

# Empathic handover : how would you feel? : handing over dementia experiences and feelings in empathic co-design

**Citation for published version (APA):**

Smeenk, W., Sturm, J. A., & Eggen, J. H. (2018). Empathic handover : how would you feel? : handing over dementia experiences and feelings in empathic co-design. *CoDesign*, 14(4), 259-274.  
<https://doi.org/10.1080/15710882.2017.1301960>

**DOI:**

[10.1080/15710882.2017.1301960](https://doi.org/10.1080/15710882.2017.1301960)

**Document status and date:**

Published: 02/10/2018

**Document Version:**

Accepted manuscript including changes made at the peer-review stage

**Please check the document version of this publication:**

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

**General rights**

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

[www.tue.nl/taverne](http://www.tue.nl/taverne)

**Take down policy**

If you believe that this document breaches copyright please contact us at:

[openaccess@tue.nl](mailto:openaccess@tue.nl)

providing details and we will investigate your claim.

## **Empathic handover: How would you feel?**

### **Handing over dementia experiences and feelings in empathic co-design**

#### **Abstract**

It is difficult to inform design with experiences from people with dementia. When it comes to involving this vulnerable user group and connecting multidisciplinary design teams, current empathic co-design methods and tools are scarce, seem fragmented and lack a coherent and structured approach. In response, we provide guidance to design teams by proposing a novel, empathic co-design approach that enables a user researcher, who encounters people with dementia, to transfer insights to team members who do not. Our proposal addresses three sequential co-design activities facilitated by an empathic principal designer: 1) individual harvest meetings, 2) collective handover workshops and 3) empathic ideation workshops. Using a case study involving a dementia simulator, we illustrate how the approach contributes to understanding users, transferring insights and translating empathy into design. The positive evaluation of the simulator led us to conclude that the approach not only guided the design team by offering a practical and coherent process, but also enabled individual team members to be receptive, inclusive and committed to people with dementia.

Keywords: user-centred design; co-design; empathic design; empathic handover; empathic ideation; dementia

#### **1. Introduction**

Imagine:

*You come home from grocery shopping to an unfamiliar kitchen and search for the refrigerator. First, you open the wrong door, but after opening another two, you find the right one. The fridge is fully packed with grapes and milk. You open your bag and start to put the groceries in. That's strange: did you buy grapes and milk again? Mmmm... Let's sit down. Suddenly, your daughter comes in;*

*she walks to the fridge while asking if you would like to have a drink. As she opens the fridge, she says: 'Oh no, did you buy grapes and milk again?'*

How would you feel?

The above anecdote is just one example of the confusing situations that people living with dementia experience every day. They find themselves in social situations where others point out what they have done wrong. They are confronted with memory loss and may not recall their purchases every time they open the refrigerator. They can also become disorientated in space and, for instance, be unable to find their own refrigerator. Being constantly confronted with these limitations can make them insecure, annoyed and frustrated. Design can help to reduce these limitations or make caregivers understand them better. It is thus vital that people with dementia inform and inspire design.

The work presented in this paper involves empathic design and is focussed on designing with people with dementia. The main aim is to provide multidisciplinary design and development teams (hereafter 'design teams') with an approach for empathically and effectively collecting, understanding and translating the experiences and perceptions of people with dementia and their caregivers. Involving people with dementia in the design process is difficult, due to the delicate context of the disease and their emotions, vulnerability and different perceptions of the world. The risk of 'harming' or confusing people even more with design activities is an ethical dilemma. Yet, to ensure authentic user insights and meaningful design outcomes, designers need to try to involve people living with dementia in designing and immerse themselves in their private contexts.

Despite the clear advantages that co-design offers in terms of involving users and engaging designers, co-designing with people with dementia is hindered by at least three factors. First, most research methods available in the design traditions of user-centred design, human-centred design, participatory design and co-design have been developed for designing with people who are cognitively and physically healthy. These methods are therefore neither directly applicable to nor ethically appropriate for designing with people with dementia. Many scholars (e.g. Bartlett 2012; Hendriks, Slegers, and Duysburgh 2015; Lindsay et al. 2012). argue that there are few specific co-design approaches suitable for use with people with dementia. Moreover, practical limitations may hinder their participation in co-design activities, due to their mental, physical and/or social impairments.

Second, young and healthy design team members often find it difficult to collaborate with users who have different abilities from them and live in difficult situations (Lindsay et al. 2012). Many feel that they lack the necessary skills and experiences to co-design with older users (Hendriks, Truyen, and Duval 2013).

Third, Friess (2012) and Postma et al. (2012) argue that, in practice, resources (budget and time) often do not allow *all* the team members to join co-design sessions, which means that some team members cannot encounter users and immerse themselves in user situations. In fact, both authors showed that there is a clear need for approaches that enable transfer of insights from user researchers, who had experience working with people with dementia, to members of the design team who did not.

These three limitations make it difficult for designers to be receptive, inclusive and committed to people with dementia (Cockton 2009, Smeenk, Tomico, and Van Turnhout 2016). Although having a connection and developing empathy with users are prerequisites for designers to be able to design meaningful products, services and

businesses, there is currently no practical, coherent and structured handover approach to guide design teams in developing empathy with dementia.

In this paper, we introduce a novel empathic handover approach for design teams. We explain, illustrate and evaluate this approach using a case study executed by a mid-sized interaction design company in the Netherlands, which resulted in a successful dementia simulator. Before we introduce the paper's structure set-up, we will first describe the simulator case.

### ***1.1 The design of a dementia simulator***

The dementia simulator case originated from a collaboration between an independent designer (our first author Smeenk) and a renowned design firm. In the simulator, visitors experience daily life situations that a person with dementia encounters. It allows healthy visitors (e.g. caregivers, family) to familiarise themselves with what goes on in the minds of people with dementia and allows the visitors to get insight into the limitations they are confronted with. The empathy and compassion that visitors derive from this experience is intended to decrease patient and caregiver burdens and improve their shared quality of life.



Figure 1. The exterior and interior of the dementia simulator. Photography by Jacqueline Gielen.

The simulator, [www.intodmentia.com](http://www.intodmentia.com), contains a lifelike experience created by a combination of virtual reality, interactive techniques, physical objects, sound effects and gaming technology (see Figure 1). A visit to the simulator consists of several steps: 1) an intake conversation to prepare visitors for the simulation, 2) the experience in the simulator, 3) a reflective conversation afterwards and 4) an empathic peer training. The experience in the simulator lasts approximately 25 minutes. The design firm's scope was to develop and build a lifelike experience about dementia in a physically representative mobile environment.

This paper is organised into four main sections. First, we will provide an overview of related work on design for dementia and empathic design. Second, we will introduce a novel design approach and illustrate it using the dementia simulator. Third,

we will discuss our insights. Finally, we will conclude with our contribution and present an outlook for future research.

## **2. Related work**

### ***2.1 Design for dementia***

It is estimated that the number of people with dementia worldwide will increase to approximately 135.5 million around 2050 (www.who.int). The lives of people with dementia slowly deteriorate as they lose cognitive, sensory, motoric and visual capacities over time, and experience behavioural changes. Due to this decline, they increasingly need attention and care from others. Dementia is becoming a social problem that not only affects the people with dementia themselves, but also the people surrounding them. The load on informal caregivers (family, friends) in terms of time, effort and flexibility increases immensely, which can cause both the caregiver and the person with dementia to have physical, mental, financial and social problems, often leading to institutionalisation of the person with dementia (Schulz and Sherwood 2008; Brodaty and Hadzi-Pavlovic 1990). Well-designed products and services (e.g. day clocks, GPS trackers) can help to safeguard, support, reassure, stimulate and empower people with dementia and their caregivers. Furthermore, design can help improve people's quality of life by providing information (e.g. the dementia simulator).

According to Topo (2009), there is a large body of knowledge on dementia, but little literature that describes peoples' own and contextual experiences. Developing relevant products and services requires insights into the authentic contextual feelings of people with dementia. One approach to get to know such experiences is involving people living with dementia in designing. Since this is a delicate user group, caregivers are often used as a substitute, but their perspectives may be biased (Brereton et al.

2015). Moreover, Topo's (2009) study showed that most research on the experiences and needs of people with dementia is aimed at *evaluating* solutions designed *for* them instead of making their experiences *inform* design.

According to many scholars (Bartlett 2012; Hendriks, Slegers, and Duysburgh 2015; Lindsay et al. 2012), there is still a limited range of methods and tools for involving and being inspired by people with dementia. The studies on design for dementia mainly provide insights into overcoming social and practical impairments that hinder these people from joining co-design sessions. To illustrate this, Hendriks, Truyen, and Duval (2013) supported designers in involving people with dementia by providing abstract design guidelines. Lindsay et al. (2012) offered tips for establishing empathic relationships with people with dementia. And others (Allan 2001; Bartlett 2012; Brereton et al. 2015) provided designers with suggestions for developing appropriate physical or visual tools. Despite a growing interest in designing with people with dementia, the current understanding is more a fragmented set of suggestions (largely about method) and lacks a more fundamental (practical, coherent and structured) co-design approach.

## ***2.2 Empathic design***

The work presented in this paper involves empathic design. (Mattelmäki and Battarbee 2002; McDonagh 2006; Wright and McCarthy 2008; Koskinen and Battarbee 2003). In empathic design, designers attempt to get closer to the users' experiences and circumstances. Users are seen as the experts regarding their own experiences and feelings and play a crucial role in both knowledge development and idea generation (Kouprie and Sleeswijk Visser 2009; Sleeswijk Visser et al. 2005). In 2009, Kouprie and Sleeswijk Visser deepened the fundamental understanding of empathy in design by reviewing the term 'empathy' in the discipline of psychology. Both Kouprie and

Sleeswijk Visser (2009) and Van Rijn et al. (2011) argue that by thoughtfully stepping into and out of the user's life, designers develop empathy. In a recent study on mixed perspectives, Smeenk et al. (2016) argue for a more systematic and fundamental understanding of these kinds of empathic co-design processes and the value of the designers' own experiences (first-person perspective) in designing.

In professional design practice, resource constraints make it difficult for *all* the design team members to encounter and empathise with users (e.g. Friess 2012; Postma et al. 2012; Hess and Fila 2016). Therefore, in many projects, this task is delegated to a research department or to one or two design team members. In the latter cases, the way to transfer the acquired user insights to the rest of the team becomes crucial. Postma et al. (2012) therefore propose a methodological change from *informing design teams of* to *engaging them in* user research. They argue that transferring insights from user research is not easy, and tools and techniques are missing. They propose a preparation kit for designers and a plenary insight session; the latter seemed promising, but became rather time consuming. According to them, this '*handover*' part of empathic design is new and largely unaddressed in the literature and is key to embedding empathic design within practice.

The study of Smeenk et al. (2016) can also be used to understand and conceptualise an empathic handover approach. They showed that designers can be *engaged* with user insights (third-person findings) by explicitly connecting these findings to the designers' own (first-person) experiences. This transition between the first- and third-person perspectives allows designers to use relevant personal experiences and intuition in a credible and intentional way. This supports motivation and increases the designer's commitment to a design project (Cockton 2009). Activating relevant personal experience that relates to the specific design situation might be key to

a successful transfer of user insights, as it empowers designers to use their first-person perspective and intuition during designing.

### **3. Empathic handover: a novel co-design approach for dementia**

Since the aim of the dementia simulator was to provoke thought and emotional responses, and to encourage reflection, we believed the designed experience should involve both cognitive and psychosocial experiences, such as confusion, disappointment, frustration, anger, anxiety, alienation, fear, aggression and insecurity. To achieve this, the design team had to connect to and develop empathy for people living with dementia. However, budget and timing issues did not allow the entire team to directly interact with users. The team also doubted whether all the designers had the specific people skills needed to respectfully engage with people with dementia, so the team had to be empathically involved and engaged in another way.

We thus developed a practical, coherent and structured approach that enabled all the designers to develop empathy without direct user involvement. By making them walk in the shoes of people living with dementia, they could emulate the experience of living with dementia, a bit like the simulator was intended to do. In this section, we will explain how we developed and employed the empathic handover approach, which consists of three sequential design activities: individual harvest meetings, collective handover workshops and an empathic ideation workshop (see Figure 2).

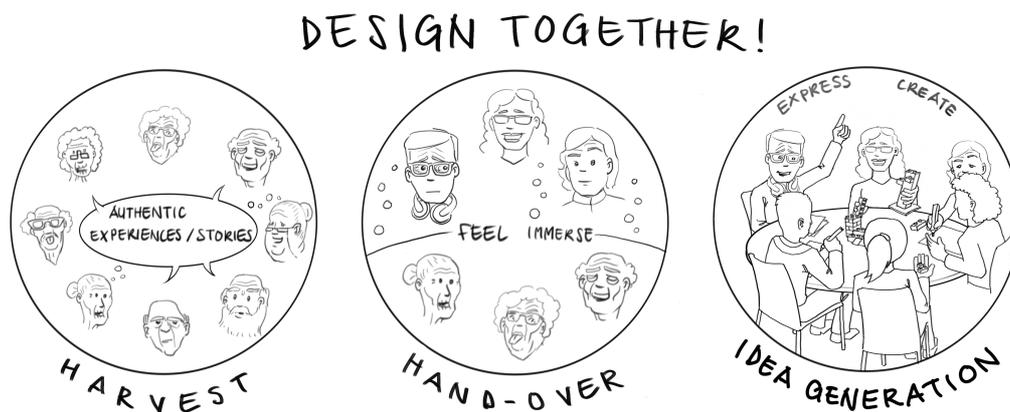


Figure 2. The empathic handover approach

### ***3.1 Step 1: Individual harvest meetings***

In this first activity of the empathic handover approach, the principal designer collects first-hand experiences, from people living with dementia. The individual harvest meetings were intended to reveal essential feelings from several perspectives to inspire the development of storylines and the physical representation of the simulator.

#### *3.1.1 Harvest meeting preparation*

*Principal Designer.* To establish respectful contact with people with dementia and their caregivers, the design firm consciously appointed a consistent point of contact for both users and the design team. This principal designer (PD), who had first-person experience as an informal dementia caregiver, assisted the design team by preparing the user research and facilitating the harvest meetings.

*Ethics.* The PD followed a practical, situated approach to ethics. She could build on personal experiences, and embraced the vision on design ethics discussed by IDEO

(2015). According to Robertson and Wagner (2012), ethical practice in design can be evaluated by reflecting on three issues: the inclusiveness of the design process, the choice of appropriate design tools, and the responsibilities and accountability of the participants. We will discuss each of these issues below. First, the participation of people living with dementia was limited to the harvest meetings due to design scope and medical concern. The simulator design did not demand design requirements, but a harvest of lifelike experiences. In addition, to prevent harm and confusion, people with dementia did not generate or evaluate simulator content. Thus, their participation was informative rather than collaborative in nature. In addition, the PD made sure that the participants understood that participation was voluntary. Before the meeting started, the partner of the person with dementia was informed about the research aims and signed a consent form for the two of them.

Next, we considered the parameters of participant engagement. Dementia includes negative experiences that trigger grief and frustration, so we purposely refrained from harvesting these emotions. We aspired to treat participants as collaborators and hoped they would release tacit experiences with the help of engaging visual prompts. To prevent confusion and bring comfort, the harvest meetings were facilitated in a separate room in the support centre facilities, with caregivers close by.

Third, we recognised the impact of our engagement and that trust comes with responsibility. We gave the participants a clear and honest explanation about the goal of their participation and how we would use and share the harvested information. We also did not share partner outcomes for reasons of privacy or trust. In engagement, we were attuned to the situation and sensitive to participants.

*Participants.* A diverse and representative sample of participants was identified and recruited through support centres and care professionals. The PD attended existing

‘coffee and newspaper’ group meetings for people with dementia at two locations in the Netherlands. In addition, she attended a peer meeting for partners. The intention was to build trust and a relationship before conducting the actual harvest meetings. In addition, these meetings enabled the PD to be informed (through careful observation) about the diversity in personal traits, ways of coping and types of relationships. This ensured that the participants and couples in our sample represented a broad range of traits.

In total, five couples were selected and invited. The five people with moderate dementia (three male, two female) lived independently with their partners, but spent working days at the support centres.

*Design tools.* Storytelling is an effective method for identifying, understanding and coming to grips with factors that capture and influence people’s experiences (e.g. Ozcelik Buskermolen, Terken, and Eggen 2015; Denning 2005) and for building empathy (van Rijn et al. 2011). Since language can be a barrier for people with dementia (Allan 2001), we used relatively simple, less lingual tools to reduce abstract thought and support our understanding of participants as a ‘whole’. As Sanders and Stappers (2008) have shown, doing something together with the help of visual prompts increases trust and enables people to exchange stories. The PD developed and used two visual design tools: *social maps* and *picture sets*.

The PD used two social drawing maps (Figure 3). The first drawing representing a couple inside their home, was aimed at understanding their physical health and emotions and perception of their partner’s wellbeing. The second drawing aimed at understanding social discourse and support, and represented a couple and their social surroundings. The social maps enabled participants to express multiple perspectives (their own and others) on relationships and social contact.

The picture sets were aimed at facilitating a more in-depth conversation about the cognitive, psychosocial and emotional aspects of dementia. Because the design tools needed to be attentive to all these aspects, the PD developed four picture sets: 1) individual people and their personal emotions and body language (e.g. happy, sad, insecure); 2) social discourse between a couple, their emotions and body language (e.g. fighting, loving, supporting); 3) daily activities, actions and situations (e.g. brushing teeth, getting dressed, watching television); and 4) physical products (e.g. clock, pills, newspaper, refrigerator).

### *3.1.2 Harvest meeting procedure*

Then, the PD conducted and facilitated ten individual harvest meetings. They were semi-structured, since people with dementia can easily drift off-topic and a rigidly scheduled meeting would not allow for that. In addition, this enabled the PD to spontaneously react to whatever happened (Kitwood 1997; Span et al. 2013). She first met with the people with dementia, and then with their partners. This meeting sequence allowed her to focus on understanding single perspectives, and prevented the caregiver's voice from being dominant (Brereton et al. 2015). Moreover, meeting separately with the caregiver allowed the PD to additionally identify areas of conflict or inconsistencies between their accounts. This meeting sequence also enabled the PD to talk with the partners to verify and complete any unclear stories from people with dementia.

At the start of the meeting, we welcomed participants and offered them coffee. We explained that the goal of the meeting was to collect information that would help us to eventually explain to 'other' people what dementia is about, and that their input was extremely valuable to achieving that goal. Then, we explained that the session would take 1 to 1.5 hours and would entail a conversation with the help of visual aids.

In the first activity of each meeting, the PD showed the participant the first social map (Figure 3) and explained that the people in the drawing represented the participants and their partners. Each participant was asked to complete the drawing from his or her perspective. Open-ended questions were asked to stimulate storytelling, for example: ‘What do you draw and why? How would you draw your faces?’. Then, the participants were shown the second drawing, which represents the participants’ social discourse. We asked the participants to express their thoughts on the engagement and support of their social surroundings, for example: ‘Who is helping you? In which way? Where are they living?’

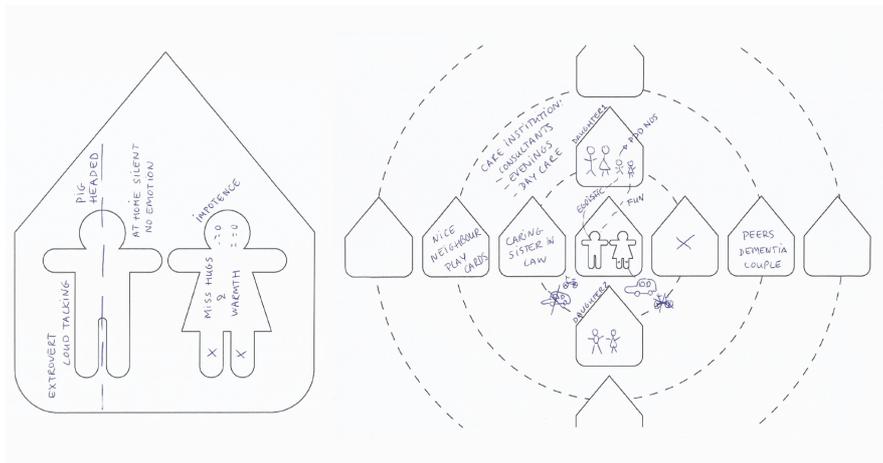


Figure 3 Example of social maps reported by a caregiver, translated to English.

In the second activity of the meeting, the PD invited the participant to respond spontaneously to each of the four picture sets (Figure 4) by asking ‘Which picture(s) fit(s) you best and why?’ The participant selected one or more pictures per set and the PD circled them. Open questions were asked to stimulate storytelling, such as ‘Why do you feel this way? In which situation does this emotion occur?’ The ‘why’ questions reveal needs and values, while the ‘situation’ questions reveal context and stories.

The harvest meetings were audio recorded. Notes were made together with participants in the drawings and pictures. The PD did not make separate notes, since her attention was focussed on the joint activities.

### *3.1.3 Harvest meeting insights*

When given the social maps, some participants with dementia started drawing right away. Others needed more guidance. In that case, short, open-ended questions supported the drawing process. For example: ‘How would you draw the two of you? Are you close or at distance? Are you happy or sad? And your partner?’ All the caregivers completed the first map themselves. This was more difficult for the people with dementia: one person was unable to complete the drawing, two were supported and two completed the drawing themselves. Since the second map required even more abstract thinking, it was only discussed with the caregivers and always filled in by the PD.

We concluded that drawing as a means seemed effective, but that drawing was not an appropriate individual action for people with dementia. Creating social maps together however provided the PD with suitable background information, which supported the facilitation of the second part of the harvest meetings.

The social maps brought up contextually sensitive topics. To illustrate this, Figure 3 shows an example of two maps drawn by a caregiver. The left map shows that the man with dementia is ‘extraverted, stubborn, talkative and at ease’ in contact with other people. However, at home with his wife, he is ‘very introverted and detached’. These two sides to his personality made this caregiver feel powerless, impotent and very sad, which she showed in her drawing by drawing a dashed vertical line through him, splitting the side he shows to the world from the one he shows to her.

The picture sets proved to be very effective conversation starters for engaging with people with dementia. They resonated with and evoked feelings from participants, triggered immediate practical responses and allowed everyone to exchange experiences comfortably.

People with dementia were very direct in responding to the picture sets. To illustrate this, the two pictures selected most often from the personal set were a woman 'sticking out her tongue' and a man 'making a long nose'. All participants with dementia indicated that they often felt like this when people want something from them. One of them said: 'You figure it out'. Another picture referred to was an 'anxious face'. One participant was 'unsure about the future, for the children, partner and self'. From the social discourse set, participants selected couples 'having fun together' or 'supporting each other'. One person with dementia said: 'These two look like us: they fit and support each other'. One couple that was having problems coping with the disease and each other chose the picture of a couple having words. The caregiver said she felt 'forced to do all the things in the house, while before we did everything together'. The last two picture sets – showing daily activities and products – complemented the more emotional stories that were harvested through the earlier sets. For example, they triggered a story about a neighbour who wanted to help with ironing, but was afraid to speak directly to the person with dementia.

All the participants shared both negative and positive emotions and experiences. The main motivation for participating seemed to be a desire for others to benefit and learn from their serious experiences. The visual stimuli provided insights into how people with dementia and their partners perceive their lives and which themes and issues are important to them. The stories and insights we collected were used to inform the design team about the *emotional qualities of life* and allowed empathy to develop.

### ***3.2 Step 2: Collective handover workshops***

The second activity of our approach concerns transferring the *harvest meeting findings* to the design team. These collective handover workshops were aimed at gradually building empathy among team members for people living with dementia in order to prepare for empathic ideation.

#### *3.2.1. Handover preparation*

*Harvest meeting analysis.* First, the PD transcribed all the harvest meeting recordings and analysed the narratives for each participant. The documents of the two individuals forming a couple were then compared and combined. For each narrative, we categorised the quotes into thoughts, feelings, actions or statements, leading to empathic story maps (based on empathy map items, e.g. Gray, Brown, and Macanuso 2010). The PD assigned a theme to each narrative, with the help of models from Dröes (1991) for the people with dementia (e.g. coping with limitations, social contact, self-image) and Meerveld et al. (2004) for the caregivers (e.g. coping with loss, social contact, secure). This resulted in five couple maps which each contained one or more narratives per theme (Figure 4). These maps were used as input for the handover workshops.

Narratives triggered by picture:	Actions	Statements	Thoughts	Feelings	Meerveld et al. (2004) Dröes (1991)
	P: "The diagnose hit me hard. I was angry when diagnosed"  C: "He thinks he has to do job interviews all the time "	P: "No one can take away my worries, although I hunt for information"  C: "I do not want him to be under pressure"	P: "Why me? "  C: "He puts his thoughts into strange sentences and words "	P: "I had to overcome my emotions. I hate having to do that. I'm not angry because of this, I'm just sad."  C: "He is vigilant, apprehensive"	Coping
	P: "You should not blame me for not going to a birthday party"  C: "He makes fun of his dementia at parties."	P: "I want to talk to people about meaningful things. I do not want to talk to people who have a big mouth"  C: "He says: I am crazy"	P: "I do not feel the need to converse with people. I have no interest"  C: "He talks to everybody"	P: "I am done with conversations. It has no use"  C: "It hurts if he behaves silly"	Social contact
	P: "I am not swallowing these"  C: "It took him two hours to fill the pillbox; he opened the pillbox, closed it again, read the prescription, started all over, etc."	P: "You (partner) can help if you do not get angry"  C: "I leave it like this"	P: "I never had these pills before"  C: "I do not understand the confusion. It is three pills per day only. He can not understand it"	P: "This is non sense"  C: "It makes me crazy. I was really annoyed. I could not look at it. I could not handle it"	Self-image
					

Figure 4. Example of a part of a couple's empathy map (P means person with dementia, C means caregiver)

*Ethics.* Before the PD could share what was learned in the harvest with the design team, she took preparations to protect the information gathered. First, she anonymised the stories for privacy reasons. Furthermore, she only used the information needed for the simulator design. For instance, she consciously left out stories about nature, the outdoors and aesthetics, since we could not reproduce those in the simulator. Finally, she informed the design team about the confidentiality of the stories.

*Participants.* Since an empathic transfer of insights cannot be realised through a report alone, it was important that all team members took part in the handover workshops and that the design tools would enable them to immerse themselves in the harvest data. The PD facilitated a half-day workshop with the design team, which took place at the design firm.

*Design tools.* The design team was engaged by means of *empathic discussion* and *role-play*. The empathic discussion was prepared by translating the empathy maps to abstract questions that allowed participants to relate to their own anecdotes and similar emotions. For example, we translated a birthday party narrative to the following abstract questions:

Can you recall a moment in which you were not willing to go to a birthday party where there would be a lot of people? Can you tell us about that moment? About what you felt? And thought? And why?

The PD prepared a discussion worksheet depicting those kinds of questions that addressed all the themes from Dröes (1991) and Meerveld et al. (2004).

For the role-play, we selected two different situations that involved people and problems: a one-on-one at-home situation concerning a practical problem, and a social situation that led to self-image problems. Role-play instructions described the roles that team members had to play. The observers were asked to reflect on what the actors seemed to think, feel, say and do with the help of an observation form.

### *3.2.2. Handover workshop procedure*

The collective handover workshops were arranged and facilitated by the PD. The PD welcomed the participants and briefly explained the goal of the workshop. The PD deliberately did not emphasise the dementia aspect nor explain how the workshops were designed to prevent bias. In the discussion, participants were asked to first reflect on the discussion worksheet individually, since developing empathy is an individual process (Smeenk, Tomico, and Van Turnhout, 2016). After 30 minutes, the PD facilitated a plenary discussion where all questions were addressed by sharing each other's experiences.

In the role-play, empathy was enhanced through a re-enactment of two scenes. The design team was split into two groups. In each sub-team, two or three people received individual role instructions. The others were asked to observe the role-play and to make notes on an observation form. To illustrate this, in the first role-play, one participant was assigned to play a person with dementia who tries to maintain their self-image. Another participant received the role of the partner and the instruction to involve the partner with dementia in the conversation. The third team member played a neighbour of the couple and was instructed to be supportive by offering to iron their clothes, but only to speak to the partner. In the handover workshops, participants made notes.

### *3.2.3 Handover workshop insights*

Team members joined the handover workshop unprepared. Although this made them a bit insecure at first when the workshop started everyone quickly became engaged.

All team members could relate to the discussion worksheet and it elicited sensitive memories as input for the discussion. To illustrate this, a programmer, who immigrated to the Netherlands, responded to the birthday questions raised earlier by saying that celebrating birthday parties in another country makes you feel awkward: ‘At first people speak English to you, but as the drinks flow, you start to feel like people are laughing at you, since they speak Dutch and you do not understand what they are saying. You feel excluded.’

We observed team members relating to the feelings of exclusion experienced by people with dementia. Another question referred to control: ‘In which situation have you felt controlled by others? Where and by whom? What did you do?’ One team member recalled a day that police officers treated him unreasonably: ‘I became furious and aggressive, because I felt powerless. In the end, I gave up, since that seemed more

sensible, although I was still so angry...’ Although this discussion seemed simple, we observed that it was an intense way of connecting to the feelings associated with dementia. The stories shared contained experiences from *all* team members that made an impact in their lives.

Participants received the role-play exercise in different ways. Some offered to play a role, while others stayed in the background and were happy to observe. When the improvisation started, all the actors quickly felt awkward as the reflections afterwards showed. A team member playing a person with dementia stated:

My task is taken from me in a devious way. What are these two people doing?  
They conspire against me. I have little to say, and I feel annoyed and carped on.  
I feel the urge to use physical strength, but the way they handle me makes me feel apathetic...

Another member playing the partner said the situation was:

...bloody annoying. I tried to keep up, but I panicked. I tried to control the situation, but that also nauseated me; you drown in it. I was happy that the neighbour came to help; together we solved the situation as conspirators.

The team members’ embodiments of dementia, observations of others’ actions and body language during the role-plays, as well as the discussion facilitated afterwards, enabled them to better understand and empathise with dementia situations that they were previously unfamiliar with. Our observations and team members’ quotes showed that the team embodied the harvest findings and that they were really surprised by what happened to them.

The discussion was a relatively safe and well-known way for team members to connect to the harvest findings. The role-play challenged some of the participants’

comfort zones more than others'. Therefore, role-play needs to be preceded by a plenary empathic discussion, in which personal experiences already opened participants up to the dementia world. The workshops demonstrated that it is possible to handover essential dementia situations in an empathic way. Moreover, the handover not only sparked inspiration for design, but also created intrinsic motivation and commitment to support the situation with design.

### ***3.3 Step 3: Empathic ideation workshop***

The final activity in our empathic co-design approach was an *ideation workshop*. This workshop released the design team's initial thoughts, intuition and ideas, derived from the empathic mind-set created in the handover.

#### *3.3.1. Empathic ideation workshop preparation*

The ideation workshop took place immediately after the handover and needed far less preparation than the first two activities. The invitation for the handover workshops included the ideation session and thus participants were already present.

#### *3.3.2. Empathic ideation workshop procedure*

Team members were first asked to individually express their initial ideas for the simulator and to generate preliminary models inspired by the stories shared. Then, participants were asked to present their ideas and models to each other, which facilitated an exchange of ideas. Notes were taken by the design firm's internal lead designer rather than the PD, since the firm would be proceeding with the outcomes.

#### *3.3.3. Empathic ideation workshop insights*

In the ideation workshop, the empathy derived from the handover was put to use. Concepts that came up here related to personal, social, physical and practical situations

that people with dementia encounter. By sharing ideas and models, participants could collectively build on each other's insights. For instance, the refrigerator scene described above was thought to be a good first action for people entering the simulator, since it directly confronts visitors with confusing thoughts.

The combination of handover and ideation was seen as an efficient and empathic alternative project briefing for and by the design team. The designers reported that their embodied frame of reference enabled them to use their intuition credibly (Cockton 2009; Smeenk, Tomico, and Van Turnhout, 2016). After this sensitisation and ideation, the team ran the project as they normally do. Ideas were developed into an initial script for the overall simulator experience and in a physical representation (see Figure 1). Most of the ideas generated in the ideation workshop were implemented in the final dementia simulator.

In an evaluation of the final simulator's effect on empathy conducted by Hattink et al. (2015), visitors (among which dementia experts) said they were touched and found the simulator experience authentic and relevant for training and introducing people to dementia, as 'the experience lingers and resonates after the encounter'.

#### **4. Conclusion and discussion**

We proposed, illustrated and evaluated a new co-design approach: Empathic Handover. By suggesting three sequential design activities in a structured and coherent process facilitated by an empathic PD (Lindsay et al. 2012), we provided practical and engaging guidance to design teams in empathic co-design *processes* concerning dementia. The approach enables people living with dementia to *inform* the design process. Applying this approach enabled us to develop a dementia simulator *product* for healthy caregivers. Next, we will discuss our experiences with introducing and employing this approach, which was meant to support design teams in transferring and translating

research insights from the principal designer (PD), who had experience working with people with dementia, to members of the design team who did not.

First, all the design team members appreciated being *engaged* in the handover and felt that they developed sensitivity and a shared understanding of dementia. Their own (first-person) experiences were crucial to understanding user research and thus third-person findings (user insights). This is in line with earlier work by Smeenk et al. (2016), who found that employing a first-person perspective enriches empathic co-design. The designers' relevant first-person experience with situations that resembled the authentic stories of the people with dementia helped them really understand the design situation and invoked intuition in designing. Their embodied understanding supported their receptiveness and inclusiveness, and enhanced their motivation and commitment to design for people living with dementia (Cockton 2009). Second, caregivers and experts judged the resulting dementia simulator to be an accurate portrayal of the experience of dementia (Hattink et al. 2015). Third, the approach was effective. The PD assisted the team by conducting the user research and facilitating the empathic handover and ideation workshops. The handover workshops replaced the original design brief and led to relevant and directly applicable design directions. Our approach thus reduced the necessary resources, which Friess (2012) and Postma et al. (2012) assert to be essential for design practice. Yet, the approach has only been employed once and needs to be validated further.

In the next sections, we will discuss several challenges regarding the role of the PD, the design tools used and the scaling opportunities of the collective handover workshops of the approach. Finally, we will discuss future work.

#### *4.1 Principal designer*

In the case study, the design firm consciously involved a senior principal designer who had first-person experience as a dementia caregiver. We found that this positively influenced the applicability of the novel approach in two ways. First, personal experience had already acquainted the PD with dementia and fostered her empathic ability. It also made her committed to the project and aware of ethical dilemmas. Second, co-design seniority fostered the development of design tools and eased user and design team facilitation. This approach could not have been developed without both these experiences.

However, the facilitation of the approach might deliver similar results with a PD who is skilled in empathic design and eliciting user insights, but who has no experience in the dementia field.

#### *4.2 Design tools*

During this study, we thought of expanding empirical research on alternative harvest and complementary handover tools. We could investigate alternatives for the social discourse drawings, which we found to be too abstract and an imperfect match for the capacities of people with dementia. Complementary tools might be needed in projects with other design scopes.

#### *4.3 Scaling*

The empathic handover approach can be applied to a broader set of design problems. The approach could be scaled to fit other dementia projects in which people with dementia are the main users. In this case, the current approach must be expanded to harvest design requirements and ideas in addition to experiences. In addition, the collective handover workshops combined with the empathic ideation workshop could be

made more generally applicable to vulnerable users in contexts other than dementia (i.e. people with a much greater diversity of abilities and limitations). By analysing the outcomes of limitation dedicated harvest meetings, compliant discussion sheets and role-play instructions can be developed and used in handover workshops.

#### *4.4 Future work*

We are preparing a comparative study with teams of design students who are involved with different vulnerable user groups under two conditions. One group will follow the new empathic handover approach, while the other will follow a ‘traditional’ user-centred design approach. This study will allow us to further explore the approach and the PD’s role, and to uncover opportunities for making this novel approach more generally applicable.

#### **Acknowledgements**

A thanks goes to all people with dementia and their partners for openly sharing their experiences and emotions that support the authentic content of the final dementia simulator. We also thank the following organisations: Minase, IJsfontein, Vrije Universiteit Amsterdam, De Wever. The authors wish to thank Jochem Galama and Jacqueline Gielen for their pictures.

#### **References**

- Allan, K. 2001. *Communication and Consultation: Exploring Ways for Staff to Involve People with Dementia in Developing Services*. Bristol, UK: Policy Press.
- Bartlett, R. 2012. “Modifying the Diary Interview Method to Research the Lives of People with Dementia.” *Qualitative Health Research* 22 (12): 1717-1726. doi:10.1177/1049732312462240.

- Brereton, M., L. Sitbon, M. H. L. Abdullah, M. Vanderberg, and S. Koplick. 2015. "Design After Design to Bridge Between People Living with Cognitive or Sensory Impairments, Their Friends and Proxies." *CoDesign: International Journal of CoCreation in Design and the Arts* 11 (1): 4-20. doi:10.1080/15710882.2015.1009471.
- Brodsky, H., and D. Hadzi-Pavlovic. 1990. "Psychosocial Effects on Carers of Living with Persons with Dementia." *Australian & New Zealand Journal of Psychiatry* 24 (3): 351-361. doi:10.3109/00048679009077702.
- Cockton, G. 2009. "Getting There: Six Meta-Principles and Interaction Design." *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* 2223-2232. doi:10.1145/1518701.1519041.
- Denning, S. 2005. *The Leader's Guide to Storytelling: Mastering the Art and Discipline of Business Narrative* (Vol. 269). Hoboken, NJ: John Wiley & Sons.
- Droes, R. M. (1991). In *Beweging; over psychosociale hulpverlening aan demente ouderen* [In movement; on psychosocial care for elderly with dementia]. *Nijkerk, The Netherlands: Intro*.
- Frascara, Jorge, ed. 2002. *Design and the Social Sciences: Making Connections*. Boca Raton, FL: CRC Press.
- Friess, E. 2012. "Personas and Decision Making in the Design Process: An Ethnographic Case Study." *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* 1209-1218. doi:10.1145/2207676.2208572.
- Gray, S. B., S. Brown, and J. Macanuso. 2010. *Gamestorming: A Playbook for Innovators, Rulebreakers, and Changemakers*. Sebastopol, CA: O'Reilly Media.
- Hattink, B. J., F. J. Meiland, C. A. Campman, J. Rietsema, M. Sitskorn, and R. M. Dröes. 2015. "Zelf Dementie Ervaren: Ontwikkeling en Evaluatie van de Into D'ementia Simulator [Experiencing Dementia: Evaluation of Into D'ementia]." *Tijdschrift van Gerontologie en Geriatrie* 46 (5): 262-281. doi:10.1007/s12439-015-0130-8.
- Hendriks, N., K. Slegers, and P. Duysburgh. 2015. "Codesign with People Living with Cognitive or Sensory Impairments: A Case for Method Stories and Uniqueness." *CoDesign: International Journal of CoCreation in Design and the Arts* 11 (1): 70-82. doi:10.1080/15710882.2015.1020316.
- Hendriks, N., F. Truyen, and E. Duval. 2013. "Designing with Dementia: Guidelines for Participatory Design Together with Persons with Dementia." In *Human-*

- Computer Interaction –INTERACT 2013*, edited by P. Kotze, G. Marsden, G. Lindgaard, J. Wesson and M. Winckler, 649-666. Berlin: Springer.
- Hess, J.L, Fila, N.D., 2016. "Empathy in Design: a Discourse Analysis of Industrial Co-Creation Practices." *Proceedings of the DTRS11 Conference on Design Thinking*
- IDEO. 2015. *The Little Book of Design Research Ethics*, London: IDEO.  
<https://lbodre.ideo.com/>
- Kitwood, T. 1997. *Dementia Reconsidered: The Person Comes First*. Buckingham, UK: Open University Press.
- Koskinen, I., and K. Battarbee. 2003. "Introduction to User Experience and Empathic Design." In *Empathic Design: User Experience in Product Design*, edited by I. Koskinen, T. Mattelmäki, and K. Battarbee, 37-50. Helsinki, Finland: Edita IT Press.
- Kouprie, M., and F. Sleeswijk Visser. 2009. "A Framework for Empathy in Design: Stepping Into and Out of the User's Life." *Journal of Engineering Design* 20 (5): 437-448. doi:10.1080/09544820902875033.
- Lindsay, S., K. Brittain, D. Jackson, C. Ladha, K. Ladha, and P. Olivier. 2012. "Empathy, Participatory Design and People with Dementia." In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* 521-530. doi:10.1145/2207676.2207749.
- Mattelmäki, T., and K. Battarbee. 2002. "Empathy Probes." In *PDC 02 Proceedings of the Participatory Design Conference*, edited by T. Binder, J. Gregory, and I. Wagner, 266-271. Retrieved from:  
<http://ojs.ruc.dk/index.php/pdc/article/viewFile/265/257>
- Meerveld, J., J. Schumacher, W. Krijger, R. Bal, and H. Nies. 2004. *Werkboek Landelijke Dementie Programma* [Workbook: National Dementia Programme], Utrecht, Netherlands: NIZW.
- Ozcelik Buskermolen, D., J. Terken, and B. Eggen. 2015. "The Co-Constructing Stories Method: Feedback of Designers on Use of the Method in Real Design Cases." *The International Journal of Design Management and Professional Practice* 8 (2): 17-28. doi:10.18848/2325-162x/cgp/v08i02/38623.
- Postma, C. E., E. Zwartkruis-Pelgrim, E. Daemen, and J. Du. 2012. "Challenges of Doing Empathic Design: Experiences from Industry." *International Journal of Design* 6 (1): 59-70.  
<http://www.ijdesign.org/ojs/index.php/IJDesign/article/view/1008>

- Robertson T. and Wagner, I., 2012. "Ethics: engagement, representation and politics in action. Simonsen, J., & Robertson, T. (Eds.). (2012). *Routledge international handbook of participatory design*. Routledge.
- Sanders, E.B.N., 2002. "From User-Centered to Participatory Design Approaches." *Design and the Social Sciences: Making Connections*. Boca Raton, FL: CRC Press.
- Sanders, N., and P. J. Stappers. 2008. "Co-Creation and the New Landscapes of Design." *CoDesign: International Journal of CoCreation in Design and the Arts* 4 (1): 5-18. doi:10.1080/15710880701875068.
- Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *The American journal of nursing*, 108(9 Suppl), 23.
- Sleeswijk Visser, F., P. J. Stappers, R. van der Lugt, and E. B. N. Sanders. 2005. "Context Mapping: Experiences from Practice." *CoDesign: International Journal of CoCreation in Design and the Arts* 1 (2): 119-149. doi:10.1080/15710880500135987.
- Smeenk, W., Tomico, O., & van Turnhout, K. (2016). A systematic analysis of mixed perspectives in empathic design: Not one perspective encompasses all. *International Journal of Design*, 10(2).
- Span, M., M. Hettinga, M. Vernooij-Dassen, J. Eefsting, and C. Smits. 2013. "Involving People with Dementia in the Development of Supportive IT Applications: A Systematic Review." *Ageing Research Reviews* 12 (2): 535-551. doi:10.1016/j.arr.2013.01.002.
- Topo, P. 2009. "Technology Studies to Meet the Needs of People with Dementia and Their Caregivers: A Literature Review." *Journal of Applied Gerontology* 28 (1): 5-37. doi:10.1177/0733464808324019.
- Van Rijn, H., F. Sleeswijk Visser, P. J. Stappers, and A. D. Özakar. 2011. "Achieving Empathy with Users: The Effects of Different Sources of Information." *CoDesign: International Journal of CoCreation in Design and the Arts* 7 (2): 65-77. doi:10.1080/15710882.2011.609889.
- Wright, P., and J. McCarthy. 2008. "Empathy and Experience in HCI." *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* 637-646. doi:10.1145/1357054.1357156.

[www.who.int](http://www.who.int)