

MinD - Designing for people with Dementia: designing for mindful self-empowerment and social engagement

1st MinD Symposium, 7 December 2016, Europe House, London

Symposium Summary

10 months into the project, the MinD consortium convened their first annual Symposium at Europe House, London, open to the public. The symposium had the purpose of bringing together researchers, healthcare professionals and designers engaged in improving the life of those living with dementia and to facilitate discussion about current approaches and developments.

After a short introduction by MinD project co-ordinator Professor Kristina Niedderer, the symposium began with the keynote of Professor Cathy Treadaway, who reported on her research and experiences of working with people with dementia through the LAUGH project funded by the AHRC as well as previous research. Prof Treadaway highlighted the need for considering the human aspects of care through focus on sensory aspects, the need for connection and personalised approaches, showing ample examples of the work conducted. The discussion also highlighted the difficulty about qualitative or 'soft' evaluation measures which are most appropriate for this kind of work, but which is not always accepted in the medical world and by funders.



The keynote was followed by three short presentations about the MinD project by Dr Isabelle Tournier from Luxembourg University, Professor Vjera Holthoff from Alexianer St Hedwig Krankenhaus Berlin, and Professor Kristina Niedderer, University of Wolverhampton. Dr Tournier introduced the concept of mindfulness with its two major schools of thought, and how it has been applied in the context of dementia care so far, and the idea of using it in the context of the MinD project. Prof Holthoff continued by presenting a summary of the data collection with people with dementia and their carers conducted as part of the first phase of the MinD. This work comprised interviews and innovative visual diaries to collect qualitative information on how people with dementia and their carers feel with regard to self-



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empowerment and social engagement in their everyday lives. Prof Holthoff also briefly contextualised the work to show the importance of involving people with dementia in primary research on decision making/empowerment related to subjective wellbeing, and not only to making an Action Plan for Dementia Care or Advance Care Planning. The third presentation by Prof Niedderer explained the possibilities of implementing mindfulness through design, including the analytical frameworks developed so far, which will be used to mine the data from Phase 1 for the design development.



The afternoon of the symposium was given over to discussion of a number of issues surrounding the state of dementia care, and our understanding of them, as well as the use, role and potential of design within dementia care. The first part was given over to a design workshop, which explored 4 themes, including: the acceptance of the diagnosis; the change in personal relationships due to and during the progression of dementia; acceptability of care and trust; and using a sense of humour to deal with the situation. For the workshop,



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participants split into four groups, each discussing one of the themes with regard to the real world scenario, the ideal scenario, and how to use design to move from the first to the second state. The brainstorming around these scenarios led participants into vivid discussions, which they reported back to everyone at the end.

The symposium concluded with a panel discussion around a further two themes concerned with the issue of 'independence and social integration' and our perceptions of interaction with persons. The three panel speakers were Prof Katy Treadaway, Prof Vjera Holthoff, and Prof Tom Denning, Nottinghamshire Healthcare NHS Foundation Trust. Unfortunately, the fourth speaker Dr Sara Milne from Alzheimer's Society, UK, had to cancel her participation at short notice due to unforeseen circumstances. The discussion highlighted various aspects such as deficit oriented language and goal orientated care, and meandered back to the issue of qualitative evaluation measures, which will be pursued jointly by the MinD and the Laugh team in the future.

Appendices

Appendix 1: Symposium Programme

Appendix 2: Keynote, Prof Cathy Treadaway, presentation notes

Appendix 3: MinD project presentation notes

Appendix 4: Design workshop notes

Appendix 5: Panel discussion notes



Appendix 1: 1st MinD Symposium Programme

1st MinD Symposium 2016

Wednesday 7 December 2016

Europe House, 32 Smith Square, London SW1P 3EU

PROGRAMME

Time Description

10.00 Arrival and registration

10.15 Introduction to the Symposium and the MinD project
Prof Kristina Niedderer, University of Wolverhampton (project coordinator)

10.30 Keynote
Prof. Cathy Treadaway, Cardiff Metropolitan University, UK
Prof Treadaway will introduce the LAUGH project, which she leads, and then focus on working with users during the research, including data collection and co-design methods, and how this has fed into the design development.

11.15 Break

11.30 MinD framework: using mindfulness to support people with dementia and their carers
Dr Isabell Tournier, University of Luxembourg

11.50 MinD data collection: methodology & initial results
Prof Vera Holthoff, Alexianer St Hedwig Hospital, Berlin

12.10 MinD design development: co-design & design propositions
Prof Kristina Niedderer, University of Wolverhampton

12.30 Buffet Lunch and Networking

13.30 Design workshops and feedback
Led by members of the consortium

The design workshop will explore and discuss potential design responses to some of the key issues that are emerging from the initial data collection, relating to social engagement, subjective well-being and decision-making.

14.45 Break



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15.00 Panel discussion

Panel members: Representatives from the fields of design and dementia care, including: Prof Cathy Treadaway, UK; Sara Miles, Alzheimer's Society UK, Prof Vera Holthoff-Detto, Germany; Prof Tom Dening, UK)

The panel discussion, will address the two themes complemented by topics from the symposium participants:

- independence and social integration: how design can help support independence and self-empowerment to support social engagement rather than to create isolation; and
- the approach to design for healthcare/dementia: appropriateness of approaches and the discrepancy between technology and user led approaches.

Panel speakers:

Prof Cathy Treadaway, Professor of Creative Practice, Cardiff Metropolitan University, UK, has key interests in creativity and wellbeing and in designing for dementia, and is principle investigator for the LAUGH project (Ludic Artifacts Using Gesture and Haptics)

Sara Miles leads the Dementia Friendly Communities Programme at Alzheimer's Society. With a background within the third sector she is passionate about enabling community change. In her 3 years at Alzheimer's Society she has worked across Dementia Friends and Dementia Friendly Communities, supporting partnerships with external organisations and evolving the programmes. Sara is currently working with housing sector organisations to produce a dementia-friendly housing charter highlighting best practice and commitments around design, training and processes that can improve the lives of people affected by dementia.

Prof Vera Holthoff-Detto, Germany. Vjera (MD, PhD, Gero-psychiatry) specialises in non-pharmacol. interventions in dementia, telemedicine, and neurocognition.

Prof Tom Dening, Nottinghamshire Healthcare NHS Foundation Trust. Tom has 20 years experience as consultant working with dementia and in dementia research.

16.00 Close (optional networking until 16.30)



Appendix 2: Keynote, Prof Cathy Treadaway, presentation notes

Papers from the LAUGH project from Cathy Treadaway can be downloaded from the LAUGH website: www.laughproject.info



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compassionate design

Prof Cathy Treadaway
Dr Gail Kenning (UTS, Australia)
Dr Jac Fennell
Dr David Prytherch (BCU)
Prof Andy Walters



playful play





sensory



personalised



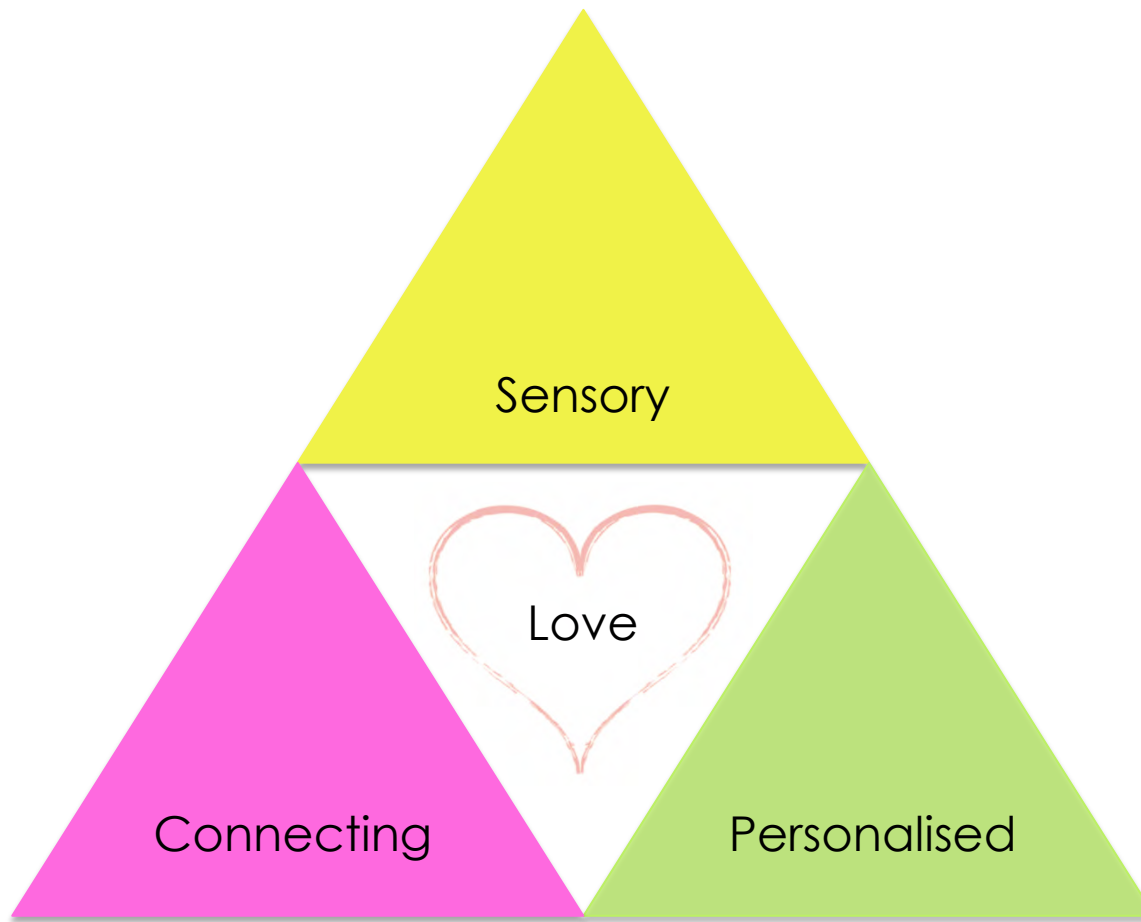


connecting









Compassionate Design

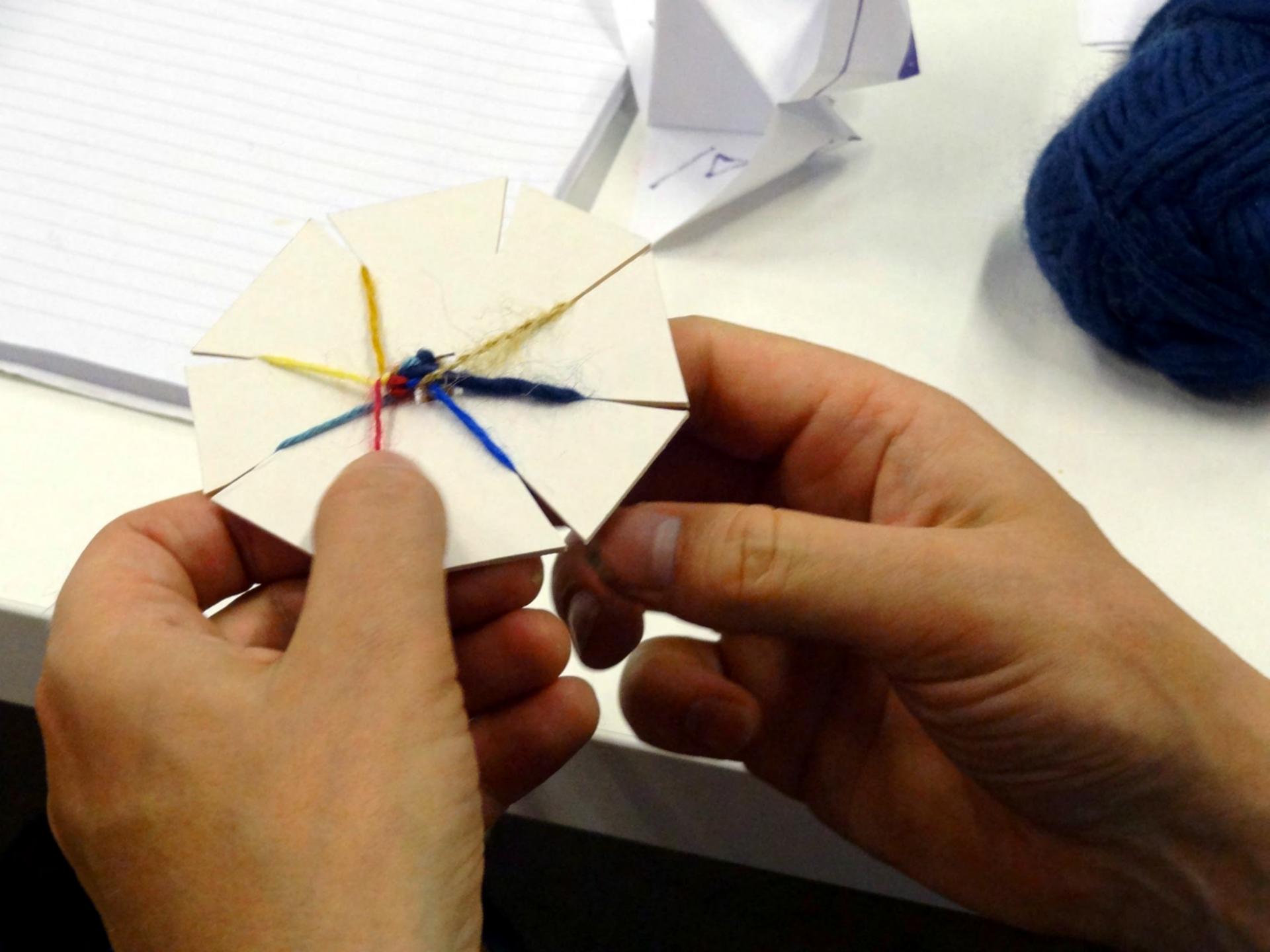
Treadaway, C. 2016

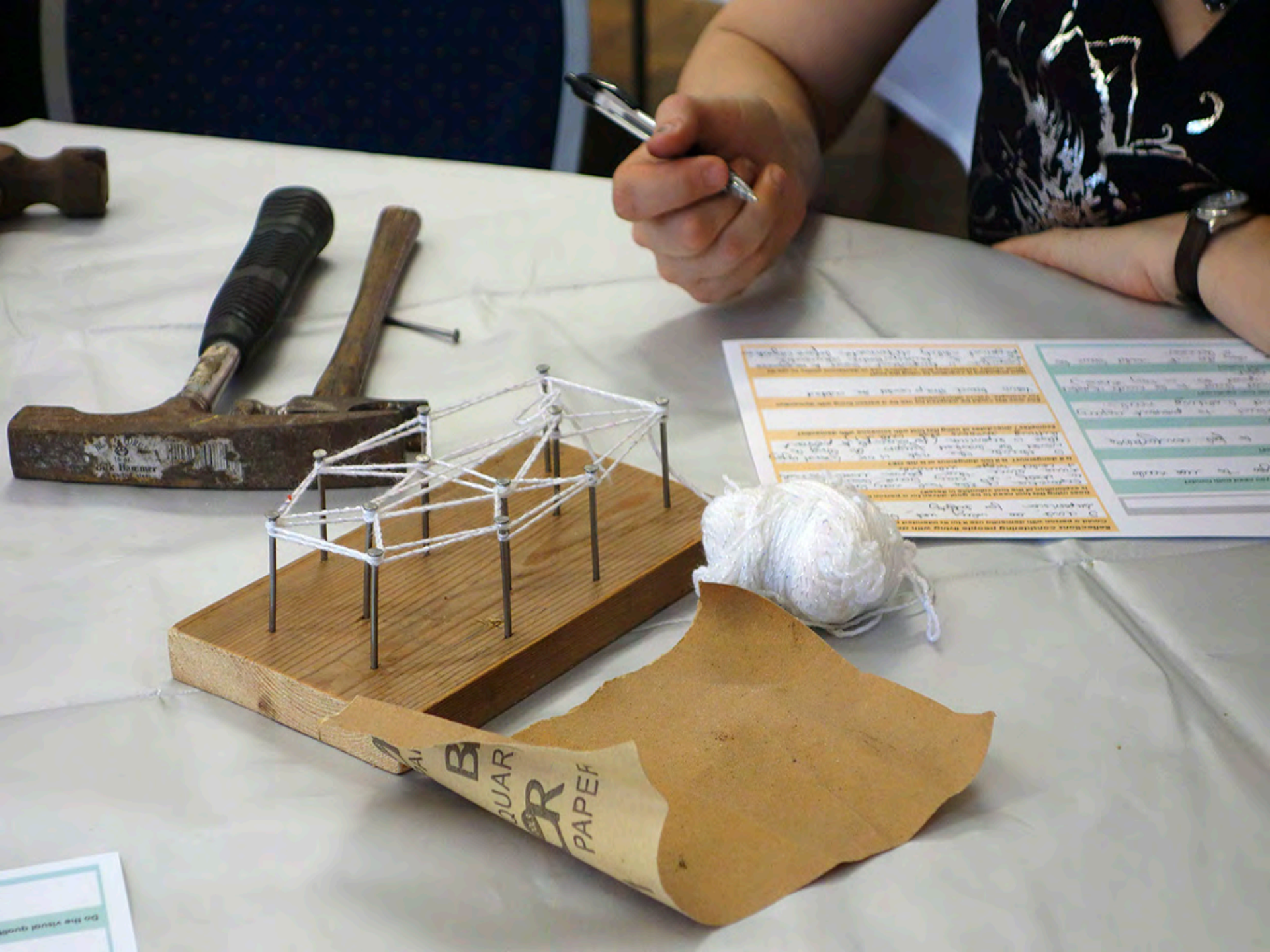
ay my

is worst than
illness.









WHAT MAKES US LAUGH?

US

PEOPLE FALLING OVER

SATIRE

ALCOHOL

MISPRONUNCIATION

PUNS (VISUAL & OTHERWISE)

OTHER PEOPLE IN AWKWARD SITUATIONS

MISUNDERSTANDINGS

WORD PLAY

FUNNY ANIMALS

KIDS (FAMILY)

OTHER PEOPLE HAVING FUN

IN-JOKES

MEMORIES (BUT IS IT MEMORIES OF THE ABOVE)?

OUR EMBARRASSMENT & THE EMBARRASSMENT OF OTHERS

SHARED EXPERIENCE

PWD

PEOPLE FALLING OVER
(CONTEXTUAL)

OTHER PEOPLE IN AWKWARD SITUATIONS(?)

OTHER PEOPLE HAVING FUN

BECAUSE THEY'RE HAPPY (?)

EMOTIONAL CONNECTIONS

FUNNY ANIMALS

SLIPSTICK / CONSEQUENCE

QUESTIONS:

- DOES THE LAUGHTER AROUND EMBARRASSMENT / SHARED EXPERIENCES FIT HERE?

- WOULD LAUGHTER HERE BE LESS CULTURALLY SPECIFIC?









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Arts & Humanities
Research Council



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BIRMINGHAM CITY
University



gofal a chymorth

Gwalia
care & support

part of **pobl** group

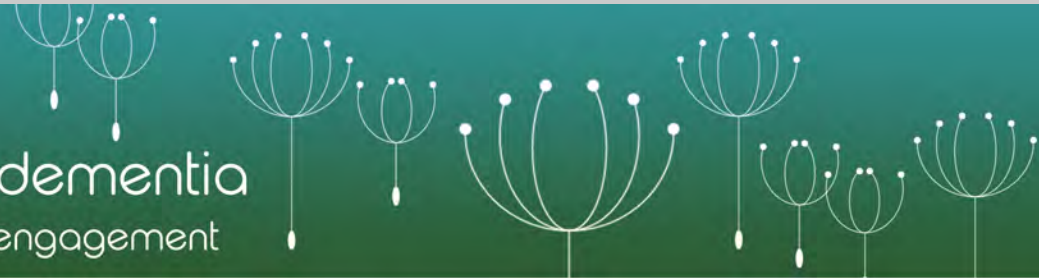
Appendix 3: MinD project presentation notes



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MinD

designing for people with dementia
mindful self-empowerment and social engagement



1st MinD Symposium 2016



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Welcome

Context: Symposium part of MinD project

Designing for People with Dementia: designing for mindful self-empowerment and social engagement

European MSCA RISE project - 13 Partners – 6 countries

March 2016 – February 2020



13 Partners

Universities

University of Wolverhampton, University of Twente, Technische Universität Dresden, University of Luxembourg , Queensland University of Technology

Dementia care & policy

Alzheimer Europe, Nottinghamshire Healthcare NHS Foundation Trust, Alexianer St Hedwig Klinik Berlin, Zorggroep Sint Maarten, INTRAS

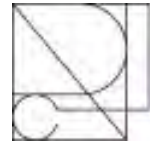
Design and ICT

Panton, Picharchitects, Eurecat, INTRAS





UNIVERSITY OF TWENTE.



zorggroep sint maarten



Nottinghamshire Healthcare
NHS Foundation Trust



The project aims

Support people with **dementia** and their carers

- **subjective well-being and self-empowerment**
- **meaningful social engagement**

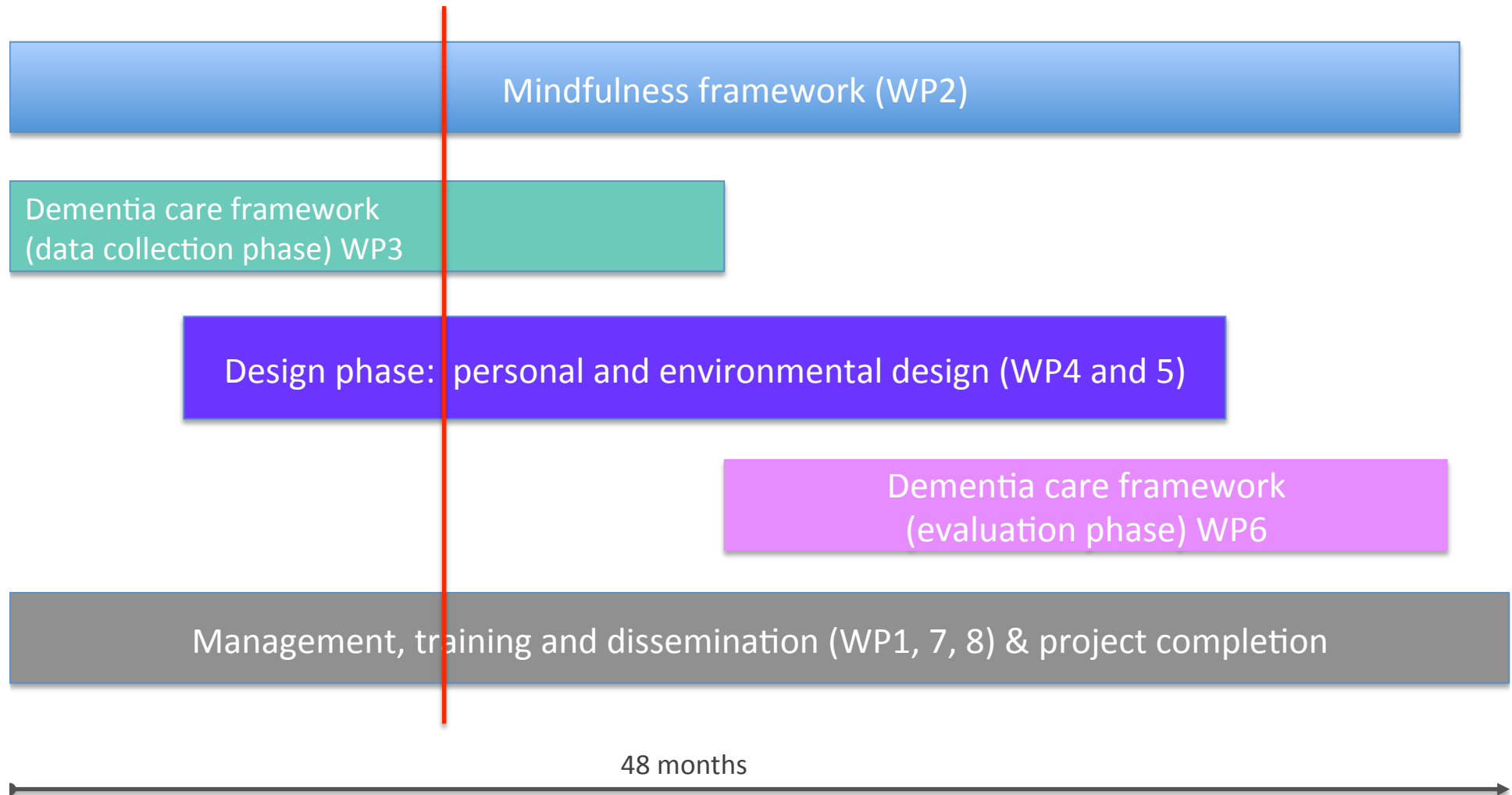
Using **design** and **mindfulness** theory/practices

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)



Project shape



The 1st MinD symposium

Purpose of the symposium:

- public engagement
- use of design and mindfulness in the dementia context
- discussion of interdisciplinary (and other) challenges

Programme:

- keynote
- project presentations
- design workshop
- panel discussion



MinD project presentations

MinD project work to date

- Mindful framework for design in dementia care

Dr Isabelle Tournier, University of Luxembourg, Psychologist with expertise in cognitive changes, adaptation and self-regulation during aging

- Conduct data collection with people with dementia and carers

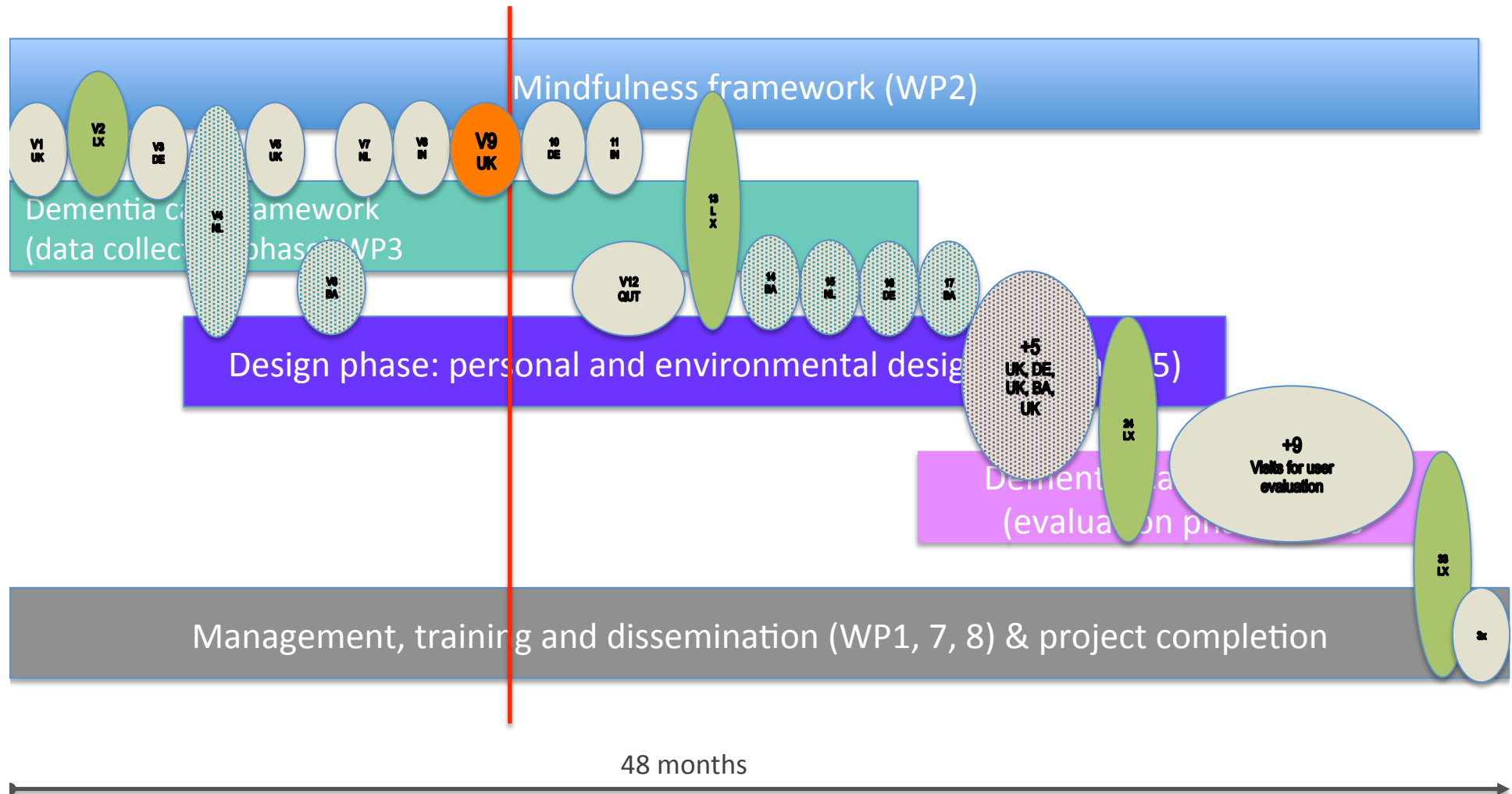
Prof Vjera Holthoff, Alexianer St Hedwig Kliniken, Berlin, Geronto-psychiatrist specialising in non-pharmacological interventions in dementia, telemedicine, and neuro-cognition

- Develop mindful design framework, design development and co-design

Dr Kristina Niedderer, University of Wolverhampton, is Professor of Design and Craft, and MinD project co-ordinator, and interested in the affect of design on human interrelationships

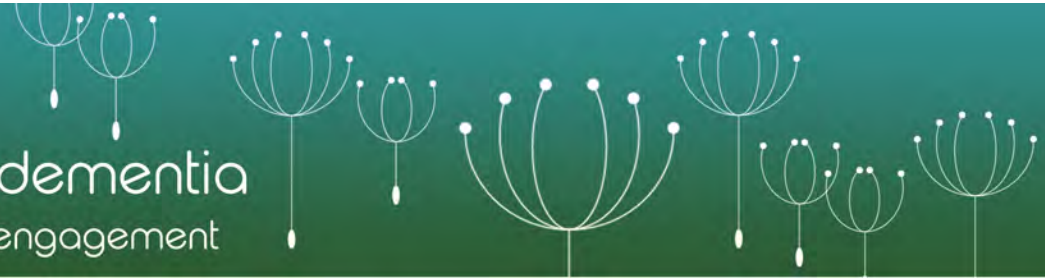


Project shape



The logo for MinD, featuring the word "MinD" in a white, lowercase, sans-serif font.

designing for people with dementia
mindful self-empowerment and social engagement



MinD framework:

**Using mindfulness to support people
with dementia and their carers**

Dr. Isabelle Tournier

University of Luxembourg

What is Mindfulness?

➔ Concept - more and more frequent in daily life: Increasing popularity

Two major theoretical frameworks defining mindfulness (Pagnini & Phillips, 2015):

- **Meditation (Jon Kabat-Zinn)**

*as paying attention in **a purposeful manner**, in the **present moment**, and **non-judgmentally**: without moral and emotional assessments*

- **Information processing (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*

What is Mindfulness?

Mindfulness: the psychological process of **bringing one's attention in the present moment** (internal and external experiences)

- **less information to process** linked to the past and the future
- **less negative emotions/ruminations** linked to the past and the future



**More efficient
information
processing**

What is Mindfulness?

- Positive effects on (Goyal et al., 2014; Winbush et al., 2017; Gard et al., 2014):
 - Anxiety: ↘
 - Depression: ↘
 - Sleep quality: ↗
 - Pain: ↘
 - Memory: ↗
 - Etc.
- Possible to train (e.g., exercises) or to induce (e.g., environment)

Which potential interest for people with dementia ?

People with dementia usually show:

- Cognitive decline (attention, memory, etc.): problems with information processing
- Less efficient emotion regulation
- Behavioural and psychosocial symptoms of dementia (e.g., agitation, irritability, anxiety, depression, apathy, etc.)



**Reduction in
activities of daily life
(and wellbeing)**

Which potential interest for carers?

- The role of (main) informal caregivers is often ensured by the **partner or a close relative** (often a wife, daughter, daughter in law...).

- A variety of tasks (Levy et al., 2012):

Help for the **basic activities** (e.g., bathing, dressing, eating) and the **instrumental activities** (e.g., cooking, shopping, managing medication) of the daily living

Which potential interest for carers?

- **Carers of people with dementia usually present:**
 - More negative affects (e.g., anxiety, depression, distress, etc.)
 - More physical pain linked to taking care (e.g., back pain)
 - Less time for their own activities/for themselves



**Reduction in wellbeing
(and quality of care)**

Mindfulness for people with dementia?

- **More and more mindfulness interventions** for older adults
- Usually: older adults without cognitive impairments
→ **a lack of interventions aiming at people with dementia**
- **Positive effects** 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)

Benefits of Mindfulness Training for Patients With Progressive Cognitive Decline and Their Caregivers

Ken A. Paller, PhD^{1,2,*}, Jessica D. Creery, BS^{1,*},
Susan M. Florczak, BA¹, Sandra Weintraub, PhD²,
M.-Marsel Mesulam, MD², Paul J. Reber, PhD¹, Jessica Kiragu, MA²,
Joshua Rooks, BA¹, Adam Safron, MS¹, Darby Morhardt, PhD²,
Mary O'Hara, MSW², Kathryn L. Gigler, MS¹,
John M. Molony, BS¹, and Michael Maslar, PsyD¹

8-week weekly training (Paller et al., 2015)

- **Participants:** 17 patients with dementia (age: 55-81) and 20 caregivers (age: 31-98).
- **Mindfulness program:** One weekly group session (8 weeks) + « homework » to perform each day (30-60 minutes)

Table 2. Mindfulness Training Sessions.

Week	Lesson	Practices
Week 1	Overview of mindfulness	Mindfulness of breath; mindfulness of body; mindful check-in
Week 2	Mindfulness as remembering; connecting mind and body	Gentle standing yoga; mindfulness of pleasant events
Week 3	Pain and suffering	Gentle floor yoga; mindfulness of pleasant and unpleasant events
Week 4	Integrating mindfulness into everyday life	Mindfulness of breath and body
Week 5	Observing what is happening without getting involved	Mindfulness of thoughts
Week 6	Having compassion when you are in pain; sleep hygiene	Loving-kindness practice
Week 7	Being open to whatever happens	Choiceless awareness; walking meditation
Week 8	How to keep up a meditation practice; outside resources for continuing practice	

Benefits of Mindfulness Training for Patients With Progressive Cognitive Decline and Their Caregivers

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- **Assessment:** several tests and questionnaires performed *before* and *after* (within 2 weeks prior to start and after completion of) the mindfulness program.

Table 4. Results for Tests Given to Patients and Caregivers.^{a,b}

Measure	Number of	Combined Group		Patient Group		Caregiver Group	
		Pre	Post	Pre	Post	Pre	Post
QOL-AD	35	37.4 ± 1.3	39.2 ± 1.3*	36.2 ± 1.5	38.4 ± 1.5*	38.6 ± 2.1	40.1 ± 1.9*
GDS	35	9.3 ± 1.2	8.0 ± 1.1*	9.7 ± 1.4	8.1 ± 1.2*	9.0 ± 1.9	7.9 ± 1.9*
PSQI	35	7.0 ± 0.7	6.1 ± 0.7	5.1 ± 0.9	4.3 ± 0.9	8.6 ± 1.0	7.7 ± 1.0
BAI	36	9.1 ± 1.6	8.3 ± 1.8	8.7 ± 2.3	9.2 ± 3.3	9.5 ± 2.2	7.6 ± 1.8
Trails A	31	63.3 ± 1.9	59.0 ± 1.9	88.8 ± 4.7	88.1 ± 4.4	36.0 ± 0.8	28.0 ± 0.5
Trails B	25	124.9 ± 15.6	106.1 ± 12.3*	202.0 ± 24.3	161.9 ± 22.8*	81.6 ± 9.3	74.7 ± 6.2
RBANS							
Total index		85.4 ± 3.8	86.2 ± 3.4	69.4 ± 3.8	72.8 ± 4.6	100.3 ± 3.4	98.8 ± 1.7
Immediate mem		87.1 ± 4.2	89.8 ± 4.2	71.1 ± 4.8	74.0 ± 5.6	102.1 ± 4.2	104.7 ± 2.7
Visuospatial/con		83.6 ± 2.5	86.2 ± 2.5	76.1 ± 2.7	81.7 ± 3.9	90.6 ± 3.1	90.4 ± 2.6
Language	31	89.2 ± 3.3	95.2 ± 3.1*	80.7 ± 4.7	85.3 ± 4.3	97.1 ± 3.8	104.6 ± 2.7
Attention	30	95.3 ± 3.9	96.3 ± 3.3	83.0 ± 4.9	86.5 ± 3.9	107.5 ± 4.1	106.1 ± 3.9
Delayed Memory	31	79.5 ± 4.5	81.9 ± 4.3	58.9 ± 5.0	64.4 ± 5.8	98.8 ± 2.1	98.3 ± 2.2

Abbreviations: QOL-AD, quality of life (AD); GDS, Geriatric Depression Scale; PSQI, Pittsburg Sleep Quality Inventory; BAI, Beck Anxiety Inventory; RBANS, Repeatable Battery for the Assessment of Neuropsychological Status; SEM, standard error of the mean.

^a Mean scores ± SEM.

^b Significant pre-post differences indicated by * (see text).

Interaction between people with dementia/relatives

- **How could mindfulness benefit the communication/** interaction between people with dementia and their relatives?
- **Active listening** is a complex task... (Schulz von Thun, 1999)

Factual information

The words used, what is evoked

Appeal

What is the potential implicit demand?



Relationship

Indication regarding the quality of the relationship

Self-revelation

What I am revealing about myself (e.g., lack of confidence, gratitude)

➡ **Verbal** (words), **paraverbal** (sound, speed, etc.) and **non verbal** (body position, space, etc.)

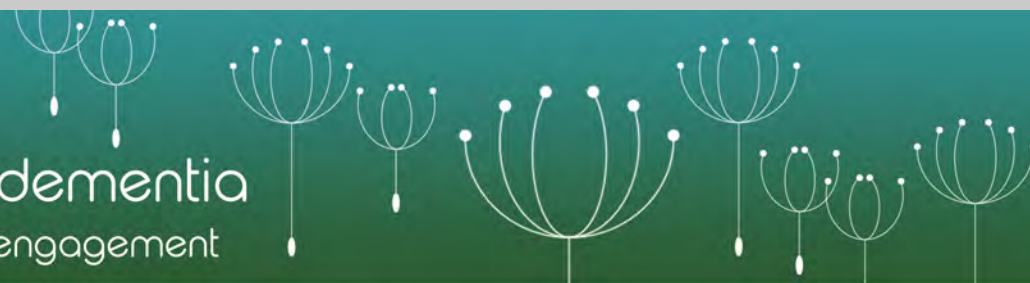
Our aim

→ To use **mindfulness** within design to **increase self-empowerment, confidence and wellbeing** of people with dementia (and their relatives...)

MinD

designing for people with dementia

mindful self-empowerment and social engagement



MinD data collection: methodology & initial results

Professor Dr. Vjera Holthoff

Department of Psychiatry, Psychotherapy and Psychosomatics

Alexianer Krankenhaus Hedwigshöhe, Berlin



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MinD data collection: methodology & initial results



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

- Design of interview guideline with open-ended questions
 - Literature search for qualitative interviews in persons with dementia
 - Expert group without dementia (caregivers, researchers, Alzheimer Europe)
 - Quality assurance through expert with dementia, caregivers
 - Interview guideline: person with dementia, caregivers
 - Interview with single interviewee
 - Focus group
- Positive ethics approval: Germany, Spain, Netherlands
- Standardized training of the interviewers
 - Methodology
 - Training interviews and supervision
 - Training in data analyses



Qualitative interviews and diaries: methods

Data collection materials

- Interview materials
- Cards
- Diaries

Schedule for data collection

- Interviews: completed in Netherlands, Spain and ongoing Germany
- Diaries: completed in Netherlands and ongoing in Spain and Germany

Data analysis (interviews, diaries) - methods and software

- Transcription
- Qualitative data analysis of interviews and diaries (MAXQDA, Nvivo, ATLAS, thematic analysis, visual analysis techniques etc)
- Translation of results into English



Overview over data collection and analyses

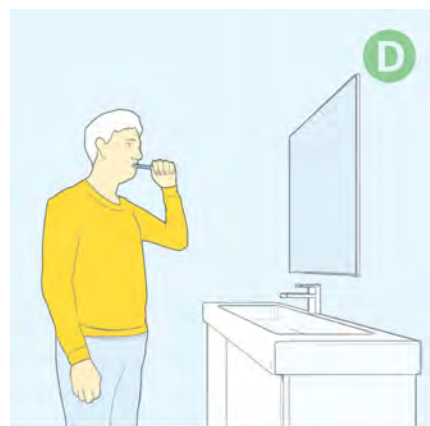
Data collection

	Spain	Netherlands	Germany
Focus Group Caregiver	1		2
Focus Group PwD			1
Interview Caregiver		4	6
Interview PwD	6	9	6
Diary	3-5	5 + interview	4-5

Research papers / literature reviews



Contribution to data collection through visual cards (n=16)



D

BATHROOM

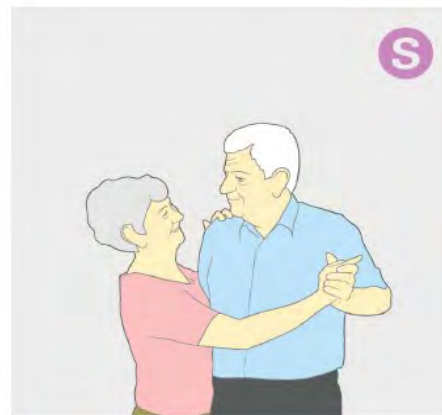
brush teeth
using the toilette
taking a shower



D

DAILY TASKS

go shopping
going to the bank
going to the doctor



S

ENTERTAINMENT

listening to music
watching TV
going to a concert



L

OUTDOORS

travelling
going for a walk
playing games



L

PETS

walking the dog
feeding it
looking after it



L

WELL-BEING

getting a massage
using makeup
going to the hairdresser



L

HOME ACTIVITIES

playing an instrument
gardening
handcrafting



L

ENTERTAINMENT

listening to music
watching TV
going to a concert

Diaries

- Diaries (n=15) remain property of participants
- Photos anonymized and taken for analysis
- Diaries consist of maps and loose leafs



Diaries: 17 tasks

Personality, empowerment and looking back in life

- Personal values
- be acknowledge for
- Experiences of your life
- Being proud of
- Being motivated, feel love of life and energy
- Memories/things to save for ever
- People who made you who you are
- Making your home your home

Looking into the future

- achievement in the future

Personal daily life

- Activities and what helps
- Things you like to take with you
- Feeling physically strong , emotionally strong



Contribution to data collection through diaries



Please tell us about some things you would like to be acknowledged for.

Please use the stickers to describe it and place them on the trophies.



This image shows a single sheet of white paper with horizontal blue lines, resembling notebook paper. The lines are evenly spaced and run across the width of the page. There is no handwriting or other markings on the paper.

This image shows a blank sheet of white paper with horizontal blue lines. At the bottom center, there are two stylized, fluffy white clouds with blue outlines. The clouds are positioned as if they are floating above the lined area.



Contribution to data collection through diaries

If you could capture anything
(for instance any moment, sound,
song, smell, view, object, place...)
and preserve it in this jar for you to
relive what would you choose?

Please use the stickers to describe it and place
them on the jars.



Diaries

Please take us along on a normal day of your life by taking 6 pictures of your activities.

You can put the pictures in the photo holder.

What did you do?
Why did you take the photographs?
How did the activity or situation make you feel?



Picture descriptions:

1	
2	
3	
4	
5	
6	
7	
8	

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:)

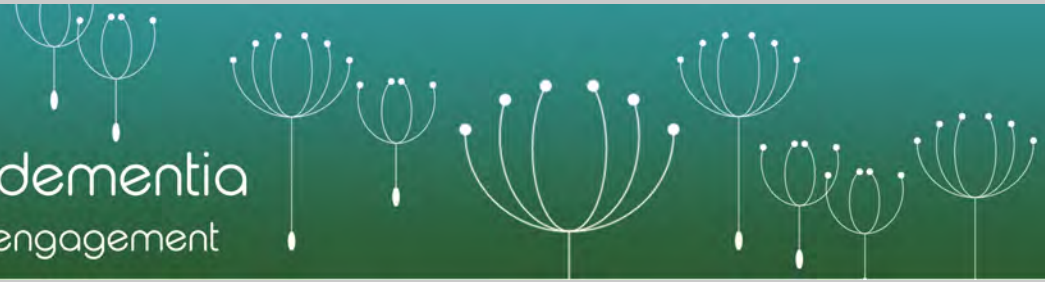
Interviews

- Caregivers tend to take a deficit-oriented perspective
- Occupation = doing 'something', no focus on meaningfulness



MinD

designing for people with dementia
mindful self-empowerment and social engagement



mindful design as a tool for self-empowerment & social change

Dr Kristina Niedderer,
Professor of Design and Craft
University of Wolverhampton, UK



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KNOWLEDGE • INNOVATION • ENTERPRISE

overview

design and its everyday influence

mindfulness

mindful design

applying mindful design in MinD

background

Design is ubiquitous

Design directs our actions through its affordances (Norman 2002)

‘human beings relate to other human beings through the mediating influence of products’ (Buchanan 2001)

problem

Conventional design usually does not consider social behaviour, and/or it reinforces negative social behaviour



mindful solutions

Mindful design offers alternatives that rethink how we behave in everyday life, and offers choice

mindful design proposition

mindfulness can be used as a key mechanism of designing for behaviour change, especially in social contexts

because it encourages reconsidering our actions and their causes, helping to adjust them to new situations and challenges (Langer and Moldoveanu 2000).

Because it can raise awareness of self and of one's context

Awareness offers choice, which in turn leads to both empowerment & responsibility

Kabat-Zinn – meditation based mindfulness

Langer (1989, 2011) – cognitive-based mindfulness

mindfulness in design

Two approaches:

Meditation based approaches

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.”

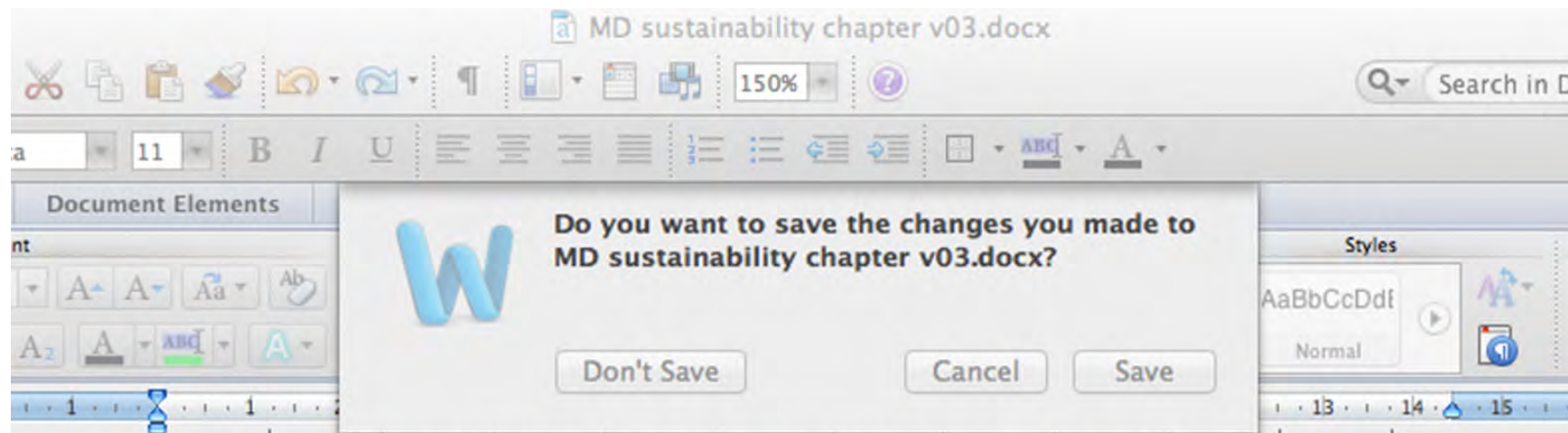
Cognitive-based mindful design

Design for cognitive mindfulness interventions (Niedderer 2007, 2013, 2014)

mindful design

mindfulness in a design context refers 'to the attentiveness of the user towards the (social etc.) consequences of their actions performed with an object' (Niedderer 2007).

mindful design works by disrupting our consciousness through disrupting our routine / expectations to make us aware and reconsider our actions and beliefs (Niedderer 2007, 2014)



The disruption of function only works when it is accompanied by a second stage, the 'thematisation', which directs the user's attention towards some content for reflection.

mindful design

One example of mindful design in both a safety and social context is the shared space model crossings, first developed in the Netherlands, and now more and more adopted in other countries, e.g. Exhibition Road in London, or in Coventry

Drachten, Netherlands

When social interactions are more powerful than rules.

<http://onthecommons.org/fewer-traffic-signs-better-safety>

benefits of mindful design

- considers human attitude and interaction
- uses positive attitude by drawing on the user's responsibility rather than relying on prohibition, persuasion and seduction
- enables (conscious) decision-making and commitment
- empowers the user through choice

applying mindful design within MinD

Mindful design framework

- mindful values
 - subjective wellbeing
 - self-empowerment
 - meaningful interaction
- mindful design development
 - mindful scenario & task analysis
 - idea generation taking into account mindful values
 - mindful co-design

applying mindful design within MinD

mindful scenario & task analysis

SCENARIO: Going to a social event where you know most people.

Timeline:	① Before going	② Getting there	③ Being there	④ Getting back	⑤ Back home
Mindfulness Related Activity	Planning, Pre-empting, Predicting, Preparing (incl. emotionally)	Coping with the journey	Activity of engagements, Physical & Practical issues.	Processing, Calming down	Resetting, Thinking about next time
Emotions	• Fear (Not wanting to go) • Building Confidence	• Silence • Talking about it	• Anxiety • Frustration • Worrying about how others will react to you / you will react to others	• Being upset → • Disappointed →	
Strategies	Informing others (in advance & whether to & how to) Signalling when to change things Accompanying / trusted persons	Recapping Strategies from ①	Relaxation techniques & aids Activating change (moving, leaving)		

applying mindful design within MinD

idea generation taking into account mindful values

- real world scenario
- ideal scenario
- how to get from A to B



applying mindful design within MinD

mindful co-design

- meetings, workshops and co-design sessions with people with dementia, their carers and policy makers

Thank you

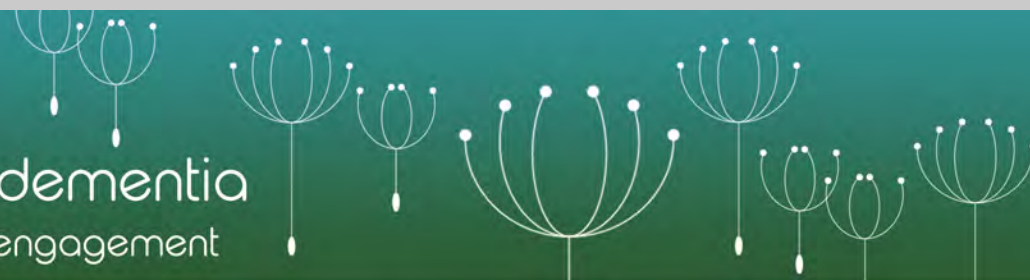
Questions?

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MinD

designing for people with dementia

mindful self-empowerment and social engagement



www.designingfordementia.eu



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Appendix 4: MinD Design Workshop Notes

MinD Symposium Design Workshop, 7 December 2016

What:

The brainstorming workshop is an opportunity to consider some of the issues and social implications that people with dementia and their loved ones face, and to explore different perspectives and solutions of how design can be used to provide support in these situations.

Themes:

- 1: Acceptance of diagnosis and living with dementia:** how can we overcome prejudices and taboos surrounding dementia, both: those which people living with dementia hold about themselves, and those that others hold about them, as well as the resulting social consequences, such as social withdrawal, insecurities etc.?
- 2:** How can we help people manage **relationship change** that occurs during the progression of the disease, e.g. between spouses, relatives, friends and acquaintances, informal or formal carers, or the wider public?
- 3: Acceptability of care** depends to a large extent on **trust**. How can trust be promoted, and care not just be made acceptable but enjoyable, not just functional but also socially rewarding?
- 4: Humour** has been mentioned as one way, which people employ to cope with the changes and challenges that living with dementia poses. How can we embed positive humour in or through design to help people with dementia face their everyday (social) challenges? When talking about positive humour we understand it here as a social competence that provides a way of coping, a positive way of dealing with mishaps and other challenges by laughing at them or oneself (rather than about others).

Each of these themes is very wide. Therefore, there is the need to narrow them in terms of their application. This can be done by focusing on real or imaginary **personas** that allow to give life to a specific case, and to define **specific scenarios** in which they may take part.

Personas

Can be different people, e.g. people with dementia, their carers (formal or informal), a friend, a neighbour, post(wo)man, or someone else they might encounter when leaving the house. They can also specify other details, e.g. a person with dementia might be at working age or retired, a man or a woman, single, married, widowed, etc.

Scenarios

A scenario may describe the situation and context within which any one anecdotal event or incident takes place, and which might have an effect on that event.

Example:

One case we identified through our work with people with dementia was that one **lady who had dementia** (*persona*) was looking forward to a **family gathering** (*scenario*), but then was disappointed afterwards because she could no longer connect with her relatives. She felt that they did not listen to her and instead talked



about things that did not concern her. They felt irritated that she repeated the same story over and over again...

Task:

- 1) Form four groups of 8-10 people (5 min.)
- 2) Each group has a pack with one of the four questions. Please discuss a persona and scenario to help you address your question (5min.)
- 3) Please discuss the real world situation (10 min.): What is currently happening? What are the challenges or obstacles? What is not desirable at present?
- 4) Please consider the ideal situation (10min.): What would be happening in an ideal world? How would people behave? What could be done to support and empower people with dementia? How could values be reconsidered, e.g. how could having dementia be seen as an opportunity rather than a disadvantage?
- 5) Consider how to move towards the ideal situation (15 min.): Please consider the differences between the real world and your ideal scenario, and what might be done to move from the first to the second?
- 6) Present your results (5 min per group): Please chose a speaker (or several people) from the group to report on your results from the discussions.

Facilitators:

Theme 1: Tina Bobbe, TU Dresden

Theme 2: Mah Rana, London.

Theme 3: Tara Boath Mooney, University of Wolverhampton

Theme 4: Alison Carminke, University of Wolverhampton,



Design Workshop Group responses

Theme 1: Acceptance of diagnosis and living with dementia:

Facilitator: Tina Bobbe

At first a persona, a fictional character, with dementia has been generated with visual help of the picture set. The group agreed on a relatively young man, who just got the diagnosis. He has a wife and children, an active social life and is running a successful business. As he uses social media regularly, he posted his diagnosis on facebook. The distance via the internet made it easier for him to tell his friends compared to face-to-face.

The real-world/worst-case scenario the group thought of was that some friends would ignore him from this post on, because of insecurity on how to deal with this situation.

The ideal-word scenario therefore was that friends do stay in contact and on top of that help him generate memories on which he can come back to, in times he would not be able to remember them.

The solution for this gap between real and ideal world is first of all a facebook-plugin called "In Touch". With a reduced and more simple interface for an easy use also in later stages of dementia, friends can get in touch online, and also create memories while uploading pictures and text. In addition, an offline solution for "in Touch" has been thought of. Friends and family of the man with dementia can also give physical objects, which has a meaning through a shared memory. These artefacts can be collected in a box and are important for addressing haptic senses. In general, these memories, on- and offline, should be collected on a regularly basis instead of once.





John

53

Mechanic

business [own / going well]

hobby - cycle racing

married to a younger woman

2 children

active social life - network of friends

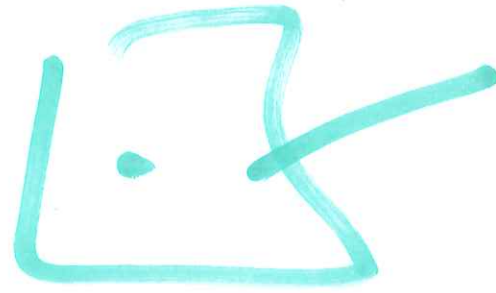
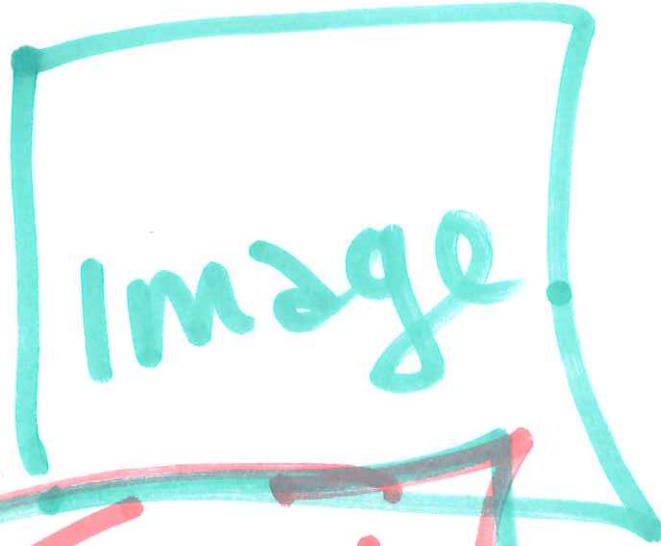
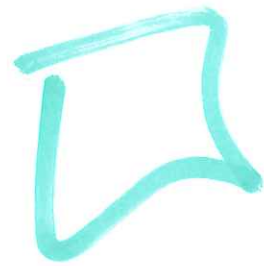
After receiving - Breaking news to his friends
diagnosis

facebook (put it up)

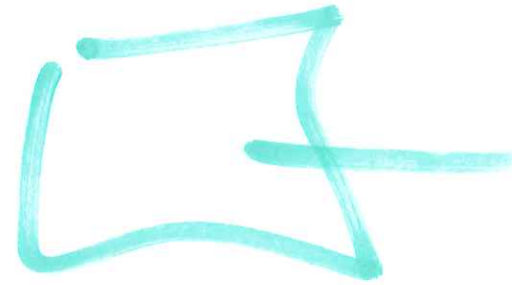
- vulnerable
- relieved
- scanned by machines
- APP: **In Touch**
- I will be the exception
slow course
- friends avoid him
clunts avoid him
- wife sad + anxious

App
friendly

Motor



people
talking



sound

~~In Touch~~
touchy

feely
talk to it

Plug-in
to
facebook

Trouma
WWII old
♀
* internet
diary.
personal
anonymous

evolving
the disease

APP?

dist. of
life exp.

Communication

please let me
explain...

giving feedback.

DEAL
world

education

taboo
Stigma.

Chronic
society

Structure
Memories

friendst

Sharing
memories

InTouch

donation

DIGITAL

—

PHYSICAL
SCRAPBOOK.

Monthly!

Social Structured.
diary

Objects

BOX

dementia
= old people!
Substandard

Facebook
plug-in.

Reaching to friends

difference
from
diff
people.

taboo

~~anonymous~~ x
distance
not F2F ✓

In Touch

motivating.

Sound -
text -
Buttons -

Interface

↳ intuitive
interaction

KEEP IN
TOUCH

friends
reacting

①
collecting

dig

box

②
enjoying

telling
people

REAL
WORLD

people
do not
respond.

Theme 2: How can we help people manage relationship change

Facilitator: Mah Rana

Betty cares for Bill, she is semi retired and an active advocate for carer's rights.

Because of his dementia, Bill has had to stop driving. this is something he misses. Betty now drives when they travel together in the car. But Betty finds this stressful because Bill is critical of her driving. He is a back-seat driver.

They have a son who lives by the coast; to get there Bill and Betty go by car- Betty drives. But at the end of the journey both Bill and Betty are tired, frustrated and stressed by the car drive.

Mindful Uber, a chauffeur service to take out the stress of driving.

The seated area for Betty and Bill is designed to provide a relaxed environment.

In-car entertainment is available, or Bill and Betty can enjoy each other's company.

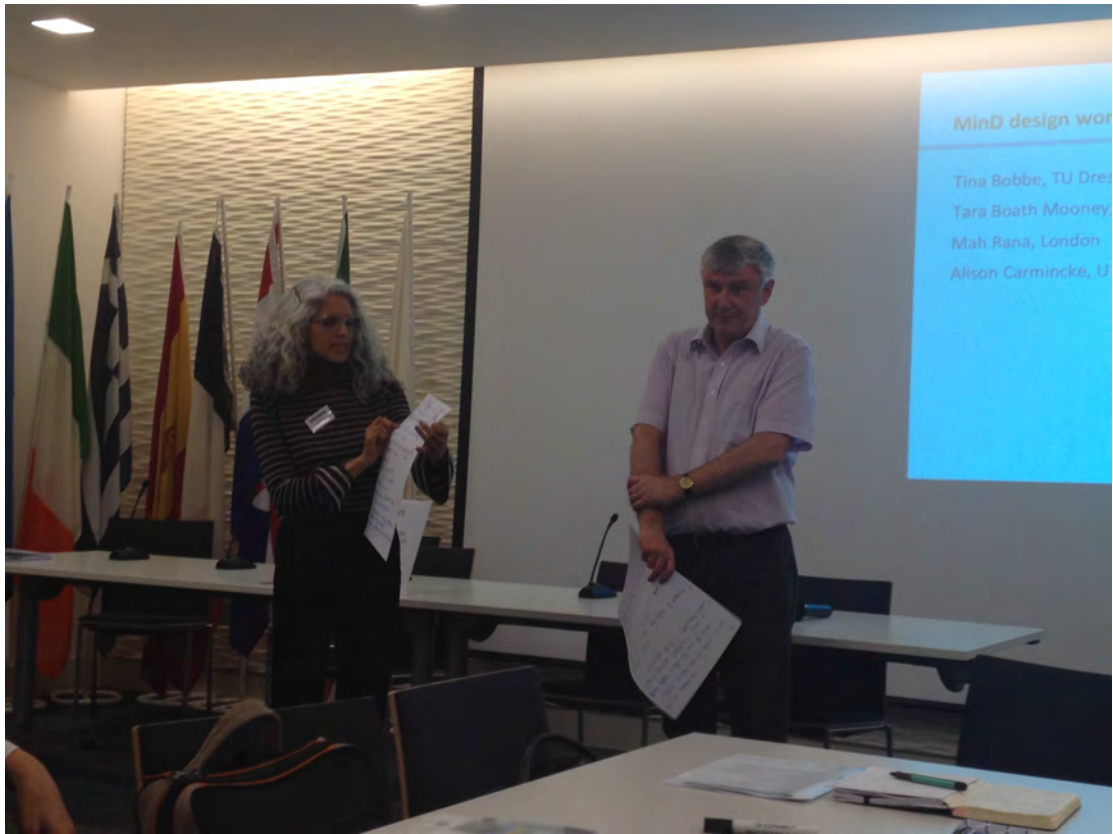
An in-car screen can be programmed to deliver 'reminder' messages for Bill, e.g. we are driving to visit 'name' in 'location'.

Wifi connectivity means gives the option to have Skype conversations, e.g Bill can talk to his son, to give him additional context as to why he and Betty are in the car.

Service stations would have someone trained to help visitors find & access toilet facilities with ease.

And the chauffeur can contact the service station in advance of arrival, so that someone is available to offer help, if needed.





Betty + Bill Kindful
Uber

Professional people now retired

She is fighting against being
swamped as a carer

However she acts as an advocate for
carers
- presents on radio

Relationship

from equal partners

→ carer + carer for

→ time commitment

Have engaged professional carers
but not straightforward

She understands his verbal utterances
the best - acts as "translator"

Can end up presuming that she knows best

NB Car will translate but they
have their own viewpoint

(2)

Experiencing the continuing humanity
of the person

Scenario going to see the family
in Bournemouth

she would always have had this

Bill would have driven

Now, she would have to do it

He tells her she's gone wrong which
leads to rows

↳ Gets stressed as it "should" be
him driving

Exhausted on arrival

IDEAL - chauffeur driver
(airport car)

alternatively some kind of share
eg Bicester friendly Ube

Driverless car or DF supervision (3)
Promote social ~~aspects~~ aspects
of the journey

by videos, ambient music, ^{sensory} materials
food + refreshment
Arrival needs to be special / fun

Automatic red carpet unfolds
fanfare of trumpets.

Host arrangements

Reality "Here's your mother arriving"

Ideal - emphasis is on the (mindful)
being together

So Betty not to fret on Bill's behalf
as this will be contagious

Also the family need to mirror this.
Betty needs to feel looked after - not
solely caring for Bill in a strange place

In car material (4)
could include various forms of info

Rest stops - where to use the toilet
Should service stations have a
concierge desk? (NB avoid stigma)

Hosts again

Are they aware of what to expect?

Bill may be declined

Skype conversations may help keep you
up to date.

Making a success of next times

Don't have to get there that quickly!
Take 12 hours or 3 days if you want.

Supported to do new things
tell us what we can do
motivation
put faith in us . . .

Theme 3: Acceptability of Care and Trust

Facilitator: Tara Baath Mooney

Scenario:

It is early morning. Brian is getting ready for his day in the care home where he lives. For safety reasons, Brian usually needs two carers to bathe and dress him because he has trouble doing things for himself due to mobility problems.

Persona:

Brian has dementia. He is a very charismatic, open man who ran community projects and interacted with people easily throughout his life.

Real World Situation:

In this scenario Brian tries to engage with the two carers that come to bathe and dress him on a daily basis.

The two carers are chatting brightly about one of the carers' preparations for her wedding. Brian interjects with a question about the number of people that they are inviting to the wedding. Brian is ignored and asks the question again, but the two carers are so focussed on the task at hand that they are not seeing or hearing what Brian has to say.

Brian is completely **disempowered** by the **lack of engagement**. This leads to him becoming quiet, he withdraws emotionally and instead of trying to engage a third time he becomes listless and **passively receives** the care being given to him. Both the givers of care and the and the receiver of care are performing their duties together but in **isolation**.

Brian stops all efforts to assist the carers in the process of dressing. This is later labelled as 'challenging behaviour'

Ideal Situation:

Brian engages with the two carers as an **equal participant** in the interaction. The task at hand recedes, as the conversation about the wedding preparations becomes the focus. Brian is **empowered by the inclusion** and physically moves to assist the carers in his own personal care. The carers are merely facilitating this choreographed bathing and dressing performance. All of the actions are a shared series of moments which **fulfill the functional need but also enrich the experience**

Moving from real to ideal, The solution:

The group felt that a focussed arts based training for all members of the extended care community would enable a scenario like this to be transformed. This would include the care team and family members occupational therapists etc.

Many care givers are badly paid and undervalued for the contributions which they make in these scenarios every day. We made a comparison between caring for people with dementia/ older people and training for childcare and found that the wages are higher and the focus is on maintaining and promoting dignity and respect through activities. Dignity and respect should support and promote rather than undermine a person's self respect.

Training for carers which includes visual arts, dance, roleplay, drama and music could shift the focus of the interaction from being a **needs based** task to being an opportunity for **interaction and empowerment**. This kind of training could also help

to shift the focus from the **heaviness** of the situation to a **lighter** and more joyful encounter for all parties. We used the example of an extended bubble bath to show the importance of being spontaneous and having fun in and with the situation. It was felt that this basic paradigm shift around training could also tackle the ill-advised use of language often used to describe isolated incidents without putting them in context. In this scenario, the phrase 'challenging behaviour' has resulted from Brian's feelings of isolation, worthlessness and disempowerment which was brought on very simply by not including him in the conversation.



Brion

Person w Dementia & 2 carers

2 Carers talk to each other
met to the person they are
~~bathtime~~ & dressing

Pw D tries to interact by making a joke
& this leads to an ignored
unresolved
upset — feeling of worthlessness

feeling of

1 Carer sitting for 10 mins with someone
in a bed.

ly

Value of Older People in Society.

- Under Paid
- Under Respected ——— Negative
- Family member

- Training - Tools for dealing w behavior

- Unhappy -

- Prevention - reaction to something

- Spotting things as they are building
unrest

- Distraction - Emotion -

- Training w family member - Alone -

- Theory of Unmet Needs framework
Cohen-Mansfield

- Needs - stimulation
boredom

Daily Personal Care - * Agency - over their bodies.

Distraction?

Stimulation - Focus in a different place.

music conversation

Unfulfilled & Worthlessness -

Early Years education - trained never to
ignore a child -

Birmingham - Care Home
making bread.

- Arts can story tell both - verbal & non verbal -

Do they need to know about the person? Or do they
need the tools to interact?

Task Oriented - there is an aim & objective - not possible to follow it through
As disease progresses - vision gets more impaired -

- Respect & Dignity -

Dressing Someone without Interacting

- Stimulation - activates brain function -

- Give the PWD some control over their own dressing.

Touch - ^{lost sense to go} Ethical, legal - practical

- Touching - with consideration stroke & hand.

Dress - Heavy -

- Joy - Lightness -
- Fun - Enjoying the possibility of play.

No Dignity -
Lack of Empathy:

Always involving the person keeping the Dignity -
by using the most appropriate language. Rocking Chair versus Nursing Chair -

Social Contact seen as a waste of time

Setting in Contact ^{with} someone for 10 minutes -

Arts training - specific family managers
staffing issues - corners

It's ok to let someone be themselves - environment.
multisensory stimulating enjoyable activities & life

Boredom Depression

- designing outfit, need to be trained -
around daily needs - help to build trust &
tune environment -
to the needs of PWD. maintain performance

Bathing/Dressing with no
Interaction

Let Brian be part of
the bathing/dressing experience
get him to control the
his own dressing-

respect & Dignity at all times
comes before PRACTICAL NEED

Social Contact is
Seen as a waste of
time

Sitting with someone for
10 mins part of your daily
routine

touching becomes part of the routine -

Look at the ideas & language around NEEDS
also language around objects - rocking chair versus
nursing chair.

tune the environment to the best context
for the persons w dementia -

Be open to Joy & Lightness.

training - tools for dealing with different
behaviours -

Using the Arts - drama - roleplay - music - visual stimuli
to train carers, family members, → all people in contact
with the person w dementia.
It's ok to let someone be themselves - so
that the carers & family are all on the same
page - building trust.

Theme 4: Humour

Facilitator: Alison Carminke

The group looked at the persona of Alan, who was finding it increasingly difficult to remember names. He enjoyed working in his garden, but felt uncomfortable when neighbours came up to chat, and he couldn't remember their names. This made him start to avoid going outside the house, which led to increasing isolation. The group thought about making a joke around not knowing names, through the design of some sort of wearable, which would have a jokey slogan to ask for names e.g. "Keep calm and tell me your name". The wearable would ideally be responsive to the wearer's body signs e.g. it would display the slogan when it felt the wearer getting stressed, and then change to a smiley face or another design when the wearer became more relaxed. It would be designed to be wearable in several different ways, to be discreet so that the wearer would not feel "labelled" – a badge, a watch, a pendant, clipping onto a hat. The design would also take into account cultural and gender norms.





PERSONA

PERSON WITH DEMENTIA
ALAN

SCENARIO

CAN'T RECOGNISE NEIGHBOURS
WHEN THEY GO PAST THE GARDEN.
FEELS EMBARRASSED, STOPS GOING INTO
THE GARDEN.

CHALLENGES

STIGMA

EMBARRASSED

AVOID SOCIAL SITUATIONS

LESS EXERCISE

ISOLATED

CIRCLE OF AVOIDANCE - CARER
- PWD
- NEIGHBOURS

NEIGHBOURS INVALIDATE PWD

NEIGHBOURS AFRAID TO USE HUMOUR

+

EMPATHY

INCLUSION

RESPECT

BUILDING A BRIDGE

POSITIVE ENGAGEMENT

ACTIVE LISTENING

CONVERSATION AROUND ENVIRONMENT

MINDFULNESS - KEEP IN PRESENT

SUGGESTIONS

BADGE TO SHOW EMOTIONS 😊 😞

USE OF OBJECTS (E.G. CARE HOMES)

- CHILDLIKE, PHYSICAL

JOKE BADGE OR SIGN - "TELL ME YOUR NAME" - COULD BE INTERACTIVE, WORDS CHANGE WHEN PERSON SAYS NAME - RIVAL

- WOULD ENCOURAGE OTHERS TO ENGAGE

- COULD BE MOOD-SENSITIVE

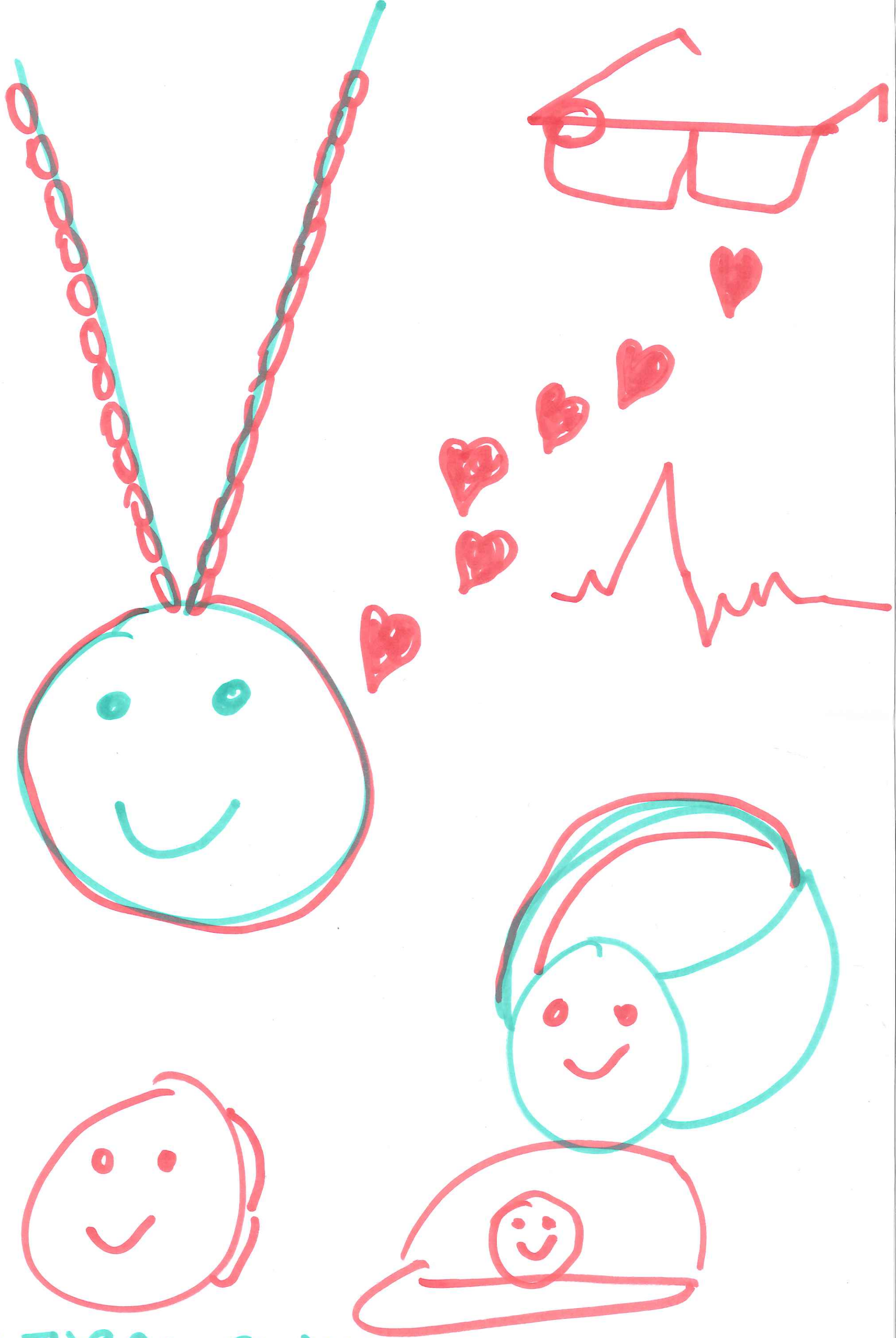
- SOME KIND OF CARTOON?

- MUSIC OR SOUND (KEY WORD SONG)

NEED TO TACKLE FEELING OF EMBARRASSMENT THROUGH HUMOUR



or
I know your name's Ted.



CULTURAL CHANGES
COLOURS MEN + WOMEN

Appendix 5: MinD Panel Discussion Notes

MinD Symposium - Panel Discussion

Panel members:

Prof Cathy Treadaway, Cardiff UK;

Prof Vjera Holthoff, Alexianer St Hedwig Hospital, Germany;

Prof Tom Denning, Nottinghamshire Healthcare NHS Foundation Trust, UK

Theme 1 and panel responses:

Independence and social integration: how can design help support independence and self-empowerment to support social engagement rather than to create isolation?

Assistive devices and other technology are often helpful in aiding with the safety, orientation and other issues of daily living that people with dementia face. However, often there is an implication in their use, which is that of saving care time, thus reducing contact time and potential social time. In addition, often care time for people with dementia is treated as purely 'functional' to accomplish certain practical tasks, such as washing, dressing, preparing meals, etc. rather than to see them also as an opportunity for valuable social time. How can we use design to change perceptions and help to accomplish both ends?

Prof Cathy Treadaway:

We need compassion to underpin the work we do - we need to consider in what ways the things we design will bring about positivity resonance – moments of high quality connection and love; mutuality and reciprocity. We need to consider the 'we' – instead of the I in how to connect with each other.

(Fredrickson, B., 2014, Love 2.0 Finding happiness and Love in Moments of Connection, Pub. Plume)

I don't believe that a robot will ever replicate human care.

Human presence, eye contact and human touch are vital – they change the whole body – blood pressure, heart health, immune system – a machine doesn't have the same effect.

Play is a way forward – moving into the play space of the person with whom we want to connect. Being with them and not expecting them to be where we are conceptually. Enjoying the moment and having a laugh – laughter connects people.

Prof Vjera Holthoff:

The public interest does not support integration of people with dementia in the community. People without dementia feel uncomfortable with them.

Persons with dementia are much better cared for in specific dementia homes and dementia villages.

You can immediately tell that persons with dementia live there because everything looks very different. That is why other elderly people would not want to live there.

Persons with dementia cared for at their homes are not welcome in public once dementia advances. Caregivers do not feel support in a restaurant, going by bus or while they go shopping.

Prof Tom Denning:

As well as being functional tasks, these care interactions are a privilege, a (shared) journey, and also potentially fun. I liked the earlier comment about 'extended bubble bath' – that captures it exactly. 'Being in the moment' is important in providing personal care. How do we promote this? A lot of it is about education. Role play can be a powerful way of entering someone else's perspective.

What design issues would help to improve matters? Let's think about food. This may include attractive food with some colour, maybe quirky decorations, attractive plates, chunky cutlery that's got some fun in it. Zazzy napkins. Eating with the person – better still, preparing the food with them. Clearing up afterwards with them. Grace, celebration, giving thanks for our food: various rituals that promote mindfulness around the food instead of regarding it as chunks of gloop to get down the person's throat by any old means as fast as possible.

Theme 2 and panel responses:

How can interaction with persons with dementia become an opportunity for persons without dementia?

Looking after a person with dementia, especially by informal carers, can be demanding on their time and resources and can include repetition in tasks and conversation. With this theme, we would like to explore what can make moments of social interaction valuable, how to take interest in the other person's perspective and to consider what is important for them and what may increase the other person's well-being. How can design be used to support this process?

Prof Cathy Treadaway:

It provides an opportunity to be in the moment.

We need to slow down – be more mindful and be in the moment (easier said than done!) People living with dementia read our unconscious body language – if we arrive stressed to visit them, we pass on our emotional turmoil to them.

When we slow down we can see things from different perspectives; we can be open minded, curious and playful, which has benefit to both the carer and care recipient.

Children, animals, play things and playful activities benefit everyone through connection, creativity and humour.

Prof Vjera Holthoff:

This means that integration of persons with dementia in every-day-life situations should be promoted actively and give the public the opportunity to live together. Mindfulness interaction and environment should be promoted for everybody in need of help (e.g. elderly, persons with dementia). Persons with dementia should not be recognizable e.g. by the assistive devices they use. Integrating elderly and persons with dementia means showing interest in individual capacities, being non-judgementally and not reacting in maladaptive ways.

Prof Tom Denning:

I gave a personal answer to this question based on my interactions with my mother, who is nearly 90 and lives in a care home. It is nowadays impossible to ring her up

as she can't manage to answer the phone. So I send her postcards, which have always been a form of currency in our family.

Conversations are difficult. When I ask her how she is, she always says she is terrible. It's difficult to discuss this much further. When we start to talk about what we are doing or have done recently, I am conscious of a huge differential in power, it just feels too unbalanced to be a real exchange. Therefore I have found it useful to do things that create more of a level playing field between us. I usually bring something along – so far I have used poetry, photos, short stories. I imagine a pet or a grandchild would be a big hit but I don't have either at the moment.

Having something between us that we are sharing creates the right kind of space and allows our mutual respect to come into play. While I am reading, no response is required from her, though she often does say something or is clearly moved. Whether she follows the plot of a story, I am not sure, but it does not matter. I think what she is responding to is the voice. The material being read has to be good enough – I couldn't just read from a magazine, for instance. It is not reminiscence, even with photos, it is to do with what happens in the moment. The challenge is what to do next, though I do have some other ideas.