

CASCADE Virtual Final Conference: 2nd February 2023

Cooperation with people with dementia and policymakers in developing and changing dementia care

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&

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Flanders Centre of Expertise on Dementia

www.cascade-dementia.eu

► Krachtig samenwerkingsverband



The Flemish Dementia Plan 2021-2025

Interreg 
2 Seas Mers Zeeën

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Set-up (1)

- Third plan in a row, after evaluation of the previous two plans
- Points out the main action-points, as defined by the Flemish government with the input of others
- Coordinator within EDV as partner-organisation = unique
- Input for the development through focus groups:
 - People with dementia
 - Family caregivers
 - Practitioners
 - Policy-makers
 - And others

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The Flemish Dementia Plan 2021-2025

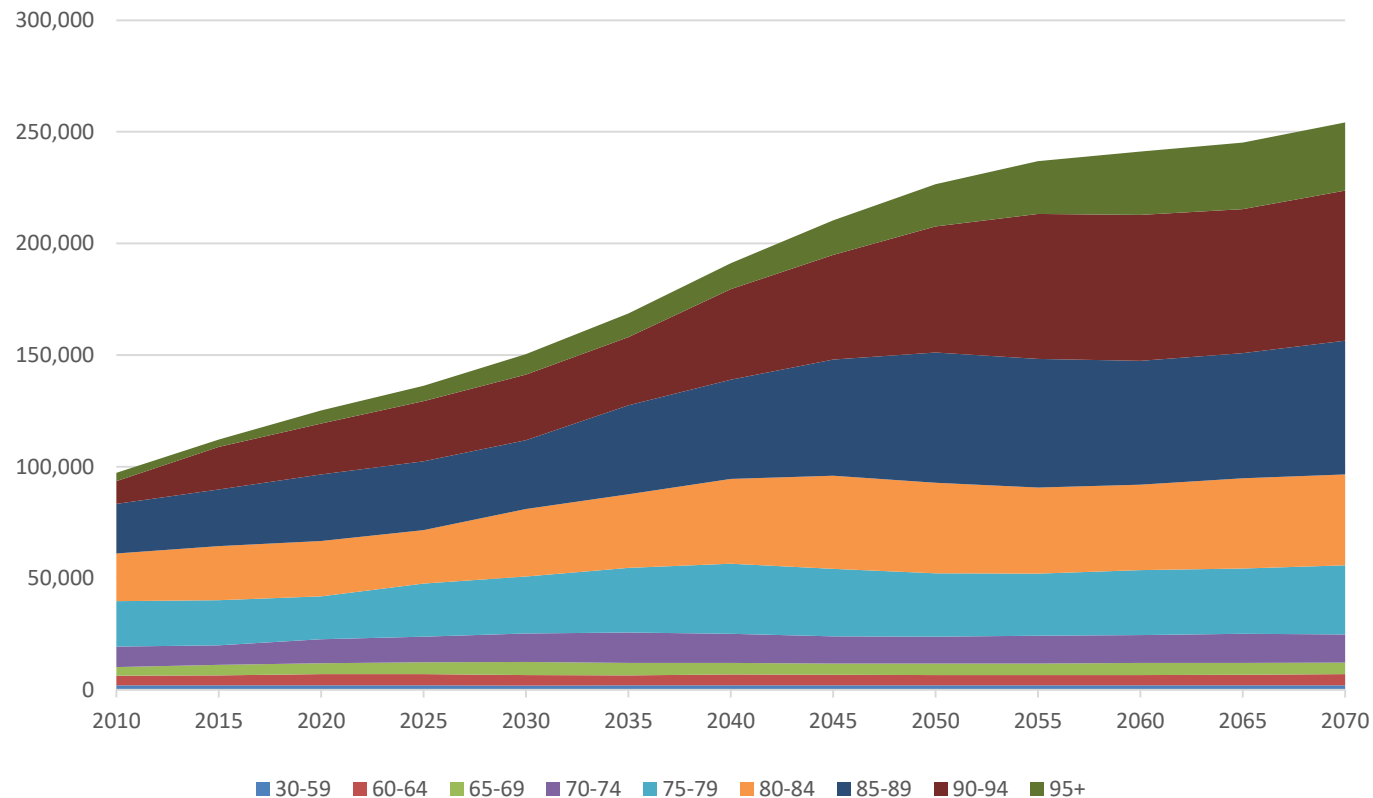
Main content: seven themes



1. Prevalence: update of the numbers
in order to inform policy-makers

Prevalence of dementia

In the Flemish community, excluding the Brussels community



Sources:

- Steyaert, J. (2020). Toekomstige prevalentie van dementie, welk scenario wordt het? . *Tijdschrift voor Geneeskunde*, 76(17), 803-805.
- Steyaert, J. (2021). Prevalentie: hoeveel personen in Vlaanderen hebben dementie? . In Expertisecentrum Dementie Vlaanderen (Ed.), *Dementie. Van begrijpen naar begeleiden. Handboek voor referentiepersonen dementie en andere betrokkenen*. Brussel: Politeia

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Main content: seven themes

2. Prevention: “What is good for your heart, is good for your brain”



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Main content: seven themes

3. Optimising the quality of care (see presentation Herlinde):

- Training personnel
- Reference framework dementia
- Reference person dementia: in different settings people take up an expert role in order to coach and inform their colleagues, set up a policy framework for the organisation

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Main content: seven themes



4. Optimising person-centred care (1):

- Easy-access to information: rewriting dementie.be
- Advanced care planning

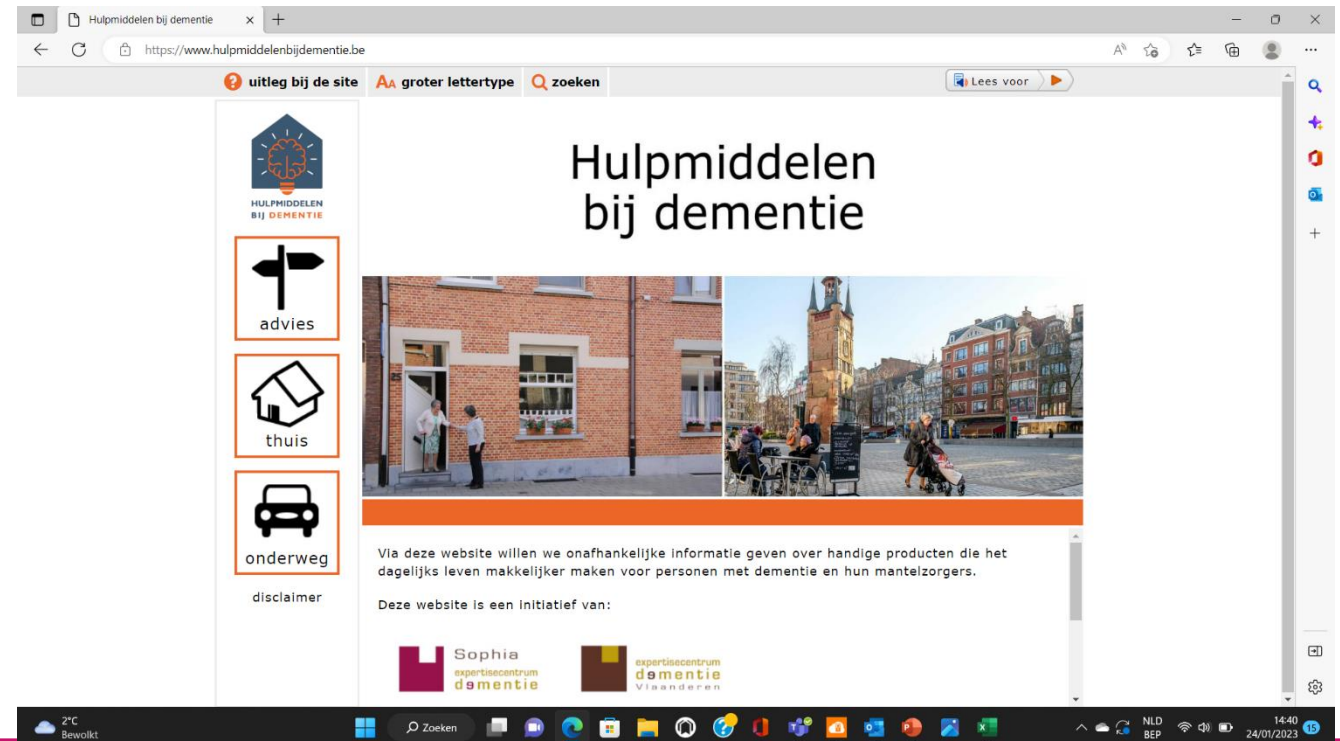
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Main content: seven themes

4. Optimising person-centred care (2):

- Assistive technology



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Main content: seven themes



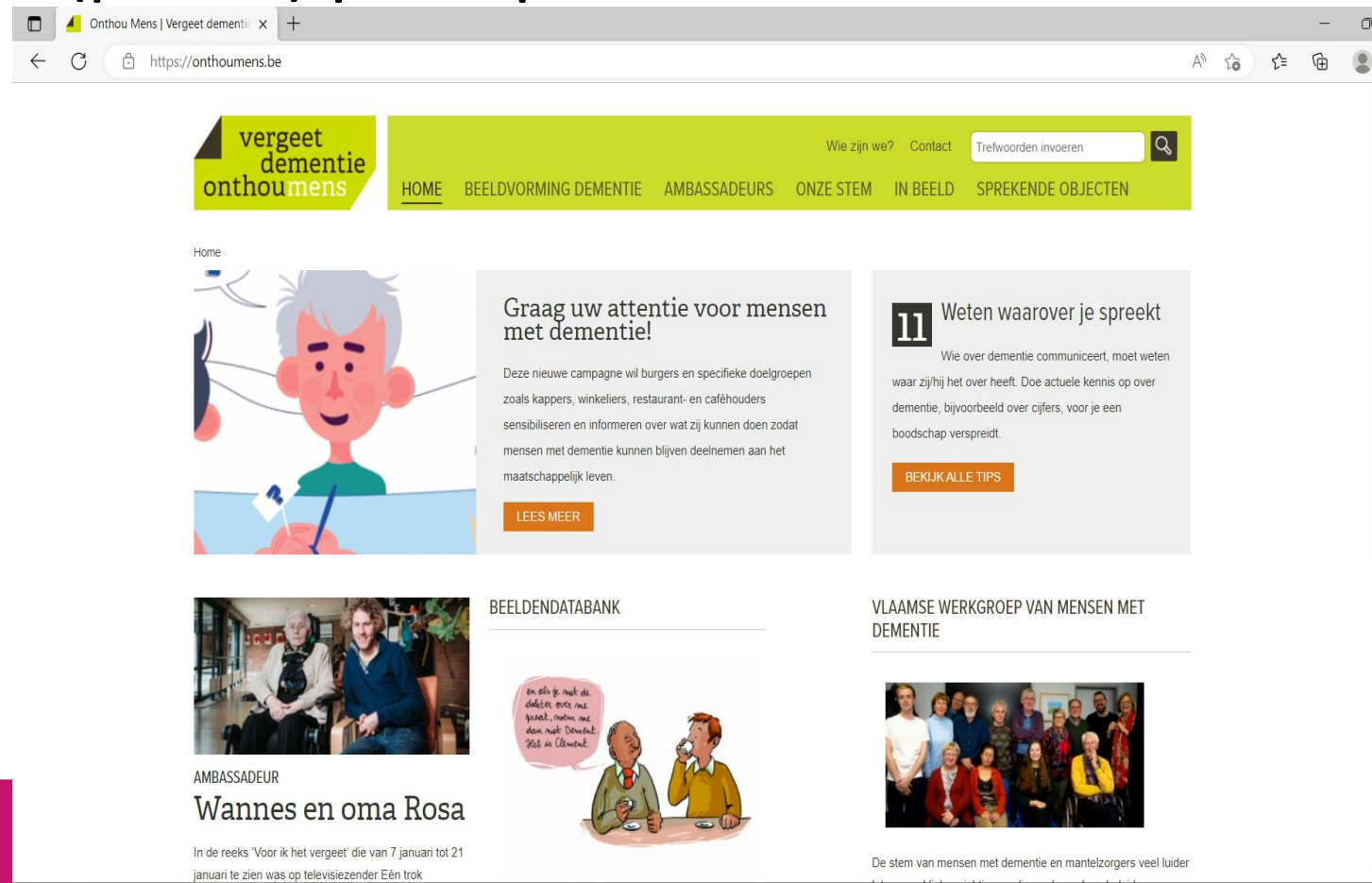
5. Optimising specific support for family caregivers:

- Training
- Buddies
- Peer support groups
- Developing digital support tools

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Main content: seven themes

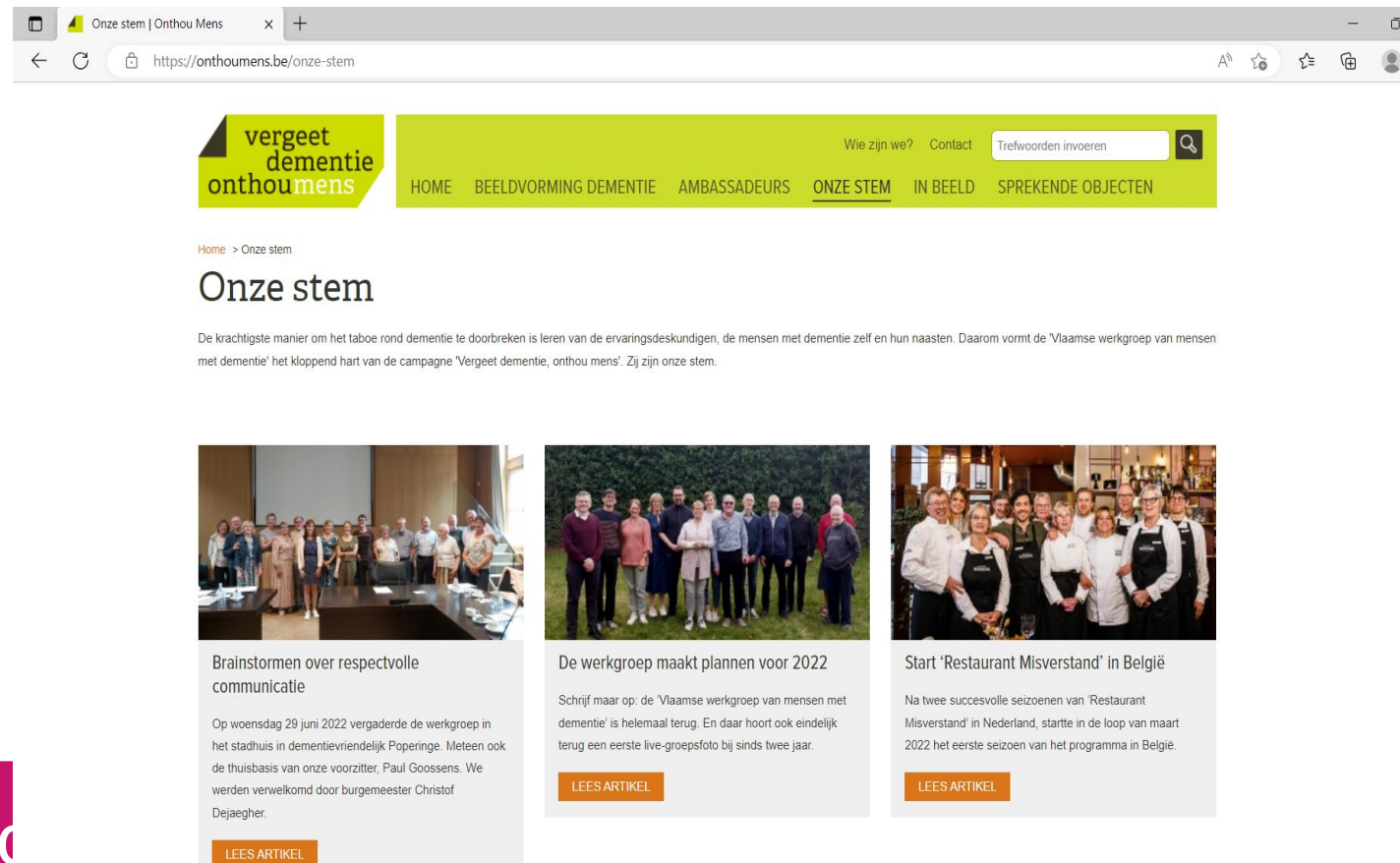
6. Nuanced (public) perception:



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Main content: seven themes

6. Nuanced perception: Working Group People with dementia also informs policy-making



The screenshot shows a web browser displaying the 'Onze stem' website. The browser's address bar shows 'https://onthoumens.be/onze-stem'. The website has a green header with the logo 'vergeet dementie onthou mens' on the left and navigation links 'HOME', 'BEELDVORMING DEMENTIE', 'AMBASSADEURS', 'ONZE STEM', 'IN BEELD', and 'SPREKENDE OBJECTEN' on the right. Below the header, the page title is 'Onze stem'. A paragraph of text explains the purpose of the website: 'De krachtigste manier om het taboe rond dementie te doorbreken is leren van de ervaringsdeskundigen, de mensen met dementie zelf en hun naasten. Daarom vormt de 'Vlaamse werkgroep van mensen met dementie' het kloppend hart van de campagne 'Vergeet dementie, onthou mens'. Zij zijn onze stem.' Below this text are three article cards. The first card is titled 'Brainstormen over respectvolle communicatie' and mentions a meeting on Wednesday 29 June 2022. The second card is titled 'De werkgroep maakt plannen voor 2022' and mentions a group photo. The third card is titled 'Start 'Restaurant Misverstand' in België' and mentions the start of a program in Belgium. Each card has a 'LEES ARTIKEL' button.

vergeet dementie onthou mens

Wie zijn we? Contact Trefwoorden invoeren

HOME BEELDVORMING DEMENTIE AMBASSADEURS ONZE STEM IN BEELD SPREKENDE OBJECTEN

Home > Onze stem

Onze stem

De krachtigste manier om het taboe rond dementie te doorbreken is leren van de ervaringsdeskundigen, de mensen met dementie zelf en hun naasten. Daarom vormt de 'Vlaamse werkgroep van mensen met dementie' het kloppend hart van de campagne 'Vergeet dementie, onthou mens'. Zij zijn onze stem.

Brainstormen over respectvolle communicatie

Op woensdag 29 juni 2022 vergaderde de werkgroep in het stadhuis in dementievriendelijk Poperinge. Meteen ook de thuisbasis van onze voorzitter, Paul Goossens. We werden verwelkomd door burgemeester Christof Dejaegher.

LEES ARTIKEL

De werkgroep maakt plannen voor 2022

Schrijf maar op: de 'Vlaamse werkgroep van mensen met dementie' is helemaal terug. En daar hoort ook eindelijk terug een eerste live-groepsfoto bij sinds twee jaar.

LEES ARTIKEL

Start 'Restaurant Misverstand' in België

Na twee succesvolle seizoenen van 'Restaurant Misverstand' in Nederland, startte in de loop van maart 2022 het eerste seizoen van het programma in België.

LEES ARTIKEL

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Main content: seven themes



7. Specific target groups

- People with young-onset dementia
- Diversity
- People with disabilities

The Flemish Dementia Plan 2021-2025

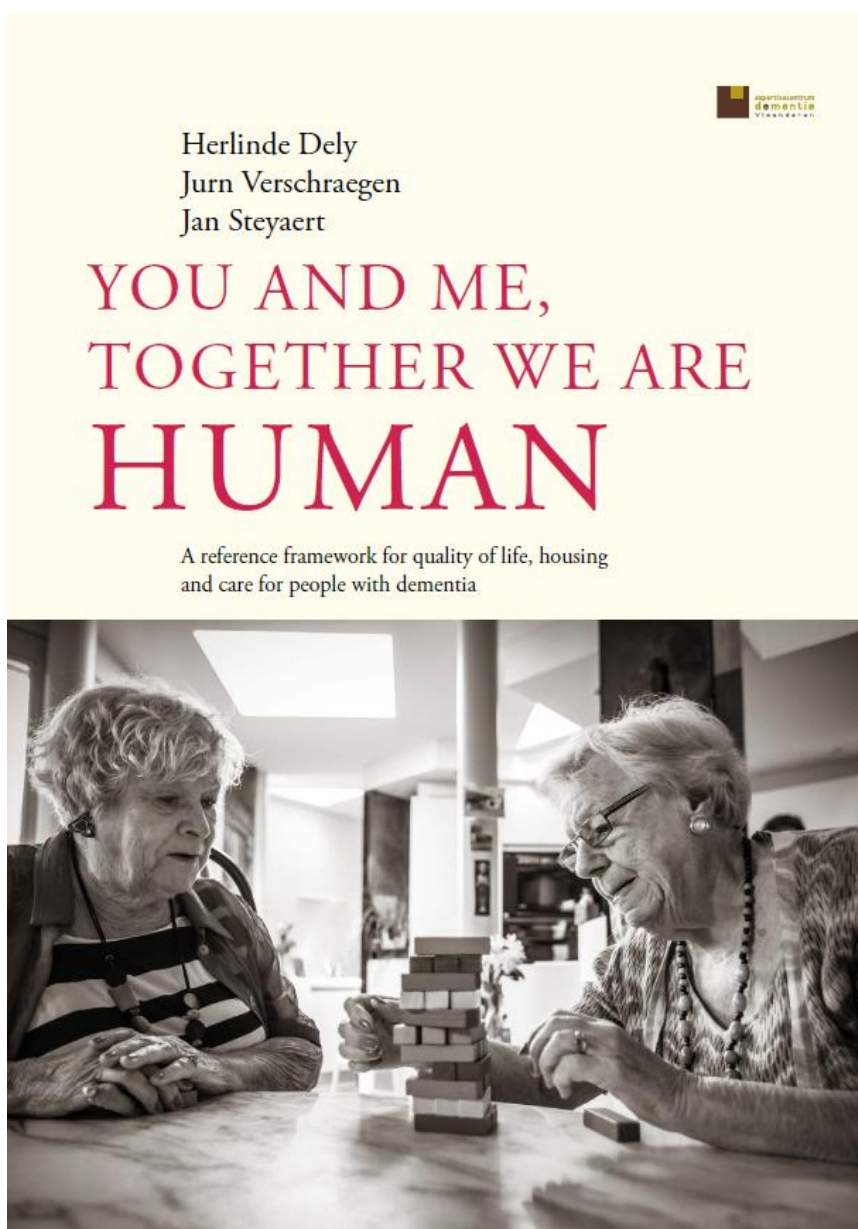


Challenges and chances

- Different political domains to be covered
- Change of minister
- Plan provides a framework but need for ensuring its actual implementation: monitoring committee and coordinator
- Involving people with dementia throughout the process, also in the monitoring committee
- Importance of care at home and family doctors: challenge for the future



Person-centered care



- On behalf of the Flemish Ministry of Welfare, Public Health and Family
- 2016 -> 2018
- Intersectoral publication

Herlinde Dely
Jurn Verschraegen
Jan Steyaert

**YOU AND ME,
TOGETHER WE ARE
HUMAN**

A reference framework for quality of life, housing
and care for people with dementia



- Why?
- Shift: from medical model to wellbeing model
- ‘Empty words’
- Intersectoral gaps
- 141.000 PwD Flanders
- Negative public perception

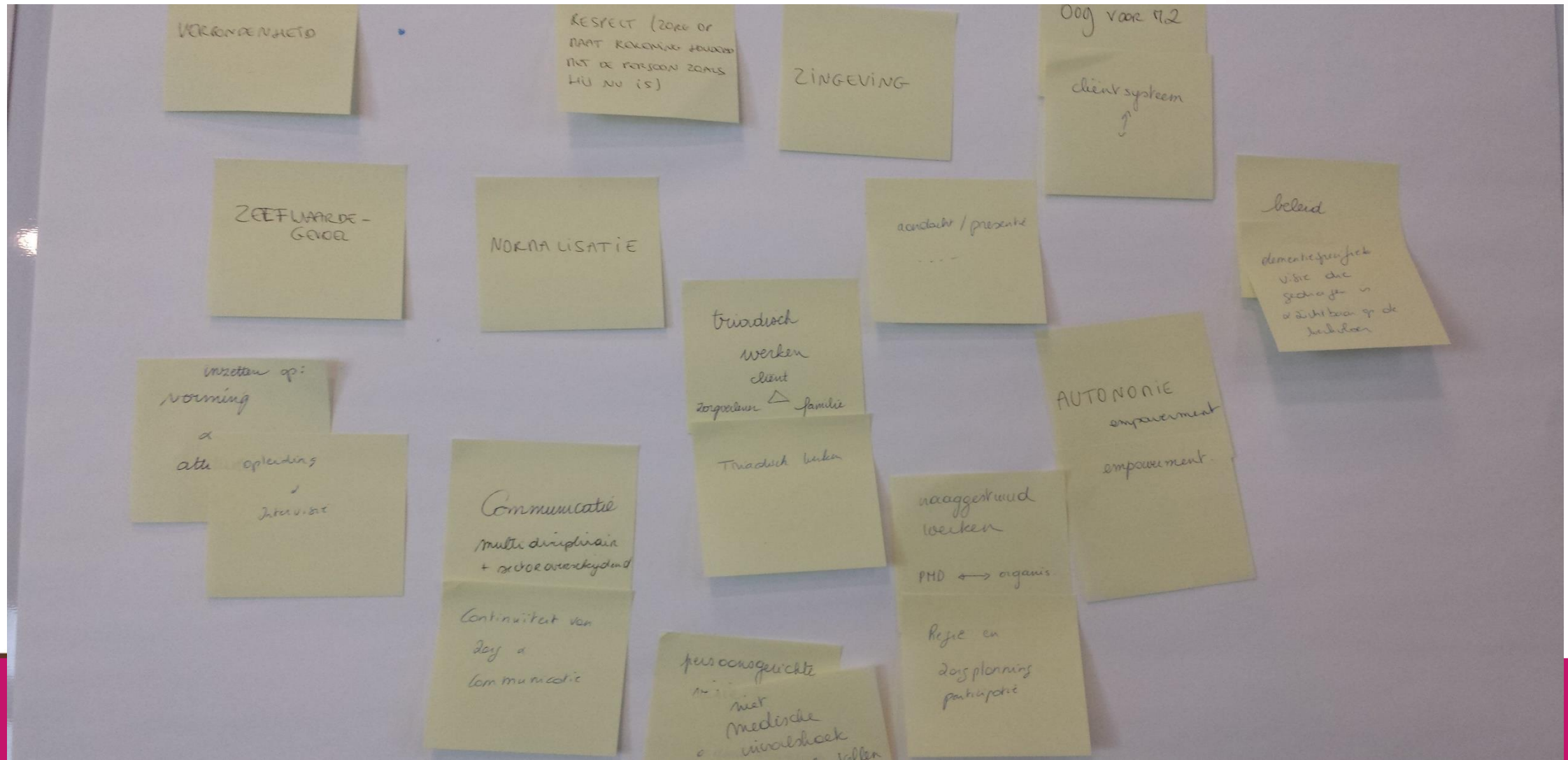
Inspirational framework
Holistic
Person-centred

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A process of cocreation



Cocreation



Vlaanderen
is zorg



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2017 & 2018

- Reading group > 50 people
- Experts per topic
- Working group dementia friendly hospitals
- Focus groups with family caregivers
- Brainstorms with professionals
- Interviews with people with dementia
- Interviews with experts
- Study visits abroad
- Observations in the working field
- ...

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Jan Steyaert



YOU AND ME, TOGETHER WE ARE HUMAN

A reference framework for quality of life, housing
and care for people with dementia



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Vlaanderen

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Jurn Verschraegen
Jan Steyaert



IK, JIJ, SAMEN MENS

Een referentiekader voor kwaliteit van leven, wonen en zorg
voor personen met dementie



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from human to human
connection
feeling human
feeling equal
freedom
love

enough food
helping in the kitchen
to plant, sow and blossom
painting
light in the dark
decide for myself what to do
staying home as long as possible
carrying the burden together
acceptance
sympathize with
respect
no pain
warmth
relief
finding peace
trust
showing interest
releasing frustration
affection
doing nice things
friendship
with heart and soul
sitting on a chair in the garden
making time
friendliness
going to bed
decide for myself when going to bed
grabbing an outstretched hand
supporting each other
cleanliness
having a garden
reading
going for a walk
making each other smile
taking care of my neighbour
trust someone
willingness
close
no stress
joy
freedom
feeling equal
feeling human
connection
patience
tenderness
being guided
getting up at my own rhythm
togetherness
helping each other
being myself
looking forward
doing household chores
being guided
getting up at my own rhythm
togetherness
helping each other
being myself
looking forward



HEARTWARE > HARDWARE

Personal and public
perception

Normalisation principle

Independence in
security

Personalised care

Family caregivers

The professional carers
and volunteers

THE CARE RELATIONSHIP

A publication. And then...?

- 2018: publication & big conference
- 2019: **active dissemination**
 - Conferences in every province of Flanders
 - Integration in every regional training
 - **Call for 6 pilot projects (2019)**
 - **Call for 20 pilot projects (2021)**





Herlinde Dely
Jurn Verschraegen
Jan Steyaert



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Een referentiekader voor kwaliteit van leven, wonen en zorg
voor personen met dementie



Media
coverage

Educational
package +
competition

English
summary

Travelling
exposition

Umbrella
organisations

Training

Study visits

...

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A publication. And then...?

- 2018: publication & big conference
- 2019: active dissemination
- **Future??**



Key element? Reference person dementia!

- Eyes & ears!
- Knowledge
- Fire

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