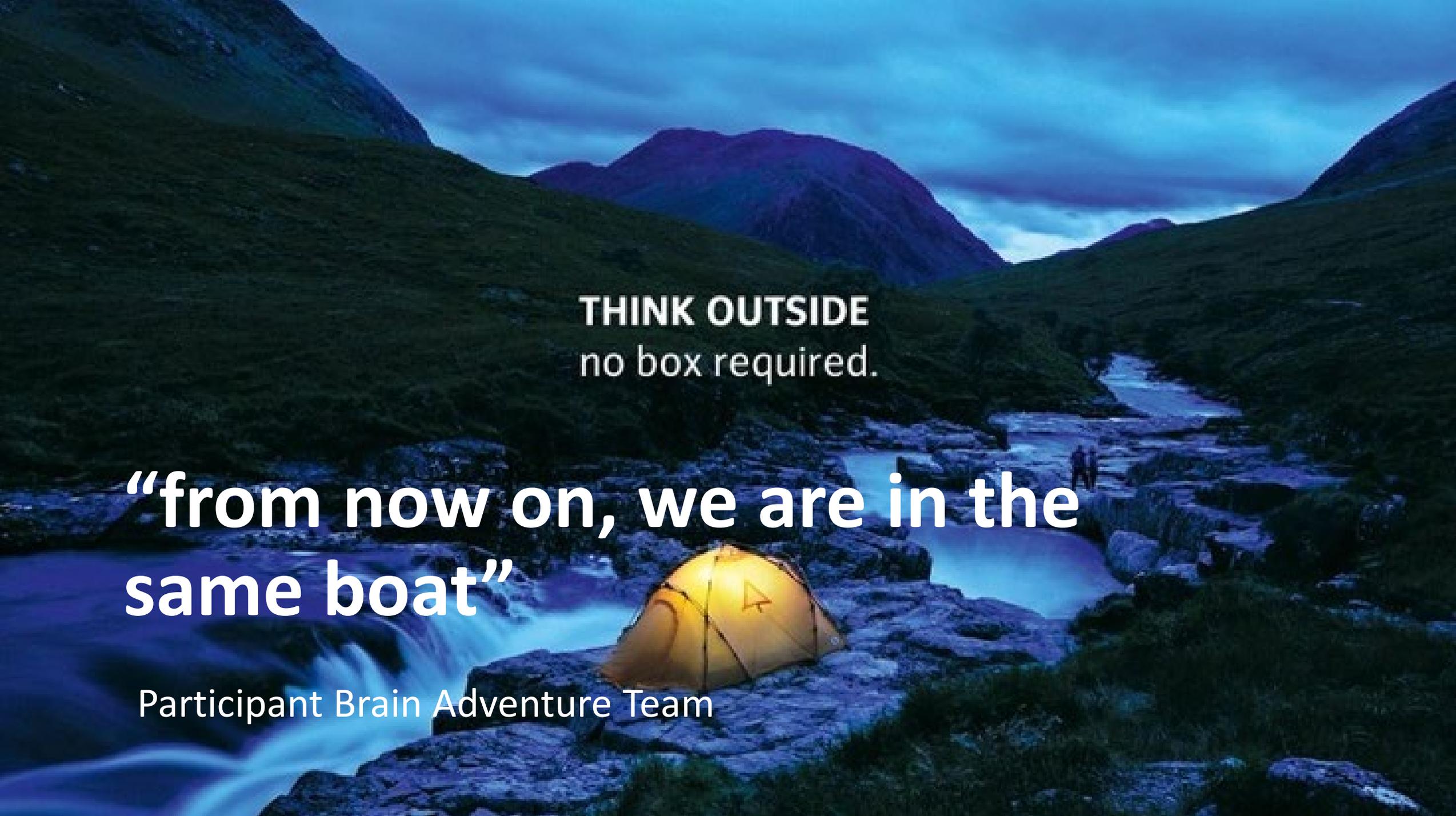
Ventiël forest

# Home care

- Meeting house – care circles Leuven
- Meeting place in day care centre(s): Bruges, Familiezorg East Flanders, ...
- Foton: information and guidance people living at home

# Residential care

- 23 specific nursing homes for people with YOD in Flanders
- Competencies of staff
- Reference persons dementia
- Regional centres of expertise on dementia involved
- Financial support +/- 30 euro / day

A scenic landscape at dusk or dawn. The sky is a deep blue with some clouds. In the foreground, a river flows over rocks, creating a small waterfall. A glowing yellow tent is pitched on a rocky bank. In the background, there are green mountains and a valley. The overall mood is serene and adventurous.

**THINK OUTSIDE**  
no box required.

**“from now on, we are in the  
same boat”**

Participant Brain Adventure Team

# MET ALZHEIMER NAAR DE ALPEN

Jurn Verschraegen Mathieu Vandenbulcke Rick de Leeuw

Een reisgids  
voor mensen  
met jongdementie



## Initiatives 'outside of the box'

- New Energy for Young Dementia Nepal
- With Alzheimer's To The Alps



**From their perspective**



## Event

# Early onset Alzheimer's disease: many mountains to climb

"The dominant image of dementia is a bedridden patient staring into the void, representing the latest stage of the disease. We wanted to show the other side of the disease by emphasizing what people with Alzheimer's disease (AD) can still do, rather than what they can't do anymore," says Mathieu Vandenbulcke.

Vandenbulcke (University Hospitals Leuven, Belgium) visualises AD as a mountain—a looming colossal obstacle of

planning, unpredictability plays a role. As it turned out airports and AD are not compatible; "safety procedures such as taking off your shoes, placing belongings in small boxes, and going through security without a companion are demanding for patients with cognitive problems. Foreign languages and non-verbal commands were difficult to understand and these stressful events had a negative impact on the cognitive abilities of our patients." Dementia-friendly environments are crucial for cognitively disabled people to compensate for deficits, but are lacking in public spaces. Another unforeseen incident was missing luggage at Kathmandu airport. However, this allowed the group to experience the city's sacred Pashupatinath, where Vandenbulcke recalls an emotional mood of end-of-life contemplation. The journey across the range towards Pokhara was relaxing, interspersed with "precious funny moments", such as one patient, a former policeman, becoming irate with the lack of traffic etiquette.

Sharing his memories of the Ghorepani Trek in the Annapurna region, Vandenbulcke's sentiment is one of triumph and pride. Spouses were amazed by what they called "moments of revival" of their partners—one helped another's wife with acrophobia cross a hanging bridge, another danced with the sherpas and a doctor in physics explained the law of gravity. Reaching the peak of Poon Hill was empowering and where the group "felt strong and safe together. with a feeling

activity-focused programmes with a buddy with training in dementia was a popular proposal. Vandenbulcke's overriding message is that life does not end with a diagnosis of AD.

Jules Morgan



Lancet Neurol 2015

Published Online  
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[http://dx.doi.org/10.1016/S1474-4422\(15\)00388-9](http://dx.doi.org/10.1016/S1474-4422(15)00388-9)



# The restaurant that makes mistakes

- 3 times on television
- Strong link between participants
- During broadcasting: ‘could we eat there’?
- Dementia friendly / inclusive?



# Building bricks of personhood

- Identity and life story
- Vulnerability, e.g. pain
- Preferences
- Personal approach and interaction
- Experiencing the social context
- Social background
- Vision of life

## *Integrated Results of the dementia-group*

Name of theme	Mentioned by	Example statements
Identity	Staff members of care organizations, scientific experts and policy makers, direct support staff, family members	"You need to know what kind of personality this person used to have." "You need to know what the person's life story is."
Vulnerabilities	Staff members of care organizations, direct support staff, family members	"You need to know if there have been certain (severe) traumas in the past." "You need to know if the person is in pain and where the person is experiencing pain."
Preferences	Staff members of care organizations, direct support staff	"You need to know what the person can enjoy." "You need to know whether the person prefers crowds or tranquility."
Personal approach and interaction	Staff members of care organizations, direct support staff, family members	"You need to know how to establish genuine connection with the person." "You need to know how to sense the person."
Experience of social context	Scientific experts and policy makers, family members	"You need to know what your own frame of reference is when describing the person." "You need to know that you lose the person multiple times (e.g., diagnosis, moving, loss of contact, and when they pass away)."
Social background	Scientific experts and policy makers, direct support staff	"You need to know the person's family context (history, the family they have formed)." "You need to know who is allowed to be near the person."
Vision of life	Scientific experts and policy makers, direct support staff	"You need to know the person's spiritual background." "You need to know how the person wants to live."

# Personhood (Kathy Ryan)



# WHO conference on dementia

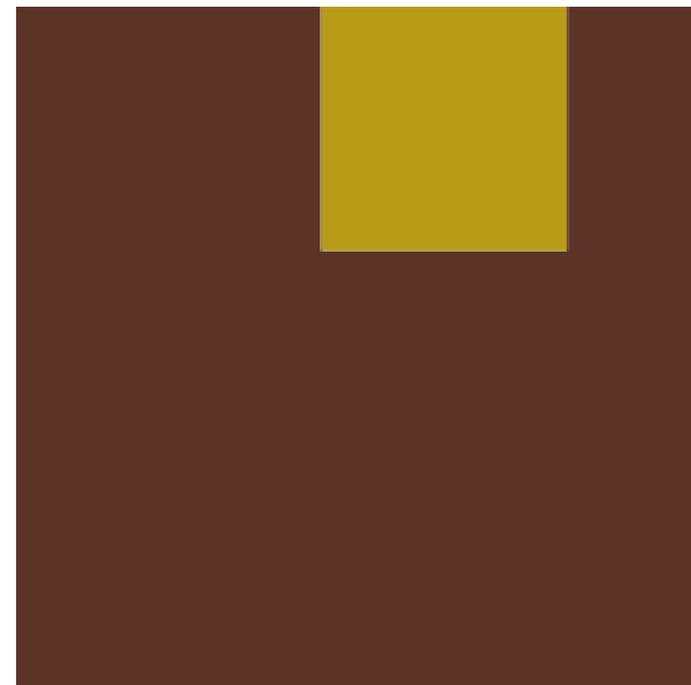


# Lobby work

- Flemish Parliament: resolutions regarding YOD
  - Demand for a individualised budget that follows the person with YOD
  - Dementia Plan Flanders 2021 - 2025
  - Eyes and ears in the field, and always with regard to the target group
- 
- With the courage of an adventurer!



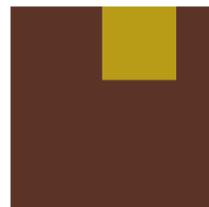




# Thank you for your attention

<https://tinyurl.com/52rc3yea>

<https://www.linkedin.com/in/jurnverschraegen/>



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