**Programme**

10.00 - 10.30  Welcome and coffee
10.30 - 11.00  Introductions MinD and presentation project results

*Prof dr Kristina Niedderer - University of Wolverhampton*

11.00 - 11.45  ‘Autonomous Ageing: A Role for Industrial Design’

*Prof dr Tischa van der Cammen - Delft University of Technology*

12.00 - 13.00  Lunch

13.00 - 13.30  Introduction to Mindful design workshop
13.30 - 14.30  Interactive workshop - break out in groups
14.30 - 15.00  Plenary presentations
15.00 - 16.00  Closure and drinks
MinD Design Workshop

Dr Kristina Niedderer
Professor of Design and Craft
MinD Project Co-ordinator
University of Wolverhampton, UK

www.designingfordementia.eu

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 691001. This document reflects only the author’s view and the Research Executive Agency is not responsible for any use that may be made of the information it contains.
Project aims

Support people with dementia and their carers
• subjective well-being and self-empowerment
• meaningful social engagement

Using design and mindfulness theory/practices

Two foci:
• designing to help with personal difficulties/opportunities with social engagement (e.g. emotion management, face recognition)
• Designing the environment to help with social engagement (e.g. mood stimulation - relaxing)
European H2020 - MSCA RISE project
4 Years: March 2016 – February 2020
15 partners – 7 countries
Inter-sectoral & cross-disciplinary
MinD project phases

12 months

Mindfulness framework

Dementia care framework: data collection

Design phase: personal and environmental design

Dementia care framework: evaluation phase

Management, training and dissemination & project completion

48 months
MinD project work to date

Mindful design framework for design in dementia care

Conduct data collection with people with dementia and carers

Design process and idea development
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Mindfulness

Two major theoretical frameworks defining mindfulness:

Meditation based mindfulness (Jon Kabat-Zinn)
as paying attention in a purposeful manner, in the present moment, and non-judgmentally: without moral and emotional assessments

Cognitive-based mindfulness (Ellen Langer)
as the process of not relying on automatic categorisations from the past but actively making new distinctions about a situation and its environment
Mindfulness for people with dementia

Positive effects of mindfulness interventions on older adults

• Without cognitive impairments:
  ↗ of wellbeing, ↗ of cognitive functioning, ↗ increase of sleep, and ↘ of pain (Chiesa et al., 2011; Morone et al., 2009)

• With mild cognitive impairment or mild dementia:
  ↗ of quality of life, ↗ of cognitive flexibility, and ↘ of depressive symptoms (Paller et al., 2015)
Mindfulness for people with dementia

Currently: mindfulness mainly used to ameliorate stress in carers

Using mindfulness to support people with dementia (and their carers)

Embed mindful support through design
Mindful design approaches

Meditation based mindful design

Design for meditation based mindfulness approaches: light globe for mental health therapy (Thieme et al. 2013)

ICT based intervention (App) administering meditation based mindfulness training: thought distancing training (Chittario and Vianella 2013):

“AEON allows the user to enter his/her thoughts and visualize them as written in ink on a parchment placed under water. By touching the screen, the user can interact with the water and produce waves that progressively dissolve each written thought.”

Cognitive-based mindful design

Dementia Care Model
& Data Collection

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Qualitative interviews and diaries: **aim**

To investigate in persons with dementia

- Relevant factors that influence daily living and social engagement as a consequence of dementia
- How that changes their lives and how they feel about that
- To learn more about what persons with dementia consider as meaningful for their personal lives
- To learn more about what would support decision making and empowerment
- To learn about acceptance of assistive devices
Qualitative interviews and diaries: methods

Data collection materials

- Interview materials
- Cards
- Visual diaries (do-books)

Schedule for data collection

- September 2016-March 2017
- In 3 countries: Netherlands, Spain and Germany
## Overview over data collection

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<th>Spain</th>
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<td>Focus Group Caregiver</td>
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<td>Focus Group PwD</td>
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<td>Interview Caregiver</td>
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<td>Interview PwD</td>
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<td>Diary</td>
<td>3</td>
<td>5 + interview</td>
<td>1</td>
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</tbody>
</table>

Total ca.: 35 people with dementia; 25 informal carers
Interview questions

Activities of Daily Living?
What are meaningful activities to you?
How are social contacts in your present life?
How does decision-making work in your present life?
Where do you personally feel empowerment?
Where do you personally feel disempowerment?
What are you most afraid of losing in your present life?
Regarding assistive devices, please share you experience and your opinion with us
Literature review and interviews: first impressions

Literature

• Very little literature on qualitative interviews in PwD
• Decision-making/empowerment are related to making of an Action Plan for Dementia Care or Advance Care Planning
• Caregiver and person with dementia differ in their perspectives (e.g. Gibson et al., 2015: assistive devices)
• Having something expected of them; gaining a sense of empowerment in their everyday lives (Olsen et al., 2015: exercise program)
• Making process of mealtimes for persons with dementia and family partners: staying connected, honouring identity and adapting to their evolving life (Keller et al., 2015: Eating Together Study)

Interviews

• Caregivers tend to take a deficit-oriented perspective
• Occupation = doing ‘something’, no focus on meaningfulness
Design themes extracted from the data collection
Self-value: Insecurity and lack of confidence

Noticeable changes can lead to feelings of insecurity, about the future and about personal abilities. Starting to lose things or disorientation can lead to lack of confidence to do things autonomously. Eventually, self-value can be affected.

"I feel emotionally strong when others respect me."

"Making a grocery shopping list together makes me feel secure."

"I am not an interesting person anymore."

"I am too slow to follow discussions in the family."

"Feeling no pride in my skills; I wouldn't know what to feel pride for."

"I get nervous the moment I have to do something... and I distract myself and I do not remember, so I get even more nervous and it worries me."

"I feel emotionally strong when others respect me."
Needing to be needed. Helping others

Continuous need to feel needed and useful by helping others. People with dementia have many skills and can be useful to others in many ways. This is not always recognized.

“I loved to take care of the grandchildren when the school called.”

“It motivates me to help others that are more physically or mentally impaired than I am. It makes me feel happy when people smile at me thankfully and ask for my help again.”

“I love to cook but nobody comes to eat with me.”

“I love needlework but nobody needs what I produce.”

“It is important to me to help others. - dependent on my health.”

“It gives me great satisfaction to be able to help, even if it is indicating to a person a direction that seeks. It forces me to think and order what I am going to say in order to help.”
Understanding and negotiating between carer and person with dementia

Carers sometimes worry when a person with dementia wants to do certain activities. A person with dementia needs autonomy and may feel very capable. This requires mutual understanding and sometimes negotiation.

“I want my children to be happy seeing that I am still able to take care of myself.”

“My daughter helps me with the financial management but she doesn’t ask me when I spend my money.”

“I am living with my sister and I respect her. Normally we discuss things and we usually agree in the end.”

“At home we have freedom to say what we think and decide together.”
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applying mindful design within MinD

Design review
Design themes
Design development
Co-design
  - Workshop
  - Co-research
9 DESIGN THEMES
@LUXEMBOURG

VISIT 14
@BARCELONA

Brainstorming 1
Design themes

Reorganize
Mindful design topics

Brainstorming 2
Design topics

Visualize
Overview chart design concepts
+ individual charts
<table>
<thead>
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<th>MIND - DESIGNCONCEPTS MATRIX - OVERVIEW</th>
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<td>1. POSITIVE SENSE</td>
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<td>5. CHANGE OVER TIME</td>
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<td>6. TOOLS FOR RENOVATING YOUR LIFE</td>
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Triangulation of data for the design development

Data

Existing designs

Mind design ideas

Map
Relating data, existing design projects and mindful design ideas: 7 transition areas
Triangulation of data for the design development 2

- Personas
- Transition areas
- Mind design ideas

Develop Tangible design ideas
MinD Design Workshop

Keynote

Lunch

Workshop:
- share results with you
- get involved
- ask your input
- working for you
Thank you

www.designingfordementia.eu
‘Autonomous Ageing: A Role for Industrial Design’

Tischa van der Cammen, MD, PhD
Professor of Autonomous Ageing
Delft University of Technology

t.j.m.vandercammen@tudelft.nl
Content

I. Background: Ageing, Multimorbidity, Functional Limitations

II. Autonomous Ageing: definition and care context

III. New Technologies: Role for Industrial Design

IV. Focus on:
   • Falls prevention
   • Dementia care
   • Integrated care

V. Conclusions and Take Home Messages

VI. Outlook on the Future
Autonomous Ageing: Bridging the gap between Care and Technology
Designed for Kids

Thames & Hudson
I. Background

- Increasing number of older people
- New government policies
- Decreased support at home
- Increasing role for Design and technology

World Ageing

- The world is ageing rapidly.
- Between 2000 -- 2050, the number of people aged ≥65 will double as a proportion of the global population, from 7% to 16%.
- By 2050, there will be more people aged ≥65 than children (aged 0–14 yrs).
- There will be a tremendous increase in the oldest old, aged ≥85.

http://esa.un.org/unpp
http://www.who.int/topics/ageing/en/
The Ageing Process

Ageing is a multidimensional process of change:

• Physical
• Mental
• Social

Leading to **functional decline**

High inter-individual variety
Ageing leads to functional decline

- Limitations in Activities of Daily Living and mobility
  - ↑ Fall risk

- Sensorial limitations
  - ↓ Eyesight, hearing, taste, smell, perception
  - ↑ Risk of malnutrition

- Autonomous nervous system changes
  - ↑ Risk of orthostatic hypotension
  - ↑ Risk of hypothermia
Ageing is associated with multimorbidity

**Multimorbidity**

- The co-occurrence of 2 or more chronic medical conditions in one person
- Correlates with age
- Represents the *most common "disease pattern"* in the elderly
- Leads to *polypharmacy* and *fragmentation of care*
The geriatric patient: Accumulation of diseases and risk factors

A Linear

- Risk factor
- Early Disease
- Advanced Disease

B Interactive Concentric

- Risk Factor Synergism
- Risk Factor B
- Risk Factor A
- Risk Factor C
- Targeted interventions
- Clinical Phenotype

II. Autonomous Ageing

Autonomy:

The freedom to determine one's own actions

In philosophy:

- The doctrine that
- the individual human
- will, is, or ought to be
- governed only by his own principles and laws
Autonomous Ageing: care context

The senior person is autonomous, in charge

At home and in care situations

Aim:

**Autonomy**
in
**comfort & safety**
with
**quality of life**
Autonomous ageing in the real world

Press releases in last week of September 2015, The Netherlands

More older patients in Accident & Emergency Rooms, accidents and falls at home, unnecessary hospital admissions (NOS)

More older patients admitted with burns, due to accidents at home, memory problems, cooking on gas, use of hot water kettles, candles, falls against radiator or heater (NOS)
III. New Technologies and Role for Industrial Design

How can Industrial Design contribute to Autonomous Ageing?
Role for Industrial Design

“Design thinking”

Design thinking is a design methodology that provides a solution-based approach to solving problems. Extremely useful in tackling complex problems that are ill-defined or unknown

• by understanding the human needs involved,
• by re-framing the problem in human-centered ways,
• by creating many ideas in brainstorming sessions, and
• by adopting a hands-on approach in prototyping and testing

• is based on the original ‘solution-based thinking’ by Nigel Cross

Role for Industrial Design, how?

By creating a link between design, technology gerontology and geriatrics, we aim to:

• **Approach and promote autonomous ageing from the viewpoint of design**

• **Solve problems for and with older adults** so they can retain their autonomy and independence in safety and comfort
Role for Industrial Design, approach

- The focus is on **supporting and reinforcing** the **reduced** physical, mental, social and functional **capacities** of older people.

- by applying **innovative design inclusive engineering methods** always starting with a **human-centered integrated approach**.
Design for whom? Population context

From a design point of view, 3 groups of older people can be distinguished:

1. **Ambitious older people**, they travel and see the world, have internet access;

2. **Domestic older people**, independent in and around the home, internet access, dependent for outdoor activities;

3. **Dependent older people**, need professional and informal care at home, usually no access to internet.
Design for whom? Care context

For the older patient and the people and systems around the patient

- Formal and informal carers
- Relatives
- Doctors
- Nurses
- Social workers

Where:
Home, hospital, rehabilitation settings
ID at TU Delft, 4 focus areas

• 1. Unlocking people

• 2. Meaningful interactions

• 3. REdUSE: Better use of the available resources so that our planet is not “used up”.

• 4. Care for our health: Healthcare, and in particular growing old with vitality.

“If we can ensure that older people can live independently for longer and the last years of life can be more pleasant, then the quality of life will be much improved”.
A Role for Industrial Design
The patient journey

is an example of user-centered design in healthcare:

https://online-learning.tudelft.nl/courses/design-in-healthcare-using-patient-journey-mapping/

It is about the different experiences patients go through in a medical context.

The patient journey *explores the interaction between the patient and the healthcare providers in all stages of the disease*; coping with treatment and dealing with expectations; and the interaction with and between different stakeholders.
IV. Focus on...

- Theme 1: Design for Falls Prevention
  - How big is the problem?
  - How can Industrial Design contribute?

- Theme 2: Design for Dementia Care
  - How big is the problem?
  - How can Industrial Design contribute?

- Theme 3: Design for Integrated Care
  - What is the problem?
  - How can Industrial Design contribute?
Theme 1: Design for Falls Prevention
Falls brought me to ID at TU Delft

Graduation Bianca Oei (2005)
Headed by Prof. Dr. Ir Chris Snijders & Dr. Ir. Armagan Albayrak

Graduation of Alen Halilovic (2014)
Headed by Dr. Ir. Johan Molenboek & Dr. Tischa van der Cammen
Falls prevention by designing an indoor shoe by Bianca Oei TU Delft-ErasmusMC
Falls in the elderly: how big is the problem?

At least one fall per year:

33% of community-dwelling people >65 yrs

50% of community-dwelling people >80 yrs
Influence of age on prevalence of falls

G, Ziere, The Rotterdam Study/PHD thesis
Postural sway and ageing

The effect of age on ‘sway’ during standing still, derived by Sheldon
Gait changes with ageing

Changes in walking pattern

- ↓ Muscle strength, unstable gait
- ↓ Reduced gait speed (♀ > ♂)
- Mean gait speed at age 77 yrs: 0.86 m/sec

Mean gait speed needed for crossing a zebra crossing during green pedestrian traffic lights: 1.22 m/sec
A fall, a minor accident?

In the category “Deaths due to accidents in the home environment among people ≥65”, falls are the number one cause of death.

NL, 2012, all ages:

Deaths due to traffic accidents: 650

Deaths due to accidents in the home environment: 3658, of which falls accounted for: 2795

www.VeiligheidNL.nl
NL, 2012: Deaths due to accidents (all ages), traffic versus home environment
Mortality due to private accidents (home environment) per 100,000 of the population in 2012

Source: CBS-NND; CBS Bevolkingsstatistiek
“Household activities”
Possible interventions on fall risk factors

Risk factors:
- Age
- Previous fall
- Diseases

Meaningful interactions:
- Shoes
- Staircases
- Environment
- Lighting
- Glasses
- Flooring
- Behaviour
- Risk recognition
- Awareness

Unlocking people
Design for falls prevention, international initiatives

A summary of international studies on Falls Prevention can be found on the website of ProFouND,

The Prevention of Falls Network for Dissemination

www.profound.eu.com
Design for Falls Prevention at ID

Video no. 1

Design of an Exochair, by Olaf Weller (2013)
Design for Falls Prevention at ID

Design of an exochair by Olaf Weller (2013)
Theme 2: Design for Dementia Care
Dementia worldwide: How big is the problem?

Proportion of the general population $\geq 60$yrs with dementia: 5-8%

Worldwide 47.5 million people have dementia at present

7.7 million new cases every year

The total number of people with dementia is projected to 75.6 million in 2030 and 135.5 million in 2050.

Dementia and ageing

Dementia is a *syndrome* including deterioration in
• memory
• thinking
• behaviour
• the ability to perform everyday activities.

Dementia mainly affects older people, but is *not a normal part of ageing*.

Alzheimer's disease is the most common cause of dementia and may contribute to 60–70% of cases.

Dementia is one of the major causes of disability and dependency, posing a major challenge for treatment and care. Patients' partners and children provide most of the informal care. Children combine their roles as caregiver with work and childcare. Risks: • Burn-out or depression, job loss • Loss of productivity on a macro-economic level. 

International design examples for dementia care include:

- Robots
- Apps
- Gaming
- Domotics
- GPS tracking
- Care platforms
Design for dementia care at ID

Videos no 2 & 3

2. Design of guiding glasses by Roeland Reitsema (2014)

http://activecues.com/en/
Design for dementia care at ID

Design of guiding glasses by Roeland Reitsema (2014)
Design for dementia care at ID
Design of a magic table for people with dementia, by Hester Anderiesen (2015)
http://activecues.com/en/
Theme 3: Design for Integrated Care
Integrated care- definition

The management and delivery of health services so clients receive a continuum of preventive and curative services, according to their needs over time and across different levels of the health system.

Ref. Waddington and Egger (2008)
Fragmentation

Underlying the current healthcare failings is a critical underappreciated problem:

Fragmentation

= Focusing and acting on the parts, without appreciating their relation to the whole

Kurt C. Stange, Ann Fam Med. 2009
Fragmented Care, How big is the problem?

No statistics available

Fragmentation of care leads to

- Inefficiency
- Ineffectiveness
- Inequality

Kurt C. Stange, Ann Fam Med. 2009
Complexity example

Frontier Economics (2012) Enablers and barriers to integrated care and implications for Monitor
Care systems are failing to cope with complexity

The complexity in the way care systems are designed leads to:

- Lack of ‘ownership’ of the person’s problem
- Lack of involvement of users and carers in their own care
- Poor communication between partners in care
- Simultaneous duplication of tasks & gaps in care
- Treating one condition without recognising others
- Poor outcomes to person, carer and the system

Frontier Economics (2012) Enablers and barriers to integrated care and implications for Monitor
Clinical Practice Guidelines and Quality of Care for Older Patients With Multiple Comorbid Diseases
Implications for Pay for Performance

Cynthia M. Boyd, MD, MPH
Jonathan Darer, MD, MPH
Chad Boul, MD, MPH, MBA
Linda P. Fried, MD, MPH
Lisa Boul, MD, MPH, MA
Albert W. Wu, MD, MPH

Context  Clinical practice guidelines (CPGs) have been developed to improve the quality of health care for many chronic conditions. Pay-for-performance initiatives assess physician adherence to interventions that may reflect CPG recommendations.

Objective  To evaluate the applicability of CPGs to the care of older individuals with several comorbid diseases.

Data Sources  The National Health Interview Survey and a nationally representative sample of Medicare beneficiaries (to identify the most prevalent chronic diseases
A 79-year old woman...

- Hypertension
- Type 2 diabetes
- Osteoporosis
- Osteoarthritis
- COPD

Her medication...

*Boyd C at al. JAMA. 2005;294:716-724*
<table>
<thead>
<tr>
<th>Time</th>
<th>Medications†</th>
<th>Other</th>
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| 7:00 AM    | Ipratropium metered dose inhaler 70 mg/wk of alendronate | Check feet  
Sit upright for 30 min on day when alendronate is taken  
Check blood sugar                                                                 |
| 8:00 AM    | 500 mg of calcium and 200 IU of vitamin D  
12.5 mg of hydrochlorothiazide  
40 mg of lisinopril  
10 mg of glyburide  
81 mg of aspirin  
850 mg of metformin  
250 mg of naproxen  
20 mg of omeprazole | Eat breakfast  
2.4 g/d of sodium  
90 mmol/d of potassium  
Low intake of dietary saturated fat and cholesterol  
Adequate intake of magnesium and calcium  
Medical nutrition therapy for diabetes‡  
DASH‡                                                                 |
| 12:00 PM   |                                                   | Eat lunch  
2.4 g/d of sodium  
90 mmol/d of potassium  
Low intake of dietary saturated fat and cholesterol  
Adequate intake of magnesium and calcium  
Medical nutrition therapy for diabetes‡  
DASH‡                                                                 |
| 1:00 PM    | Ipratropium metered dose inhaler 500 mg of calcium and 200 IU of vitamin D |                                                                   |
| 7:00 PM    | Ipratropium metered dose inhaler  
850 mg of metformin  
500 mg of calcium and 200 IU of vitamin D  
40 mg of lovastatin  
250 mg of naproxen | Eat dinner  
2.4 g/d of sodium  
90 mmol/d of potassium  
Low intake of dietary saturated fat and cholesterol  
Adequate intake of magnesium and calcium  
Medical nutrition therapy for diabetes‡  
DASH‡                                                                 |
| 11:00 PM   | Ipratropium metered dose inhaler  
As needed | Albuterol metered dose inhaler                                                                 |
Medication regimen

• 12 separate medications
• 19 doses per day
• 5 times a day

Boyd C at al. JAMA. 2005;294:716-724
Non-pharmacological treatment

14 non-pharmacological activities recommended…

How does a 79-year old woman incorporate all this?

The need for integrated care………. 
Integration, people-centered approach

“The concept of integrated care should be centered on the needs of service users, their families, and the communities to which they belong”

Goodwin N. Int J Integr Care 2016 Apr-Jun; 16(2): 15
The importance of **co-production** was recently articulated by the WHO in their recent vote to adopt a resolution to support the

*WHO Framework on Integrated People-Centred Health Services*

Design for integrated care at ID

Videos no 4 & 5

HIPP Highly Individualized Patient Project

5. Information platform by Jesse Hoeksema (2014)  
HIPP Highly Individualized Patient Project
Design for Integrated Care at ID

Personalized rehabilitation by Ana Benito Junquera (2014)
HIPP Highly Individualized Patient Project
Design for Integrated Care at ID

Information platform by Jesse Hoeksema (2014)
HIPP Highly Individualized Patient Project
V. Conclusions and Take Home Messages
V. Conclusions and Take Home Messages

- **Ageing** is a multidimensional process of change in the physical, mental and social domain, leading to **functional decline**
- **Design thinking** is a **powerful tool** to address the challenges of ageing
- A **patient-centered integrated design approach** is essential for Design for Autonomous Ageing
- Research and development in Design for Autonomous Ageing can best move on as a **collaboration between users, clinicians and designers, academia and industry**
V. Conclusions and THOMs (2)

- With their focus on the user, **industrial design engineers** can play an important role in **bridging the gap between technology and healthcare**

- The examples in the presentation demonstrate how technology and design might improve the quality of (health)care for older persons.
V. Conclusions and THOMs (3)

Design Innovation for Ageing at Industrial Design Engineering TU Delft aims to contribute substantially to supporting and reinforcing the reduced physical and mental capacities of older people by applying ground-breaking, innovative Design Inclusive Engineering methods.

*Design is the key to improvement of care of older people*

[www.designinnovationforageing.org](http://www.designinnovationforageing.org)
Welcome to the website of the DIFA: Design Innovation for Ageing. An initiative of the faculty Industrial Design Engineering at the Delft University of Technology. This DIFA website is part of the activities within the DIFA working group. For more information about DIFA, please click here.

The aim of this website is to inform and showcase Research by means of Master thesis/projects and Publications written by students and faculty members within the faculty Industrial Design Engineering at the Delft University of Technology. By doing this we want to contribute substantially to supporting and reinforcing the reduced physical and mental capacities of older people by applying groundbreaking, innovative Design Inclusive Engineering methods.

Please take a look around. If you would like more information on the Design Innovation for Ageing initiative or on a specific topic within this website, please take a look at the Contact page for further contact details.
VI. Outlook on the future
THANK YOU FOR YOUR ATTENTION

Time for discussion
The faculty of Industrial Design Engineering (IDE)

Founded in 1969
Largest university-based design course worldwide
2000 students
5000 alumni
200 scientific staff
20 professors in various disciplines
3 departments
1 BSc program
3 MSc programs
100 PhD students
www.ide.tudelft.nl
The departments of IDE

Department of Industrial Design
appearance, interaction, use, design techniques

Department of Design Engineering
mechanics, materials, manufacturing, cost, CAD

Department of Product Innovation & Management
consumer behavior, marketing, product management, design methodology
① BALANCE

② USERGROUPS → PERSONA'S (9)
   ABILITIES & PREFERENCES FOR RATIO M & S

③ DOMAINS
   OF PERSONAL WELLBEING AFFECTED BY DEMENTIA

④ NEEDS
   CONCERNING ONE'S
   • INTERNAL WORLD
   • RELATIONS
   • ACTIVITIES
   CHANGING

⑤ TRANSITIONS
   THESE NEEDS ARE THE RESULTS OF 7 MAIN
   TRANSITIONS WITHIN THE DOMAINS OF WELLBEING

⑥ WORKSHOP
   A → CREATE IDEAS TO SUPPORT PEOPLE (PERSONA'S)
   DEAL WITH TRANSITIONS
   → SPECIFY DESIGN PROCESS INPUT
   B → ADD AND/OR ADJUST PERSONAS & TRANSITIONS
Results of the Workshop Groups A and B

Group A1:

1. Ideas for Maike, feeling useful and helping others
   - Craft tutorials in the local community to continue with a creative hobby and feeling useful
   - Journal of daily tasks/memories, as a help for the later stage to share with friends
2. What do designers need?
   - Overview of interesting documentaries focusing on the influence dementia has in someone’s life.
   - Make personas available to use for others

Group A2:

1. Idea for Juan, Coming to terms with the diagnosis: acceptance, self-value and identity
   - Juan’s lecture on HIS dementia
     Personalized guide on dementia, which helps Juan to deal with his diagnosis, to express his feelings and help negotiate with his family and friends, to create a positive look into the future. Include: I am struggling with..., Don’t talk to me about..., How I want to be treated..., Bucket list (things I want to do in my life)
2. What do designers need
   - Personas to use during a design process
   - Person/patient journeys
   - Make scientific results more visible and available for designers (e.g. observations of behaviours of PwD, Quotes from PwD but also all other “actors” who are involved in care)
   - Methods how to talk to PwD when e.g. interviewing them, but also how to write about them, how do they want to be addressed

Group A3:

1. Ideas for Werner, Self-realisation through purposeful activities: compensating limitations through new activities
   - Social engagement, self-realisation, emotion
   - Use local clubs (connected to persons interests and qualities e.g. Football), to do a purposeful activity, “voluntary” work, help others and meet people

Group A4:

1. Ideas for Ursula, maintaining social participation
   - Sleep well exercise, routine before sleeping for better sleep and therefore to be more active and cope better during the day
   - Social connection service: Dinder (like Tinder). Connect with people and local activities and services
2. What do designers need?
   - Anecdotes make it easier to understand frame
   - Portraits vs. personas (more detail)
   - Clips and videos of roleplay of dementia incidents.
   - How to find PwD and their caregivers and how to talk to them? Make them react honestly instead of polite.

Group B1:
- Diversity is missing: multicultural group, ethnical background (immigration). Might be harder to reach since they might not go to nursing homes, possible language problems.
- Carer is also a patient.
- Flexibility of care: what can we provide? Caring at home is difficult.
- Missing transitions: Moving to a nursing home. When is the right time to move? Connected with feeling of guilt of carers, family does not want to see the PwD going worse.

**Group B2:**

- Use validation within the mindful framework. “Being with” instead of “being in the moment”.
- Difference between “meaningful” and “purposeful” activities:
  - “Meaningful” implies intrinsic motivation and is a strength factor
  - “Purposeful” can be determined by others. It has to do with society’s expectations of being a productive member of society – disability effect.
- Focus on routines and rituals as anchor points.
- Resilience measure.
- Changing relationships: parenting the parent.
- Nature based/sensory environments are important.
- Needing to be needed: Grannies Finest
Worksheet designers

Thank you for your willingness to use your creative skills to come up with solutions that support people with demential.

We ask you to participate in three workshops.

**Workshop 1) New ideas**

1. Select a persona (and read the description to get acquainted with the group of people this persona represents).
2. Select a transition (describing a change in a domain of wellbeing and the need resulting from this change).
3. Write down (or draw) ideas to support the persona dealing with the transition (or resisting the transition).
4. Select the best three ideas and describe (or draw) these in the boxes below. Name your idea, describe how it supports in the transition and list the benefits for this persona.

**Title idea 1:**

*Creative food diary*  
*2: Feeling useful by helping*  
*Persona: Mike Benson*

**Description (how does it support dealing with the transition)**

Mixed media journal of daily tasks / processes

**Benefits for the persona:**

Help for the hard days, to share with family / friends

**Title idea 2:**

*Craft materials*  
*2*  
*Persona: Mary*

**Description (how does it support dealing with the transition)**

Craft materials in local community

**Benefits for the persona:**

Continual of creative hobby / feeling of fulfillment

**Title idea 3:**

*Description (how does it support dealing with the transition)*

**Benefits for the persona:**
Worksheet designers

Thank you for your willingness to use your creative skills to come up with solutions that support people with demential

We ask you to participate in three workshops.

**Workshop 1) New ideas**

1. Select a persona (and read the description to get acquainted with the group of people this persona represents). *Maite Beveren*
2. Select a transition (describing a change in a domain of wellbeing and the need resulting from this change). *Feeling useful by helping other people*
3. Write down (or draw) ideas to support the persona dealing with the transition (or resisting the transition).
4. Select the best three ideas and describe (or draw) these in the boxes below. Name you idea, describe how it supports in the transition and list the benefits for this persona

**Title idea 1:** ........................................ Transition:........................................ Persona: ......................

*Description (how does it support dealing with the transition)*

*Benefits for the persona:*

**Title idea 2:** ........................................ Transition:........................................ Persona: ......................

*Description (how does it support dealing with the transition)*

*Benefits for the persona:*

**Title idea 3:** ........................................ Transition:........................................ Persona: ......................

*Description (how does it support dealing with the transition)*

*Benefits for the persona:*
Workshop 2) What do designers need?
In this project we investigate the challenges people face when dealing with dementia. Hopefully in the future this knowledge helps you create many useful solutions to support people with dementia and their caregivers. To make sure we create information you can use, we would like you to answer a few questions.

What information would you want to obtain from this MinD project to use in your design projects? (more than one choice possible)

- Data
- Personas
- Methods
- Tools
- Other: ..........................................................

Please explain in the box below a bit more in detail what you would expect

- overview of interesting documentaries focusing on the influence dementia has on someone’s life
- person’s available to use for others as well

What experiences in and suggestions for designing for people with dementia or their caregivers would you like to share with us?

Other comments:
H2 prepare for when more difficulties remembering?

- Documenting of the processes - photo/text/drawing
  - Example: documentation of recipes, cooking processes

- Documenting of memories - sharing with friends/family, blog, photos

- Make physical tokens and place them in spots where you need to remember something

- Letter to future self (on video's)?

- Try to organise mindfully with totem's
H2 continue practising a creative hobby in your home environment?

* DEFINE A SPACE / PLACE WHERE TO DO IT
* SHARE WITH OTHERS - GROUP / CLUB (ie: bake club)
  - involve the members of the household - share the knowledge
  - make small presents for others
  - teach others (online?)

make notes of how to do basic things / elements of the hobby

set up a group of like-minded people
H2 reach out to people with your offer of help?

- advertise handmade products internet
- tell other people you are available advertisement board in shopping centre cards to neighbours

find OUTLETS (STORES / GALLERIES)
fine NETWORKS (ONLINE / WITHIN LOCAL COMMUNITY)
- start inside of the family (grandchildren, sisters)
1.2 Make other people reach out to you for help?

- Organise a need - help meeting
- Ask others if they know someone

* Skull Pages (Bake, skills for time)
* Join networks (DEM - CAFÉ)
* Collect the things you can do effectively
Diary - personal notes

Sharing your notes with others

Reaching out to others to ask/provide help
person: Maike
- creative
- lives with sister
- open about dementia

Feeling helpful by helping others

1. creative note-taking
   - mixed media notes of daily tasks
     - personal
     - to share

2. craft tutorials
   - sharing knowledge
   - community - offline
   - presents
A2
Worksheet designers

Thank you for your willingness to use your creative skills to come up with solutions that support people with dementia!

We ask you to participate in three workshops.

**Workshop 1) New ideas**

1. Select a persona (and read the description to get acquainted with the group of people this persona represents).
2. Select a transition (describing a change in a domain of wellbeing and the need resulting from this change).
3. Write down (or draw) ideas to support the persona dealing with the transition (or resisting the transition).
4. Select the best three ideas and describe (or draw) these in the boxes below. Name your idea, describe how it supports in the transition and list the benefits for this persona.

   **Juan Lezume**

   **Title idea 1:** E.A.His...dementia Transition: ........................................ Persona: ........................................

   **Description (how does it support dealing with the transition)**

   Personal guide for friends & family. Juan can personalize it. E.g., don't talk to me about topic xy, things he is struggling with.

   **Benefits for the persona:**

   - Express no emotion
   - Inform their loved ones
   - Create awareness
   - Gain support
   - Buckets list (positive focus: things to look forward)
   - Act positive feedback from family & friends
   - Conversation starter

   **Title idea 2:** ........................................ Transition: ........................................ Persona: ........................................

   **Description (how does it support dealing with the transition)**

   Benefits for the persona:

   **Title idea 3:** ........................................ Transition: ........................................ Persona: ........................................

   **Description (how does it support dealing with the transition)**

   Benefits for the persona:
Workshop 2) What do designers need?
In this project we investigate the challenges people face when dealing with dementia. Hopefully in the future this knowledge helps you create many useful solutions to support people with dementia and their caregivers. To make sure we create information you can use, we would like you to answer a few questions.

What information would you want to obtain from this MinD project to use in your design projects? (more than one choice possible)

- Data
- Personas
- Methods
- Tools
- Other: PERSON JOURNEY

Please explain in the box below a bit more in detail what you would expect

Method: How to communicate with people with dementia in different stages.
Quotes from patients and actors around him/her
Observations of behavior
Available scientific results
Other solutions

What experiences in and suggestions for designing for people with dementia or their caregivers would you like to share with us?

Invite people with dementia and their caregivers as well. The caregivers can tell their story and acts as a spokesperson.
Also talk to the person with dementia, involve them in the design process.

Other comments:
Workshop 3) Elaborate on early ideas

Title idea 1: ............................................

My idea to improve or detail this idea:

Juan's lecture on his dementia improves idea no. A2

Title idea 2: ............................................

My idea to improve or detail this idea:

A3 letter to your future list, include a bucket list

Title idea 3: ............................................

My idea to improve or detail this idea:

F3

cheap google cardboard, send them to participants
VR glasses
JUAN

PROBLEMS

IDENTITY

EXPRESSIONS EMOTIONS

DEPENDENT

MIND

PLANNING

LANGUAGE

ACCEPTANCE

Depressed

KEEP JUAN INFORMED,

WALKING, TEACHING, SOCIAL

BE PROUD, FOCUS ON THINGS HE STILL CAN.

SUPPORT TO BE MORE INDEPENDENT.

FEARED THAT PEOPLE DON'T TREAT HIM AS THEY USE TO DO

EMOTIONAL PROBLEMS: TALKING SUPPORT DIARY.

I'M MAD TODAY.

NOT ONLY FOCUS ON CARE

spend the time in a positive way

SCHEDULE: I NEED REST

REMEMBER & SHOW WHAT HE STILL CAN DO
**Digital Schedule**

- Positive Look into the Future
  - Bucket List
  - Focus

- What is he afraid of?
  - Losing Identity: Active, Social, Teacher
  - Positive Feedback: Calm

- Hand in Hand Booklet
  - Personal guide for friends & family and for the PWD as well
  - Express his emotion
  - Inform loved ones
  - Support

- Share experience with people in the same situation
  - Diary & Information
  - Involve family in the process

**Remain is not the end of the world**
**Awareness**
**Positive**
**Support**
Juan's lecture on his dementia
A3
PERSONA

- SOCIAL ENGAGEMENT →

- SELF REALISATION → loses ability to do his job.

- EMOTION → slightly depressed, low self esteem.

↓

not much opportunity to see/talk people.
+ help people.

DISCOVER something new about yourself. I can not do my core quality. What do I do now?

Goal: self-realisation by purposeful activities.
(e.g.) helping others.
Local clubs (football)

Purpose

Help others

Use of other quality

Know what people are present in this life?

Family?

Career?

Amateur football club

Friends

Tool
USE OF QUALITIES

PURPOSE

HELP OTHERS

FIND QUALITIES → TOOL

FIND PARTIES INVOLVED

GATHER INFORMATION

FIND QUALITIES
TRANSACTION

- coming to terms with the diagnosis
- feeling useful by helping others
- self-realisation by purposeful activities
- coming to terms with emotions
- keeping going (empathy)
- feelings, planning negotiations
- maintain social participation
- nego-planning/planing — easy tasks
Werner

Depressed

- Not going out
- Not driving

Low self realisation

Be aware of qualities

Select new activities (help others)

Profile

Tool

Friends

Care givers

Family
A4
Worksheet designers

Thank you for your willingness to use your creative skills to come up with solutions that support people with dementia!

We ask you to participate in three workshops.

Workshop 1) New ideas

1. Select a persona (and read the description to get acquainted with the group of people this persona represents).
2. Select a transition (describing a change in a domain of wellbeing and the need resulting from this change).
3. Write down (or draw) ideas to support the persona dealing with the transition (or resisting the transition).
4. Select the best three ideas and describe (or draw) these in the boxes below. Name you idea, describe how it supports in the transition and list the benefits for this persona.

Title idea 1: Meditation App. Transition: from lonely social isolation. Person: U. Pilea

Description (how does it support dealing with the transition)
- sleep-well-exercise
  - More active before sleeping
  - Set of breathing exercises
  - Feelings of personal balance

Benefits for the persona:
- Better sleep time
- Active and more stamina in the day

Title idea 2: Social Companion. Transition: stroke-recovery maintenance. Person: M. Jones

Description (how does it support dealing with the transition)
- Social companion - for orientation: Local
- Needs rel. activity
- Needs support in daily life
- Social connectivity service

Benefits for the persona:
- Existing: disability service
- Support needed
- Social contacts

Title idea 3: Insight time. Headspace. Transition: allow to forget. Person: K. Knott

Description (how does it support dealing with the transition)
- Allowed to forget
- Allowed to imagine

Benefits for the persona:
- Good introspection
- Have appropriate cognitive intervention
- Not happy
- stigma about dementia
- assumptions about dementia need to unravel differences
  requires different methods/tools
- own DIY solutions, existing solutions not known
Workshop 2) What do designers need?
In this project we investigate the challenges people face when dealing with dementia. Hopefully in the future this knowledge helps you create many useful solutions to support people with dementia and their caregivers. To make sure we create information you can use, we would like you to answer a few questions.

What information would you want to obtain from this MinD project to use in your design projects?
(more than one choice possible)
- Data
- Personas
- Methods
- Tools
- Other: ..........................................................

Please explain in the box below a bit more in detail what you would expect:
- anecdotes to better explain from both sides
- portraits vs personas
- clips/videos or role play of dementia incidents
- more money or polite

What experiences in and suggestions for designing for people with dementia or their caregivers would you like to share with us?

Other comments:
Book:

The 36th Day

 ciągły las Alzheimera

 the continuous task

 for the cerebral cortex
PROBLEM: SHE DOES NOT GO OUTSIDE ALONE

- SLEEP
- FEELS EMOTIONALLY WEAK

MEDITATION

"A SLEEP WELL EXCERISE"

- breathing
- body awareness
- music
**Worksheet designers**

Thank you for your willingness to use your creative skills to come up with solutions that support people with dementia!

We ask you to participate in three workshops.

**Workshop 1) New ideas**

1. Select a persona (and read the description to get acquainted with the group of people this persona represents). **Ursula Wagner**.
2. Select a transition (describing a change in a domain of wellbeing and the need resulting from this change).
3. Write down (or draw) ideas to support the persona dealing with the transition (or resisting the transition).
4. Select the best three ideas and describe (or draw) these in the boxes below. Name your idea, describe how it supports in the transition and list the benefits for this persona.

<table>
<thead>
<tr>
<th>Title idea 1: ________________________</th>
<th>Transition: ______________</th>
<th>Persona: Ursula Wagner</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description</strong> (how does it support dealing with the transition)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Benefits for the persona:</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Title idea 2: ________________________</th>
<th>Transition: ________________________</th>
<th>Persona: ________________________</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Description</strong> (how does it support dealing with the transition)</td>
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</table>

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<thead>
<tr>
<th>Title idea 3: ________________________</th>
<th>Transition: ________________________</th>
<th>Persona: ________________________</th>
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Workshop 2) What do designers need?
In this project we investigate the challenges people face when dealing with dementia. Hopefully in the future this knowledge helps you create many useful solutions to support people with dementia and their caregivers. To make sure we create information you can use, we would like you to answer a few questions.

What information would you want to obtain from this MinD project to use in your design projects? (more than one choice possible)
- Data
- Personas
- Methods
- Tools
- Other

Please explain in the box below a bit more in detail what you would expect

* Anecdotes that help to explain the

What experiences in and suggestions for designing for people with dementia or their caregivers would you like to share with us?

Other comments:
Workshop 2) What do designers need?
In this project we investigate the challenges people face when dealing with dementia. Hopefully in the future this knowledge helps you create many useful solutions to support people with dementia and their caregivers. To make sure we create information you can use, we would like you to answer a few questions.

What information would you want to obtain from this MinD project to use in your design projects? (more than one choice possible)
- Data
- Personas
- Methods
- Tools
- Other: people with dementia and their caregivers

Please explain in the box below a bit more in detail what you would expect

How to find them?
and how to talk to them,
find out their needs, making them react honestly and not only politely.

What experiences in and suggestions for designing for people with dementia or their caregivers would you like to share with us?

Other comments:
Sheets are overloaded with information.

Too much text.

Two perspectives

Former caring for mother

Q: do we provide for patient

"do we provide flexible enough care?"

Do we have services nice for patient and informal caregiver?

Missing diversity, not representative for multi-cultural group.

Group multi-cult is difficult as they are even further away from what is recognized to them.

Missing: ethnic background (immigration)

Losing not going to nursing home, possible language problem.

Patient group

Lack of flexibility in care

What can we provide instead of what they do?

In the patient need?

limits & care at home \[\rightarrow \text{6 hours a day, Nancy Mac}\

limits & care at home \[\rightarrow \text{no patient transition between home and NH.}\

Most difficult moment: - decision of going into care home

- denial of family: don't want to see Ph.D. going worse.

- Depression/Guilt in carers

"Caren is also a patient"
Into Dementia

BSMS - centre for dementia studies

https://www.bsms.ac.uk/about/news

conference celebrate time for Dementia project - BSMS

To create empathy, give the caregivers the skills, "ask for help."

* Pictograms for making things understandable.

• gezondheidsvaardigheden.nl

• Alzheimer Café

→ Asking/information meeting

• Naomi Feil

→ Validation Therapy
Missing

- Education Caregiver
- Education PwD
- **Coping** Strategy
- Diversity → gender
  → ethnic background
  → language
- Social background
- Lack of personalized care
- Communication with caregivers
- Role of informal caregiver

Improvement
- Visual presentation
- Validation

- "Being with" instead of "Being in the moment"

- Purposeful vs. Meaningful Activities.

- "Meaningful" implies intrinsic motivation, and is a strength factor

- "Purposeful" can be determined by others, so has to do with society's expectations of being a productive member of society – can have a disabling effect.

Focus on Routines and Rituals as anchors.

- Resilience measure: People with dementia caregivers

- Changing Relationships: Parenting the parent.

- Changing interaction with the built/physical environment. Nature-based environments.

Blue Zones +100 y.o.

Resources
Mail list
Mutual Relation Ship

- Onderlinge Relatie Familieleden
- Needing to be Needed; Meer Uitwerken
- Motivatie tot Bewegen
- Grannies First
- Half Life Decay
→ Mutual Relation - Family

→ Motivation to physical active

→ Needing to be needed
  - Granny's Finest
  - Park Attendant
Validation "Being"

Purposeful vs Meaningful

Judgement

intrinsic motivation

Routines
Rituals → anchors

Parenting the parent

Interactions with physical/built environment