vol. 1

DEMENTIA LAB: THE ROLE OF DESIGN

Reflections on designing with
and for people with dementia

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DEMENTIA LAB the role of design



Niels Hendriks & Andrea Wilkinson – editors
Founders of Dementia Lab – www.dementialab.com

Photo by Lukas Venne for Dementia Lab

Letter from the Editors

What you will be reading in this book reflects most of the discussions and presentations held at the Dementia Lab event that was held in 2016 in Essen, Germany. This Dementia Lab Event took place in September 2016 and was titled "The challenge of designing for and together with people with dementia - reflections on design education, research and practice". Its aim was to gather design researchers, educators and practitioners for a two-day event that would inspire and encourage those in attendance to open up their design practice to working both together and with people with dementia, as well as give the opportunity to share stories and recommendations on how to go about this successfully. The event brought together 65 participants from all over the world, who as a common denominator shared their concern with the role of designing for people with dementia ànd how to involve those with dementia in the process. The event raised three central topics: (1) how to facilitate design education focusing on (participatory) designing for persons with dementia, (2) the challenge for design students, practitioners and researchers to involve persons with dementia in the design process, and, (3) reflect on the ways in which working with individuals with dementia impacts a designer's current and future way of working. The event valued the contribution of all forms of design and above all wanted to make explicit the presence of a group of researchers, design educators and practitioners who were facing similar challenges. This book is a culmination of these challenges and experiences from these two days in September in Essen.



Photo by Lukas Venne for Dementia Lab

These stories come from Helma Van Rijn, Nina Pillen, John Vines, Jayne Wallace, Tommy Dykes, Stefanie Schwarz, Rita Maldonado Branco, Lasse Rosenfeld, Andrea Wilkinson and Niels Hendriks.

Despite the fact that some parts of the text will resemble typical academic writing, this book places focus on personal stories instead of purely academic reflections. It is a collection of personal accounts from several designers who have, over the past decade, designed for and together with people with dementia and tells the story of how they experienced this process. This storytelling approach is in line with previous research on designing for and together with people with sensory and cognitive impairments (such as dementia[1]), suggesting that the best way to share and learn about this topic is through the telling of stories about previous experiences. This provides a 'better understanding of what happened' that can be seen in the more reflective parts of this publication. At the same time, and specific to the research described here, these reflections add to the relational character of this type of research and make apparent the researcher's and the designer's voice in the design process. Although this publication will not provide a one-size-fits-all way of working for and together with people with dementia, we at the Dementia Lab believe that because the disease affects a person with dementia in such a profound and personal way, so too must a designer's way of working be personal. As a result of this, the goal of this book is to present aspects of the work of others in order to inspire the future undertakings in the field of its readers.

[1] Hendriks, N., Slegers, K., & Duysburgh, P. (2015). Codesign with people living with cognitive or sensory impairments: a case for method stories and uniqueness. *CoDesign*, *11*(1), 70–82. https://doi.org/10.1080/15710882.2015.1020316



Photo by Lukas Venne for Dementia Lab

About the project, and the experiences which got us here

Frustration is one of the best way to describe the stimulus which inspired us (Niels Hendriks and Andrea Wilkinson) almost 6 years ago to begin working for people with dementia in the way we do now. At the time, we were working on a large-scale, multi-partner and interdisciplinary project which involved residential care centres, a psychiatric clinic, several research partners and a variety of industrial partners. The goal of the project was to set up an intelligent network of technology (combining sensors and consumer electronics in a network architecture) and people (caregivers, person with dementia) and attempt to 'improve' the quality of life in a dementia ward in a residential care facility. In this 2.5-year project the research consortium wished to explore the potential of the so-called *internet of things*[1] in dementia care. We were partially responsible for the ethnographic research, the interface design of the resulting digital tool and the participatory design[2] with the caregivers and the people with dementia. We interviewed psychiatrists about their patients, tagged along with psychologists going on home visits, had hour-long discussions with people responsible for self-help groups, visited family and partners of persons with dementia and above all spent days (and nights) in the homes of people with dementia and in residential care settings, blending in with the care staff, residents and visiting families.

How an impromptu discussion led to a fundamental shift

On one of these occasions, while walking around with the head nurse, we were discussing the course of our research project. Although she was very appreciative of what we were doing and told us she really valued what we did, she stood still and asked if we could perhaps help her out with one of her older female residents. The problem wasn't '*a dementia problem*' but rather a knock-on effect of how dementia was causing a problem in an individual's life and thus impacting the life of those around her. Despite the resident being 95 and having dementia, she was in very good physical condition. Having been a nun, she was used to living with several people on one floor, sharing a common living room and having a common rhythm of the day (eating at the same time, going to bed at the same moment, doing an activity together, etc); the routine within a care facility suited her well. In the days when she had lived in a cloister, the nuns needed to be up each morning for prayer at 7, followed by everyone in the cloister having breakfast together, and followed by the daily routines of chores and social work. Having moved into the dementia ward, this

[1] Participatory design is the term used to express a collaboration between designers and those affected by a design in a design process

[2] The concept of Internet of Things can be explained as everyday appliances and objects (your table, chair, fridge, etc) are linked to each other and connected to the internet.



Photo by Crisp

fervour for routine continued. She was already up and about at 7 a.m., but would get irritated at the other 'lazy' people who were still in their beds. She saw it as her duty to wake up the other residents and help them begin the day. In principle, the issue of waking up others would be more of a nuisance than a problem, but the issue evolved into something more dramatic than this. She started waking up people in the middle of the night, in the afternoon, at all times of the day. Her condition (how dementia affected her understanding) caused her to misinterpret her digital alarm clock. Whenever she saw a 7, be it 2:07 a.m. or 4:37 p.m., she believed it to be 7 o'clock and thus hurriedly got up and proceeded to wake others for the start of the day. "If only you could help us out on this," the head nurse of the dementia ward suggested. Although this was outside of our own skillset, we knew this would not be difficult to achieve through design. We took this idea back to our colleagues at our design school and discussed it with one of the technical 'tinkerers', who quickly came up with a design solution to this problem: if we altered the digital clock to where it would go from 02:06 to 02:08 in the span of two minutes (without showing the 7) and only showed a 7 at 07:00 a.m., then this problem would be solved. He could make a prototype of this, he said, if we gave him a day or two. Unfortunately however, this did not fit into the aim of this well-funded, 2.5 year research project.

This frustrated us: this challenge for the dementia ward was a real one and something that required immediate action. Moreover, the qualities and competences of a designer were right for the job. This led us to decide that outside of this 2.5 year project, we would try to begin researching in a way that would bring us closer to care and enable us to respond to the daily challenges of living with dementia, with the aim of making life for persons with dementia more pleasant. Our goal became to create designs (artefacts, prototypes, small interventions) that would be acceptable in use (not disturbing daily routine), feasible in cost (open to any budget) and easy to implement (durability, manageable learning curve, not disturbing caregiver's routine etc). Next to this, we placed the person with dementia in the centre and we wished to invest time in creating methodological experiments in participatory designing together with people with dementia. To achieve this, we set up a course module with design masters students, working on the subject of individual people with dementia. This 9-week module led to imaginative, practical and very personal responses to the life conditions of persons with dementia in residential care.

This way of working and its end results (the designs themselves) are all very personal: created by one designer for one person with dementia living in a care facility. As the way dementia affects daily life is different for each person, our approach does not start from the stage a person with dementia is in, but rather proceeds from the individual's experience of dementia. In general, what we try to do is adapt our ways of working to the lived experience and the condition of the person with dementia. If a person with dementia is lucid and likes to talk, then talking will be the way to connect to them; if they like walking, then walking will be part of our process, and so on. The same goes for the end results of the design process. We do not design in a generalised way (working for the whole group of persons with dementia or a whole group being diagnosed with a mild or a more severe form of dementia) but instead our students collaborate with one person with dementia. In most cases, the resulting artefacts are not generalised, but rather they are often transferrable from their intended user to other persons with dementia.

The outcomes of this module (both in methodology and in artefacts) as well as the other research we have carried out since that initial 2.5 year project drew the attention of a German non-profit organisation, the Robert Bosch Stiftung. Out of their long-standing interest in the support of the elderly and persons with dementia, the organisation, proposed that we submit a project plan that would lead to the design of tools and artefacts for this target audience in Germany, as well as initiating and renewing interest for this subject in design schools and among young designers. The project started in 2015 and was comprised of 3 actions: (1) setting up workshops at several design schools in Germany; (2) organising an event to share these experiences and (3) documenting and sharing these experiences in publication format.


Photo by Niels Hendriks

Since 2015, the Dementia Lab (Niels Hendriks and Andrea Wilkinson) have been doing just that. We have worked with design schools in Germany from Berlin to Stuttgart to Essen and have carried out workshops with student designers on the subject of designing for dementia and supported them in both workshop weeks and semester-long projects in which they worked in care facilities, together with residents and caregivers.

This publication tries to bring together real-life experiences and personal reflections on a variety of topics concerning designing for and together with people with dementia.

In order to reach this, we have attempted to approach the voice of our presenters as authentically as is possible in print. Their experiences should inspire those wanting to engage in design projects for people with dementia, be it within or outside of design education. The topics covered in this book deal with participatory design and how to involve people with dementia in this process, starting with the individual with dementia and the important role the family, partners or caregivers play (section 1), reflections on how a designer is asked to step into the *reality* of the person with dementia and respond through designs based on their understanding of this reality (section 2), and finally suggests that the designer is not a *lone ranger*, but instead will need to rely on the competences of a multidisciplinary team, either coming from the field of design or from the care domain (section 3). The fourth section deals with how this type of design process can be integrated in an educational and industrial context. In closing, the publication gives an outlook to the future and the challenges that need to be tackled (section 5). A short bio on all contributors can be found at the back of this publication.



Photo by Helma van Rijn

When designing with and for people with dementia, the person with dementia is central: *the importance of formal caregivers, partners, family and friends*

In 2008, one of the founding fathers of participatory design (PD), Pelle Ehn, provided a definition of PD which looked back on and forward to the legacy and prospective use of PD. "Participatory design started from the simple standpoint that those affected by a design should have a say in the design process. This was a political conviction not expecting consensus, but also controversies and conflicts around an emerging design object. Hence, participatory design sided with resource weak stakeholders… and developed project strategies for their effective and legitimate participation."[1] In the early days of PD, the resource weak stakeholders were labourers in factories whose work was affected by automatization and digitalization, changes they could not master. These labourers were dis-abled in taking control of the design and implementation of the new tools in their workspace, as they were either not heard or not en-abled to raise their own concerns or desires. It was the task of the PD researchers to provide them with ways of participating in technology design that supported and included their perspectives and needs with all the other stakeholders (such as management or the developers). In 40 years, PD has shifted from a political interest through democratic systems development in the workplace, to a more encompassing notion of accountability within technology design. With this shift, the resource weak participants are not only labourers, but a variety of people such as inhabitants of a town, children or persons with dementia.

[1] Ehn, P. (2008). Participation in Design Things. In *Proceedings of the Tenth Anniversary Conference on Participatory Design 2008* (pp. 92–101). Indianapolis, IN, USA: Indiana University. Retrieved from http://dl.acm.org/citation.cfm?id=1795234.1795248

Trying to involve persons with dementia into the design process can be stressful and, speaking from our own experience, can lead to frustrations, challenges and doubts. Throughout our projects we questioned the reliability of the responses of persons with dementia (does she really like what we're showing her?) and their loved ones (perceiving their family member as weaker or stronger than they actually are); we experienced involving a person with dementia in design workshops as quite stressful, both for the persons with dementia (getting tired, losing interest,…) as well as for the designer (getting emotionally involved, seeing a continuous physical and mental deterioration of their participants[2]); we faced ethical challenges (e.g. how to maintain a certain distance when the researcher-designer is regarded as a long lost brother or a neighbour); and struggled with the relational aspects of participation (when the researcher-designer becomes more than 'just' a researcher, but also a friend, someone persons with dementia relate to and vice versa), etc.

We were not the first ones to experience these difficulties. The traditional participatory design methods seem not fully appropriate to deal with persons with dementia. These methods assume that the participants are cognitively able; can make use of visual and hands-on techniques; or require a high level of abstraction from the person with dementia[3]. Dawe states that "[t]raditional user-centered design and PD activities often ask users to describe previous usage scenarios or imagine future ones"[4] and that this is a challenging activity for amongst others persons with cognitive impairments (such as dementia). In his work with persons with dementia, Lindsay[5] sees that traditional participatory design techniques focus on productivity and work and assume that each participant is cognitively able, which is certainly not the case when working with persons with dementia.

Along with other researchers and designers in the field, we promote an approach that takes the human relationship as the central element. The designer/researcher

[2] Hendriks, N., Huybrechts, L., Wilkinson, A., & Slegers, K. (2014). Challenges in doing participatory design with people with dementia (pp. 33–36). Presented at the Proceedings of the 13th Participatory Design Conference: Short Papers, Industry Cases, Workshop Descriptions, Doctoral Consortium papers, and Keynote abstracts-Volume 2, ACM. https://doi.org/http://dx.doi.org/10.1145/2662155.2662196

[3] Muller, M. J. (2003). Participatory design: the third space in HCI. *Human-Computer Interaction: Development Process*, 165–185.

[4] Dawe, M. (2007). *Reflective Design-in-use: Co-designing an Assistive Remote Communication System with Individuals with Cognitive Disabilities and Their Families*. University of Colorado at Boulder, Boulder, CO, USA. Retrieved from http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.124.5778&rep=rep1&type=pdf

[5] Lindsay, S., Brittain, K., Jackson, D., Ladha, C., Ladha, K., & Olivier, P. (2012). Empathy, participatory design and people with dementia (pp. 521–530). Presented at the Proceedings of the 2012 ACM annual conference on Human Factors in Computing Systems, ACM.

commits to establishing a good relation with the persons with dementia and generally starts from trying to get an understanding of how the person with dementia experienced and experiences life. Looking at the past, processing biographical information coming from family, friends, a partner,… all of this can be of use. Questions that play on several levels are important: what were the person's hobbies, her professional activities? Did she have kids and how many were there? What were defining events in the course of her life and what were the rituals of everyday? and so on. Looking at the way the person with dementia experiences the now takes into account her subjective interpretation of the world, with her own ways of behaving, meaning-giving, rituals, set of beliefs, etc. that might be rooted in the past but get interpreted in the present. Acquiring an understanding of the subjective interpretation of the present can happen through repeated encounters with the person with dementia. These encounters can be functional or goal driven (i.e. directly related to the design process), but will more often be non-functional: just being there, joining them in the dementia choir, helping out during mealtime, etc. all for the sake of trying to build a rapport with the person with dementia. Both the past and the present will inform the designer/researcher about potential handles that can be used to involve the person with dementia in the design process.



Photo by John Vines

This design process is a highly individual track, starting from the designer's relation with the person with dementia. Valuing the person with dementia as an individual is based on the principles of person-centered care. Despite the fact that there is no uniform definition of what person-centered care (for the care of persons with dementia) exactly is[6], some similarities in defining person-centered care can be found. Central to this idea is the concept of personhood, which Kitwood defines as "a standing or status that is bestowed on one human being by another, in the context of relationship and social being. It implies recognition, respect and trust"[7]. As Surr indicates, the concept of personhood is not a property of the person with dementia, "but (is) a status that can only be provided or assured in the context of a mutually recognising, respecting and trusting relationship."[8]. This relational and personal aspect is also strongly foregrounded in the Dementia Lab research.

In this section we present a number of stories about the way researchers around the world have experienced their designing for and together with persons with dementia. Again, these stories are not abstract reflections of research work delivered in bullet-pointed lists, but stories on designing for and together with persons with dementia. These narratives will often (but not always) start from a personal starting point: Rita Maldonado Branco, for instance, recounts how she took her first steps in designing for persons with dementia after being confronted with two grandparents with dementia. This experience has influenced her way of working afterwards and still continues to define her as a designer and a researcher. The stories told by other researchers and designers do not start from this intimate perspective. However, their narratives also shift to a personal view as they zoom in on the longitudinal encounters with individuals with dementia, or the story of Helma van Rijn who continuously has to remind the 97 year old woman she is working with that the artefact they are creating will be her birthday present, causing the woman to smile with joy each and every time Helma reminds her of this.

[6] Lann-Wolcott, H., Medvene, L. J., & Williams, K. (2011). Measuring the Person-Centeredness of Caregivers Working With Nursing Home Residents With Dementia. *Behavior Therapy*, *42*(1), 89–99. https://doi.org/10.1016/j.beth.2010.02.005

[7] Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. London: Open University Press.

[8] Surr, C. A. (2006). Preservation of self in people with dementia living in residential care: A socio-biographical approach. *Social Science & Medicine*, *62*(7), 1720–1730. https://doi.org/10.1016/j.socscimed.2005.08.025



Photo by Helma van Rijn

Helma (referring to an experience while working in a care facility) I remember an encounter with an older woman who was about to turn 97. I was making a flower arrangement with her, and she was so happy. Every minute she said she wanted to buy the basket, and asked for her wallet. Each time I said I wanted to give it to her as birthday present, which made her very happy. She smiled from ear to ear that morning.

I believe all these moments contribute to your design process and enable you designing meaningful solutions for people with dementia and their caretakers.

The thing that designers are looking for is information about users, empathy with users and inspiration for new ideas and solutions. In my thesis I referred to this as creative understanding. An understanding about users where you can creatively act upon.

Logically, many designers start with desktop research. However, you still don't yet know what it's like to suffer from dementia or have a partner with Alzheimers. And it's hard to design based upon numbers of descriptions of diseases. You need empathy to know what you're talking about, and inspiration for design.

In design literature, you find three ways for obtaining empathy with users: direct contact, indirect contact such as video from user researchers, and imagination e.g. with experience probes, such as blindfolding yourself to feel what it's like to be blind.

I've conducted studies where designers brainstormed based on these different sources of information. As I expected, the ones with close contact with the user group developed the best concepts according to caregivers who judged the quality of ideas.

What I value about direct contact is that it forces you to do, not just speculate and think. For direct contact you need to set up a collaboration.

Testing your presumptions with prototypes is a perfect approach to discover what works, as verbal communication is often limited. In this way, you can open the dialogue with the people you're designing for.

Rita: on working with people

Strongly influenced by the values of person-centred care and guided by ethical concerns, my practice-based research uses a research through design approach that valorises empathy, and draws upon ethnographic methods and participatory approaches to get a deeper understanding of the experience of dementia and engage with those diagnosed in the design process. There is a lot of effort on finding ways to include people, constantly adapting the process, which requires a flexible and open approach and attitude, so that different forms of participation can be accepted and valued. Another key aspect in my research is to try to ensure that the participatory process is enjoyed and pleasurable for all involved. […]

Although the experience of dementia and designing for people with this condition was already well-known for me, it was necessary and extremely valuable to allow some time to get closer and immersed in the institutional context before trying to involve people in activities straight away. The encounters with other individuals with dementia and observing the work of healthcare professionals became an invaluable learning that contributed to an improved sensibility and understanding, in parallel and related to a continuous ethical growth.

John, on working with communities:

In Newcastle I'm very lucky to work with a great team of PhD students and postdoctoral researchers, who are all exploring these issues. The projects we do often involve collaborating with local authorities, community care organisations, civil society and community groups, as well as charities and non-profits. These engagements and projects often work at a very local level to begin with, then we look to scale them to other organisations and sites over time. We are very responsive to contexts set by partners, conducting initial participatory activities with them or the citizens they have relationships with to scope matters of concern, identity opportunities around these and think through the role that technology might play in supporting new processes and practices in relation to these.

What is very important here for us is that it is not just about doing participatory design with these diverse parties, but also to support the development of participatory practices – for us, it is the practices and the processes and actions that support them that can mean the work we do can be sustained over a period of time. For a project called DemYouth from several years back, I was involved in a project with some collaborators at Newcastle, where we

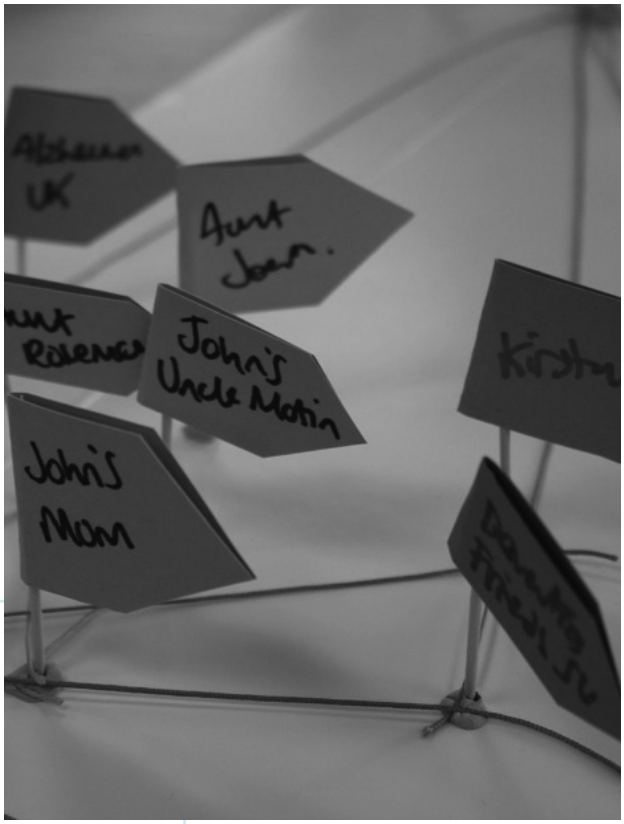

Photo by John Vines

were creating a toolkit for effective communication with people with dementia for family members and carers. This was eventually turned into a basic website called demtalk. This site has been used a lot by both family and professional carers over the last couple of years. What we didn't deal with so well in this project is thinking about how this information might be useful to younger audiences, especially young carers or younger family members with loved ones with dementia.

In the DemYouth project we have been conducting workshops with young people who are "touched by dementia" in different ways. Some were young carers, some were simply people who had grandparents with dementia, and a small number volunteered in care facilities. The workshops were framed to be very open and

exploratory, with activities designed to draw out reflections and experiences of spending time with family members and with other people with dementia.

Through this process we found out, of course, that what we assumed may be the problem, was not the problem at all. At the start we assumed that one of the big challenges young people face was that there wasn't any information out there that was "young person friendly" in terms of how to communicate with and to be sensitive to dementia. But actually, the main issues we started to identify in the project was that young people had a lack of opportunities to actually spend time with loved ones with dementia in the first place.

Family members like parents, uncles, aunts, would put in barriers rather than enablers to visit and be with grandparents who had been diagnosed. If they did get a chance to spend time with their older family members, then they were worried about not "how" to talk to their grandparent, but more simply "what" they talk about and the ways they could get a conversation started in the first place. The groups we worked with noted that these issues were impacted further because they felt there were few opportunities to talk with friends and other young people about these issues, and they wouldn't know where to spend time with a family member with dementia other than their own home.

Quite a lot of the work we did near the end of this project was playing around with ideas that the groups we met had come up with for digital tools and platforms that respond to these issues.

For example, one of the concepts we have explored was StorySharer, which was envisaged as an application that supports peer-interviews with other people you know

who have experiences of dementia. Here we can see some of our core group mapping out their dementia network, exploring what people they might like to interview. Another concept we have explored was using rating and review type applications to do appraisals of local cafes, shops and spaces for their dementia friendliness. And then the final concept we explored was Ticket-to-Talk. This was envisioned as an app that would allow someone to make a simple profile of a loved one, from which they would be prompted to start collecting snippets of media that relate to their biography and key stages in their lives. So, the app has a dual purpose. It aims to get young family members talking to older family members about their lives, then to find some media related to this—photos, videos, audio—and bring this back into the app. Then the phone itself can act as a simple repository of media to use as a resource in conversations.

It has been the ticket to talk application that was really seen as having lots of potential by the groups we have worked with. We're currently in the final stages of developing it as a mobile application, which is intended for younger family members but can also be shared with, and used by, others in the network of care. In the next few months we will be doing some initial studies of its use with families and as part of intergenerational programmes between schools and residential facilities.



Photo by John Vines

Jayne

The talk ‘objects as dialogues in designs for dementia’ gave me a space to discuss how I’ve used objects to enable dialogues and in many cases become dialogues with people living with dementia. I showed a collection of projects, all made within the research exploration of personhood in dementia—which, put briefly, is the construction/maintenance of self, which develops in relation to other people—this fluid and changing aspect of all of our experiences of the world is brought into sharp focus by dementia when this fluidity and change is accelerated with cognitive decline.



Photo by Jayne

One of the things that I'm most interested in is if and how jewellery objects may act as conduits to experiences and meanings within the wearer's life with the potential to be:

- comforting objects for the individual and people close to her/him
- anchors or bonds to treasured memories, idiosyncratic aspects of identity and meaningful relationships
- sustained expressions of the individual's personality and self acting to maintain and nourish self and to act as a bridge from self to others over time (perhaps in severe cognitive decline)
- tangible supports within the nexus of people around the individual living with dementia that aid the maintenance of these relationships
- celebrations of the relationships within this nexus of people – where perhaps the pieces are sites to reflect and reminisce, but also to create content (i.e. future focused as well as references to the past)

The uniqueness of jewellery as a medium comes to the fore in this context:

- As objects that we invite into our personal space, jewellery worn by someone with dementia can act as an intimate expression of self to both the individual and to other people. Jewellery can be a bridge from the inner to the outer; from internal meaning to an expression of this on the body – in later stages of dementia, where means for the individual to communicate these things have become impeded, jewellery can act as 'a way in' for other people and a bridge from the individual to others. Philosophers of dementia care and of self maintain that even in late stages of cognitive impairment the body still expresses our idiosyncratic gestures that themselves show much of the person we are.
- Jewellery as guardians of personal meanings that have the ability to transport us to other places, people and events can keep certain aspects of self, personal histories and valued aspects of relationships alive in the minds of both the individual with dementia and those close to him/her.

Befriending was really important to me and not only as a student and as a designer, but as a person as well.

Tommy Dykes



Photo by Andrea Wilkinson

Considering the role of the designer and stepping into the world of a person with dementia: *design and personal engagement*

Dementia is an umbrella term used to describe a variety of psychiatric and cognitive symptoms and the way dementia affects daily life is different for each person. This is apparent not only in the range of symptoms typically associated with dementia (one person with dementia will be affected by aphasia, while another person will have no issues with communication), but also in the coping style, way of interacting with relatives, care staff or strangers or the way a person with dementia gives meaning to the world that surrounds her. As individual as this disease is, so should the design approach be personal. For this reason, we favour a one-on-one design setup in which each designer is coupled to one person with dementia.

The way of working we suggest is heavily based on the person-centered care approach. Person-centered care (PCC) focuses on understanding the person with dementia in context (their vision of the world, their reality) and adapting the communication and caregiving to this understanding. Before the 90s, the view on dementia focused on the biological aspects of the affliction as a disease, not recognising the 'self' in the person with dementia and not granting those affected agency, control or awareness[1]. This reductive view led to depersonalised care[2] , or a form of care which perceived persons with dementia as "dehumanized units of work"[3]. Care would then be 'limited' to keeping individuals warm, clothed, clean and fed[4]. As a critique on these biomedical conceptualizations of dementia, a more humanistic approach, based on the client-centred psychotherapy of Carl Rogers was conceptualized. It was Tom Kitwood who brought this person centered care approach to dementia care. The central aim of person centered care is to recognize the 'self' in the person with dementia despite their distorted consciousness, frequent memory failures and physical and cognitive frailty. Other potential characteristics of person-centered care include: working individually, the insignificance of task-orientedness, the focus on the relational, the necessity for flexibility, the biographical self as a starting point concurrent with the need to step into the lived reality of the person with dementia, and, the body as a form of communication.

Many of the stories below will deal with how these principles of person-centered care are adopted and adapted in the design process for and together with persons with dementia. These narratives engage with the need to step into the world of the person with dementia, how she perceives reality and how this approach requires a considerable degree of flexibility, enabling the designer to respond to the situation at hand, to changing moods or the way the person with dementia perceives reality. The design and research process is grounded in the context of care and living, and starts from making personal connections with the person you're working with. A fair amount of effort should be invested in avoiding being a stranger, but becoming more of a familiar face. This can take up a lot of time, which probably is not always spent in a clearly functional way. Communication does not only come about verbally, but also heralds bodily ways of interaction. Methodology and resulting artefact would then be an empathic response to the person with dementia.

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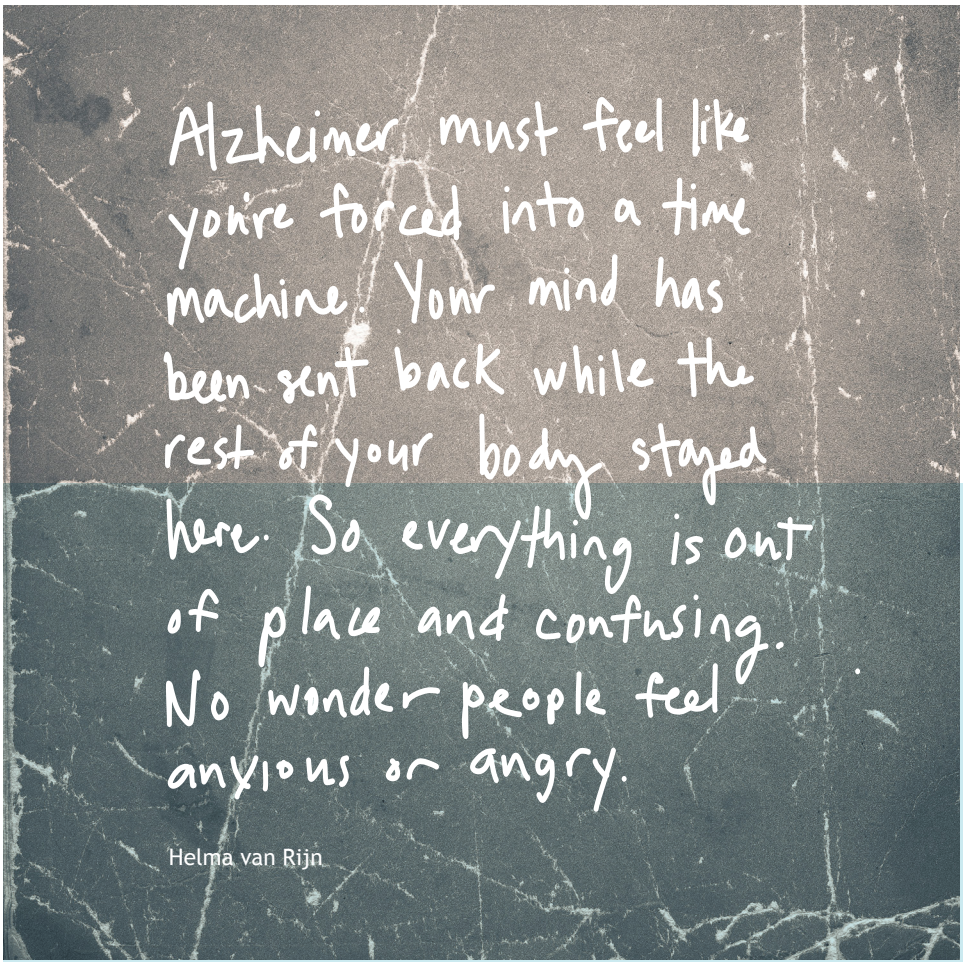
[1] Penrod, J., Yu, F., Kolanowski, A., Fick, D. M., Loeb, S. J., & Hupcey, J. E. (2007). Reframing person-centered nursing care for persons with dementia. *Research and Theory for Nursing Practice*, *21*(1), 57–72.

[2] Davis, D. H. J. (2004). Dementia: sociological and philosophical constructions. Social Science & Medicine, 58(2), 369–378. https://doi.org/10.1016/S0277-9536(03)00202-8

[3] Kontos, P. C., & Naglie, G. (2007). Bridging theory and practice: Imagination, the body, and person-centred dementia care. Dementia, 6(4), 549–569.

[4] Edvardsson, D., & Innes, A. (2010). Measuring person-centered care: a critical comparative review of published tools. The Gerontologist, 50(6), 834–846.



This engaged approach inevitably confronts the designer/researcher with several challenges: working this closely with a certain person how do you deal with befriending and, when the project is over, what will be your exit strategy? How do you define the relationship with the family and partners of persons with dementia? How can you be sensitive towards their relationship (rooted in history but crucially defined by the present)? How do you deal with the stress of working with persons in constant physical and mental decline? How do you deal with tools necessary to the design and research process (such as sketchbooks, photography or video material) that might form a literal barrier between you and the person you are working with?



Photo by M. Unal Ozmen

Helma: reflection

One important finding from my PhD research is that you learn more and better when you feel relaxed. When you're coping with survival in a new situation, you're not yet able to do your job in capturing experience data. So try to make yourself at home as soon as possible. It helps to ask personnel what you're allowed to do. For me, it always works to help along, because the clients see me as someone who works there anyway.

One thing that often must be arranged, but takes time, is consent from family. Especially when you take photo or video recordings.

In my research I discovered that recording stood in the way of empathy. It gives you a safety zone, a reason not to interact. In this way it stands literally in the way of direct contact or interaction with people. Sometimes you need these recordings, I know. My advice is to think what you need, and balance.

The most valuable about direct contact is a mismatch that occurs. It's likely that by meeting someone very different from yourself, that you're surprised by this other's point of view. These moments are important, then you really learn.

I remember when we first drove our garden trolley early-stage prototype into the living room; the people said it was an ice-cream trolley. It was the best happy-association I could imagine, as that idea made them happy. For me me too, from scooping earth into pots. But we realised we needed a more garden-look, with more plants as to not disappoint them with our garden activities instead of ice cream.

By means of prototypes or other ambiguous objects you can actively search for mismatches. You can see it as testing a hypothesis. That's why it is helpful to write down expectations on the forehand. In this way you explicate your learnings.

I would like to conclude with a mismatch I experienced in my first project for dementia. I discovered the hard way how sensitive the subject can be for family. I presumed the family would like to help me, as I was helping them. But they ignored my difficult questions. Later on, I felt so stupid; that I was so un-sensitive, as I was opening up wounds with family. They were slowly losing their loved one. Of course they were not happy to talk about it. This mistake I will not make so quickly again.

This is not something happy to end with, so let's think about birds and flowers again, or the thought of that happy old woman who wanted to keep her basket.

Rita: reflection

So far, I have used a very individualized approach that included people at different stages with dementia and their families. In this way, it is possible to focus on the idiosyncrasies of the person, finding suitable ways to communicate, discover what they like doing and what moves them, while inviting the family to participate in defining these strategies.

This is an important part for me. When I was working with my grandparents who had dementia, being a relative of the person deeply influenced and motivated the design work, but on the other hand, the design work also helped me to understand and deal with the situation, and eventually become a better carer. This insight led me to set up the research in this way, exploring the potential of design and codesign to develop tools for providing opportunities for communication between people with dementia and their family. Additionally, there is the chance that empathy an understanding might emerge for the relatives through this process, possibly constituting a positive moment, and alleviating feelings of helplessness.

Andrea: reflection

Although we work as researchers and designers ourselves, my own personal research interests lies heavily within design education. Niels and I have a specific vision about bringing design and dementia closer together. On one hand, our course is simply placing design into a new context, however it is this context which seems at times so special. With our students we specifically focus on *designing for one*. In this way one student interacts with one particular person with dementia. They are not designing for the generic implications of dementia, but rather one person's experience of it and how this impacts this person's daily life.

This doesn't mean that students are only learning to be good designers for people with dementia, but we believe that this experience also makes them better designers in general. Students often say that they learn patience, become better listeners and better communicators (all of which helps to build empathy). It's these 'soft skills' which become important in our way of working and it's great to have the opportunity to encourage honing these types of skills (which are not often discussed within design education) as well as design skills such as user-testing, prototyping, interface or graphic design, etc.



Photo by Andrea Wilkinson

One of the best stories to highlight this sort of experience, happened to one of our students named Ruud. Ruud worked together with a woman with dementia who, because of her dementia, always wanted to stay in motion and would be very agitated if forced to stop walking. The caregivers found this to have a significant health problems for the woman as she wouldn't take the time to eat or rest. The woman was very hunched in the back and her eyes seemed to focus only on the ground. On one hand this was a design problem, on the other hand this was a real people problem. For Ruud, the idea of 'design' took on new meaning; design wasn't something looking nice or simply functioning, design had actual real purpose and he tried many design experiments to see what, if any, would have impact on slowing her down; from knee-level food that fit in the hand to wayfinding stickers on the floor.

One day Ruud came into the care facility to try some new attempts. He was surprised to see the woman sitting down and calm. He was told that the woman had been walking in the halls for the last 24 hours and was exhausted. The caregivers were so pleased that he was there and asked if he would stay by her side long enough to sit with her while she had a foot bath…

Ruud went on to make a design which followed on from his initial prototypes. For me as an educator, however, this specific moment of interaction was equally as important. When we are working together with people with dementia and when our students are as well, we take on different roles. We are not designers safely taking notes and observations from a distance, we are there as active listeners to caregivers and loved ones, active volunteers or friends doing activities… If Ruud hadn't been there, this woman would have potentially missed out on having a foot bath. Ruud slid into the role of carer. The foot bath had little to do with design per se, but the action of being present was such an important experience to have as a designer.

Tapping into other resources; a cross-disciplinary approach

Working with persons with dementia requires tapping into other resources and taking on a cross-disciplinary approach; in the following section, we explore this multidisciplinary approach. For the Dementia Lab, the care domain itself is seen as one of the crucial partners in the design and research process. In their approach, solidly embedded in the care facility, the caregivers are indispensable in the design and research process as they draw from their own experiences and knowledge on the person with dementia to aid the designer in taking appropriate measures fitted to the person they are engaging with and the context he/she is living in. In order to integrate the caregiver in the design process, first a considerable amount of openness between both parties should be created.

In this section Rita Maldonado Branco, reflects on how the collaboration with others (not designers or researchers but a psychologist, a textile maker, etc) turned out to be a necessity in working with persons with dementia.

The last story I want to share is about Amelia, and her caring husband Gabriel, who attend the day centre services of one of the institutions. They are also one of the participant families in my project. She has nearly no verbal communication, making it very hard to engage her in responding to most of the activities proposed in the game.

The couple was invited to define a personalised design brief that could suit their needs and preferences.

In order to support this, two exercises were created drawing on the person-centred thinking tools, used by dementia services to gather information to deliver individualised care.

The first one is about the weekly routine of the person with dementia and their close family, in order to identify plausible opportunities of use.

The other exercise asks about how a perfect day and a bad day would be like for both the person diagnosed and the main family carer. The goal was to understand what is important for both: things they like and dislike doing, their interests and preferences, so that these were taken into consideration in design ideation.

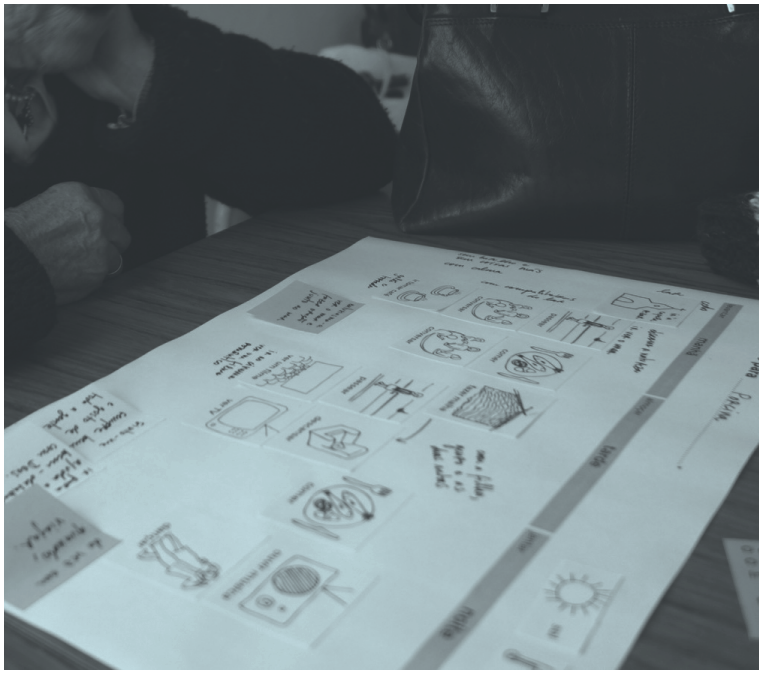
Based on these two exercises we concluded that it would be good to do something to entertain and stimulate Amelia on weekend afternoons, when the couple is less supported since they stay at home. During this time, Gabriel would

[1] Participatory design is the term used to express a collaboration between designers and those affected by a design in a design process

[2] The concept of Internet of Things can be explained as everyday appliances and objects (your table, chair, fridge, etc) are linked to each other and connected to the internet.

Photos by Rita Maldonado Branco





prefer to rest, watch TV or read, but Amelia is often agitated and wants to move around the house.

The "perfect day" exercise regarding Amelia pointed to the possibility of exploring tactile stimulation with textiles since she used to love knitting and lace making. Gabriel added that she always took care of laundry and clothes and, even today, if she sees clothes she likes to touch them. The idea of tactile stimulation was also associated with my experience of how Amelia would take my hand and "explore it", pressing each finger one by one, and sometimes the whole hand.

Although Amelia was present, it was not possible for her to respond to the exercises therefore, Gabriel answered for both. These exercises were crucial to get to know the couple a bit better and to give directions on how to start. However it was clear that if Amelia was to be engaged in the design process, it should not imply any verbal activities, but instead giving her things to try out and observe how she reacted non-verbally.

Since the work with textiles is out of my field of expertise, I invited a fashion designer to collaborate.

We started by giving Amelia different fabric samples and observed how she reacted to them. Her reactions were noted for each sample: how she touched them, moved them, folded them, with one hand, two hands, how she placed them on her legs, how she combined them, how long she kept them, if she didn't seem to care too much, if she grabbed it from my hand, etc.

Amelia was entertained for nearly an hour in this activity. She was visibly happy, smiling and laughing at times, and she even stood up to hug me at the end. Amelia seemed to have a preference for soft and warm fabrics and she usually touched fabrics individually on both sides, and this influenced our design decisions. In this way, Carla, the fashion designer, suggested two ways of combining different fabrics that allow each material to be touched individually on both sides, one using circles and the other one using rings. These options were given to Amelia to try, and she tactually explored both during some time.

From here, the fashion designer suggested that we could try to create something that could work both as stimulation material and as a piece of clothing.



Photos by Rita Maldonado Branco

We observed that, when seated, Amelia usually placed her hands on her legs, and did the same with the fabrics. Therefore, we thought to make a blanket or a shawl that reached her lap, serving both to make her warm and for stimulation. A prototype was produced, using the circles combination, and was brought to Amelia. She looked tired on that day but engaged with touching the different fabrics of the prototype for a while. Having it on her lap made the various textures more accessible to her hands, rather than having it on her back, as a shawl, where she could only reach the ends of the prototype.

In order to better, and externally evaluate the work developed, the psychologist of the institution was consulted. The clinician

valorised the prototype developed for promoting tactile stimulation that enables exploration and discovery, and for the possibility of being worn, offering involvement, comfort, warmness, which can induce positive emotions and the sensation of protection. In this way, this prototype can serve as a relaxation moment, a calmer stimulation.

Taking these insights into account, the shawl evolved into a poncho, enhancing the characteristic of being involved and warm. In this way, by placing the textured circles at the front of the poncho, they became more accessible to Amelia's hands. We included more fabrics with different textures, choosing fabrics that have different textures on both sides.

The psychologist appreciated the ring combination for being more playful. This combination was crocheted, since it allows other kinds of textures and could possibly trigger some reminiscence. Here we used more vivid colours for a more active stimulation.

Amelia wore the poncho for about an hour. She was well during this time, always entertained touching the circles, passing from one circle to the other and feeling them on both sides, sometimes also putting her hands in between them. And also, from time to time, she stopped with her hands and looked carefully at the circles.

It was only possible to observe Amelia's interaction with the crocheted ring combination for a short time, but she did explore the different textures in the rings. The fact that she offered resistance when the caregiver tried to take it from her hands is also a hint that she was probably enjoying it.



Photos by Rita Maldonado Branco

Additionally, this piece, probably for the vivid colours but also for the strangeness and non-identifiable shape, aroused interest from other people in the room, who also wanted to interact with it. Another lady was visibly enthusiastic about this piece and kept it and explored it for a while.



Photo by Lukas Venne for Dementia Lab

A view on the future; integrating social design activities into design education

Integrating a topic like dementia into design education as well as industry places it squarely under the term of Social Design. As design education often responds to trending topics with a primary focus on the end-designs, it often lacks the authentic and long-term investment that Social Design values[1]. Dementia Lab has learned in the past 6 years that a project like the present one requires long-term investment. It takes such effort to establish and could lead to such potential impact, that the one-off engagement that is often associated with design briefs within design education, seems insufficient. This prolonged engagement is precisely what generates real and shareable knowledge. In the case of the Dementia Lab, this working across a care context over the course of several years helps to accredit the designs created there and warrants the prerequisite that design must seamlessly integrate into care, otherwise taking the risk of becoming obsolete. Although we cannot propose that this way of working is 'better' than other approaches, we can assure that this way of going about things leads to 'knowing more' and a greater sensitivity to the routines and processes involved in care.

Because the Dementia Lab works within a design education and research context, we have been able to make incremental changes to our design process year in and year out, focused on knowledge of the context, designing together with those impacted by a design, and creating cross-discipline relationships with those 'on the floor'. This mirrors the suggestion that the UK funding body AHRC brought forward in their review of Social Design projects. Their findings suggested that that design should become more about relationships instead of just designing artefacts[2] . For the Dementia Lab, this move away from focusing on end-result has contributed to our ability to build strong relationships with care organisations. As some sort of *slow design* process, our investment is about forging relationships across the board; from teacher to student to caregiver to person with dementia to family member to management. It is these relationships which give our project its social relevance.

[1] Armstrong, L., Bailey, J., Julier, G., & Kimbell, L. (2014). *Social Design Futures: HEI Research and the AHRC* (Report (for external body)). University of Brighton. Retrieved from http://mappingsocialdesign.org
[2] Armstrong, L., Bailey, J., Julier, G., & Kimbell, L. (2014). *Social Design Futures: HEI Research and the AHRC* (Report (for external body)). University of Brighton. Retrieved from http://mappingsocialdesign.org

Those familiar with the term Social Design will be aware of its leaning towards dealing with 'wicked problems'. Countering the classical paradigm that problems can be defined and designed for (solution oriented) the term 'wicked problems' was first coined as a way to describe the difficulty of working with societal systems[3]. Because this 'wickedness' is characterised by complexity where there are "competing and often contradictory drivers, and scenarios in which there are multiple 'correct' answers to design problems", 'wicked design challenges require the design process to be social, inclusive and human-centred[4]'. For designers who normally work towards resolved end-designs and for a design industry that focuses on offering refined solutions, a lack of a be-all, end-all finite solution causes issue. Although the subject of dementia might not be classified as a wicked problem, working within this domain brings up issues related to healthcare access, such as costs, mobility, individualised care, etc. One cannot work within a care facility without seeing the person with dementia as part of a much larger whole. For students, building an awareness of this greater whole adds value to a design education which previously lacked the ability or context to even 'perhaps' discuss these issues.

With these apparent issues relating to the time required for investment and a focus on relationship instead of outcome, design education possesses the potential to be a driving force that is able to initiate and contribute to long-term change. Although this brings about new issues such as whether student designers are adequately equipped to deal with these types of wicked problems and how even to educate them to be active participants[5], design education can potentially offer a broader spectrum of focus than that of only preparing student designers for jobs in the creative industry. It shifts to potentially preparing future designers for future positions that will prioritise socially relevant design issues.

Educating future designers to work with these sort of need-based user populations and social design issues is a way to nudge the industry itself; a trickle-up effect[6]. For the Dementia Lab, designing together for and with people with dementia, and bringing students into direct contact with people with dementia, their caregivers and family, is a way to support this shift in design education. This does not only impact the creative industry, but also the field of care. The Dementia Lab's vision for the future is that the link between design and care will no longer be novel or strange. Instead both care and design will see each other as mutually beneficial partners and this partnership will lead to addressing wider societal issues, one person at a time.

The Dementia Lab event in Essen brought together design researchers, educators, industry designers and design students and provided the opportunity to discuss the designer of the future and what role he/she would have specifically in care. The following section shares these personal insights and reflections on the role of design education.

[3] Rittel, H. W., & Webber, M. M. (1973). Dilemmas in a general theory of planning. Policy Sciences, 4(2), 155–169.
[4] Thorpe, A., & Gamman, L. (2011). Design with society: why socially responsive design is good enough. CoDesign, 7(3-4), 217-230.
[5] Nussbaum, B. (2011, April 5). Design Thinking Is A Failed Experiment. So What's Next? Retrieved May 16, 2016, from http://www.fastcodesign.com/1663558/design-thinking-is-a-failed-experiment-so-whats-next
[6] Margolin, V., & Margolin, S. (2002). A "social model" of design: Issues of practice and research. Design Issues, 18(4), 24–30.



Photo by Niels Hendriks

Within design education, how do you approach the challenges that come from working in a multidisciplinarya way on such a topic?

Nina Pillen
Folkwang Universität der Künste
Folkwang University of the Arts, Essen, Germany

The discussion on the topic of knowledge transfer is not only topical in classic universities, but also concerns the art schools. Even though, this represents the artistic rather than the scientific disciplines, the transfer into and the exchange with society is an important issue. If one understands a university of arts as part of a diverse society, it is always regrettable to note that a large proportion of the population perceive consumption and participation in art and culture as elitist, which leads to excluding them from participation. A project by Prof. (stv.) Carolin Schreiber, Nina Pillen and Benedikt Neuhäuser, the Folkwang LAB "Do we know each other?", where students worked in the field for six months together with dementia patients in nursing home residences, many bridges were built. Projects like this involve people who may have never had contact with design before. They make processes and results tangible. Not only a transfer of knowledge into the population can be achieved, but also a high degree of depth and realism of the student work is achieved. The extraordinary cooperation with those concerned and the students involved, was covered in various magazines and articles, enabling new perspectives for the general population on university teaching, project depth and the idea of a citizen-oriented university.

As a result, this also promotes and encourages the population and the (city) actors to introduce new offerings and requests for joint projects with the university. For the Folkwang University of arts, there are already many other possibilities for participatory design projects that are located in the "Social Design" team of Prof. (deputy) Carolin Schreiber and Nina Pillen.

Looking at participatory design teaching projects under the definition of today's "Good university teaching," their potential is confirmed in terms of teaching methods, learning objectives and successes. It was also confirmed by the Founders' Association and by the German Higher Education Rectors' Conference, who gave the Folkwang lab "Do you Know us?" The Ars Legendi Prize 2016 for excellent university teaching. The creation of such projects promotes positive self and external perception in the academic and artistic context and ensures successful continuation at the university. The Folkwang University of Arts is spread over many locations in the Ruhr area and is closely associated with people and places. According to the Folkwang idea, formulated by Karl Ernst Osthaus, 90 years ago, the university aspires to reconcile art and life with each other and to improve human living conditions. In order to maintain this idea, it is important to seek new ways of working in society, to adopt relevant issues and societal challenges, to identify potentials of design and to make the university an active and accessible part of the society.



Photo by Andrea Wilkinson

What are the challenges of working on a social design topic within a design course that is not used to working in this tradition?

Stefanie Schwarz
Stuttgart State Academy of Art and Design, Stuttgart, Germany

"Every care facility should have a designer." This is a quote from a design student who participated in a workshop about "Design for and with people with dementia". Although it tells a lot about the relevance of this topic, in order to adopt this attitude one first has to enter this field and deal with it in-depth. In my opinion this is still the main challenge when trying to introduce and promote a project like this, as a course or a workshop, first among lecturers and professors and then among students. The following thoughts are based on my experience as a lecturer of a communication design course that usually doesn't deal with social relevant topics, and where participatory design is not taught as core approach to design projects.

When I planned the workshop/project "Design for and with people with dementia" (held by Niels Hendriks and Andrea Wilkinson) colleagues and students from the adjoining industrial design course were immediately interested, whereas many of the communication design lecturers and students were initially hesitant and needed to be convinced. Myself, a traditionally trained graphic designer, who studied in Germany and the US, also didn't know much about the

domain of social design and participatory design, until my MA studies at Central Saint Martins College in London. A fellow student, Rita Maldonado Branco, focused on the subject of design and dementia. Because of her I became aware of how communication designers can work in that area. Before, I couldn't really imagine that what I feel is one of the main problems to get other "traditional" designers interested to work in that field.

Additionally, in traditional graphic design schools, lecturers and professors usually stand for a certain discipline and teach in a specific area, like typography or illustration. Often the course or assignment determines a medium from the beginning – that a book, a website or a spatial situation has to be designed, which seems quite contrary to the design approach of participatory design, where embracing various design disciplines and working result- or media-open is key.

In order to promote social design topics within educational contexts, it would be beneficial to have more successful results published. In particular material that outlines what kind of projects can be done and strategies to achieve them. Ideally this should be aimed at or at least take into account designers, design students and educators, who are unfamiliar with such topics. When preparing the workshop at my academy and explaining it to colleagues and students, I usually described some projects I knew in that field. Access to vivid examples, collected and presented in a proper way, would have been very helpful to outline the possibilities and potential of such a project. Besides an indispensable dedication of individual designers, this might be a helpful tool to convince other designers (students and educators) to include such courses and topics in the curriculum on a larger scale.



In the summer of 2016, I participated in the Dementia Lab in Berlin during the project week. The task was to visit a daily facility for people with dementia to find a problem and to think of a solution. The point at which the program was crucially different from ordinary lessons was the approach of actually interacting with its target audience. Normally we work with statistics and personas, but in this project we came into direct contact with the target group.

Photo by Lukas Venne for Dementia Lab

How did you experience this project as a student? What will you take with you? Will it influence you?

Lasse Rosenfeld
Communication Design Student
BTK University for Art & Design, Berlin, Germany

Direct contact with people with dementia gave us not only a factual overview, but also an emotional attachment to the topic. When we entered the institution for the first time, we had already received a brief introduction to the subject of dementia, but there were still gaps. We did not know how they would react to us or how we could connect with them. However, the friendly and open staff quickly replaced this prejudice. The director presented us to the group that was sitting outside in the garden and gave us tips for when we would not know what to do. We sat between the people with dementia, had lunch with them, talked with them, or just watched. What struck me was that everyone liked to eat, but hardly any were drinking. Motivated by this, as well as the staff mentioning that getting them to drink was often a problem, I asked myself the question: how can I make drinking something more pleasing?

The prototype that arose from this question was a set of drinking glasses, at the bottom of each glass images were glued, and the images were only visible when the glass had been emptied. In addition, there was a game board on which you could see the pictures again in large and recognize them and see them as a collection.

At the end of the week we visited the facility a second time to try out our ideas. The game was surprisingly well received and the caregivers used it to talk to the residents about the animals shown on the pictures. The director was very enthusiastic and all in all, it was a success. This project was enriching for me in three ways: first, it showed me that the problem-solving strategies that I had otherwise used only in the graphic sector could also be applied in completely different areas. Secondly, this week I was introduced to the field of human centered design. Over the course of my studies, I had become a little tired of working exclusively for products and brands. That I could also use my skills to satisfy needs rather than initiate them was a great motivation for me. And finally, without this project and without these impetuses, I would not be where I am today.

I am writing this text from Amsterdam, where I am studying for a semester, design thinking and doing a module specializing in human centered design. Before the project week last summer, I had no concrete idea what exactly I wanted to do after graduation, but through the project I now have a clearer direction in mind, and this direction is human centered design.



Photo by Lukas Venne for Dementia Lab

What advice to you give students wanting to work in this space?

John Vines
Professor of Design, Northumbria School of Design
Northumbria University, Newcastle upon Tyne, UK

Most of my teaching at Newcastle the last two years has centered around a Master's in Research, which is the first year of a four-year doctoral training programme. The training programme is focused on the topic of "digital civics"—which I won't try to explain here—but in essence this means almost all of the students engage in collaborative engagements with a diverse range of, often quite marginalized, groups, often with a view to supporting new forms of participatory practice and design digital platforms.

There are a number of things that I try to emphasise to these students very early on, which touches on some of the points already raised in other discussions. A first issue I talk about with students relates to finding the right partners and building relationships with them. Sometimes there is a desire to go big very quickly, perhaps engaging with municipal authorities or local councils, or even industrial collaborators. Our experience has been that working at a more local level, with smaller, more dynamic organisations is best to begin with as a way of piloting ideas and then starting to demonstrate their value. From here you can start to translate these to other similar organisations. Then when you have a critical mass of examples, you can go to larger organisations that might benefit from using or building on the work you have done.

Second is the need to align to the temporalities and immediate concerns of others. Large partners often have very specific activities they want to do in a short period of time, which again is not ideal for these extensive relationship building processes. However, smaller organisations also can be very resource limited and it's a case of ensuring your work does not disrupt these and add additional burdens to their work. Furthermore, when working with families who may be experiencing "crises" around the diagnosis of a loved one, or with people who experience highly fluctuating conditions, you need to respect they will have priorities far beyond engaging in some design activities or a research project. I try to stress to students that actually these "challenges" in themselves are deeply insightful about the contexts and lives of the people being designed for.

Third, I tell many of my students to try and engage in the moment, and reflect on this afterwards. We've already discussed challenges students and researchers face with documenting what they do, and sometimes we've been really bad at that. But it's often because it is inappropriate to record everything, to sit there making notes or clearly being seen to be observing people rather than participating. Generally, then, the approach I've tried to take is one where we engage with the activities or situations we find ourselves in with collaborators and participants, and then reflect on these carefully through structured group interviews and discussion between students and researchers shortly after the fieldwork.

Fourth, an ongoing challenge is sustaining what you do. We've had problems with projects ending and the processes established not being sustained. This is a particularly big issue in community oriented research where there is some element of technology, as often these systems are not maintained beyond the end of a project. Sometimes though you realise, only at the end of a project, that it has been the researchers that have completely driven an initiative. Therefore, it is important that the process itself gives control and agency to those collaborated with, so they have ownership and see value in the work to continue it on in their own way. It also means building systems that rely less on bespoke technologies and equipment so that they can be more easily maintained and fixed through off-the-shelf and consumer items.

Finally, I stress to my students that there is no such thing as a toolkit and recipe book. I run a design methods module, and straight from the start students often just want to know which methods are the best for certain situations, or what the results of doing something one way rather than another would be. For me, all of this comes from experience. We've talked a lot about how people with dementia have highly individual circumstances and experiences, and that is also the same for those who enter the worlds of these individuals. Techniques, competencies, methods that one person can get to work well, might work less well for others. Instead, I try to stress competencies of being flexible, being able to improvise, and to be sensitive to listening to and responding to what those you work and spend time with say and do.

Based on your own experience during your doctorate, what would you suggest to other designers and design researchers?

Tommy Dykes
Product & Interaction Designer
Northumbria University, Newcastle upon Tyne, UK

As a student, when I began my PhD I found much literature in dementia care daunting as it had strong negative connotations that did little to convey the realities of being with a person who lives with the condition. To gain first-hand experience of dementia, I befriended through a local charity, an experience that not only influenced my reading of the literature and practical development of my PhD project, but changed me personally. Initially when imagining dementia, I saw a series of problems, after all, papers tended to frame a series of impairments. Through my own personal interactions however, it became clear that dementia was deeply entwined with the complex realities of daily life and the uniqueness of my own experiences and relationship with my befriendee.
In getting to know my befriendee I became more adept at introducing and finding opportunities for meaningful engagement. I began to see artefacts in the home (like the inside of a desktop computer), online content (like Google Street View and the National Football Archive) as resources that allowed us to get to know each other, by relaxing into each other's company, as friends. I began using various

resources in a manner that was flexible and responsive, emerging out of particular insights or conversations and being dependent on my befriendees well-being at any moment. Over time, through befriending and the design of artefacts for social engagement in the care environment, I began to see digital technology as a resource, which has the potential for engagement in an open and receptive manner, but is dependent on various factors like time of day, culture of care, closeness and the enthusiasm of carers. This was in contrast to the suggestion that artefacts are necessarily *for* something in particular, that they can solve a particular problem or consistently provide therapy with specified outcomes. In many ways, a resource supports broader opportunities for digital designers to create meaning within care environments, but humbly accepts that artefacts and their use is heavily dependent on social, cultural and institutional factors.

My own befriending experience and the notion of a digital resource raises important questions for design and our understanding of artefacts. Rather than focusing on specific methods alone, should social designers be encouraged to develop first-hand experiential knowledge through immersive activities like volunteering? What influence does life experience, maturity and personal development have on design work? Could designers be embedded within care environments over the long term, to provide on going support for designed artefacts and design thinking? In turn, how does this influence the long term use and meaning of digital artefacts within existing cultures of care?

Reflecting on the state of now with a view to the future

Much like the section on design education, the Dementia Lab event concluded with a reflection and discussion on what had been shared in the two day event. Dr. Catherine Stones, Deputy Director of Research and Innovation and BA Graphic and Communication Design Programme Leader at the University of Leeds School of Design chaired and initiated a roundtable discussion.

As the presenters talked about their experiences and how their projects were personal and bespoke, in her summation, Catherine suggested that the event reminded those present that design as a discipline possessed the potential to initiate meaningfulness. As an academic she was critical of how this individualised and bespoke approach might be accepted by other academics as 'research' and she asked if their specific formats or methods that were more appropriate or suited this sort of research and already accepted by the research community.

Next to this, she reflected on the idea of evaluation: How one determines the success of a project and how designer/researchers should evaluate the work of our fellow researchers and students.

Jayne: It depends on what you're trying to achieve. The staff at different levels can notice change in behaviour and, for instance, willingness to communicate which is a form of continuous assessment. On the downside, this change is resistant to a series of measurement tools.
Helma: Another way of going about this is to establish whether caregivers value your product and/or process. We could also measure interaction in order to evaluate whether or not a given product improves social interaction. Potentially, it might be worthwhile to collaborate with other disciplines to acquire demonstrable proof? From a commercial point of view, another way of evaluation might be whether or not people are willing to pay for it.

Because the combination of design and dementia is currently an area of growth in design research, Catherine suggested that analysing existing evaluation methods might be a good area for designer-researchers working in this area to explore. Drawing these from other research disciplines may be insufficient and new forms might need to be created and tested that are better suited to this sort of bespoke and relation-based work.

Linked to this idea of evaluation, Catherine, as well as others present, noted the absence of carers at the event, thus one of the questions discussed was what could be done to integrate them into this discussion? Would the discussion have to be less design and more care? Or was


Photo by Lukas Venne for Dementia Lab

there some common language that could be used to reflect?

Would healthcare specialists respond better if we offered more rigorous methods of testing? Are their ethos and expectations similar to that of designers'?

Jayne: Designers are used to more flexibility. Healthcare has become 'medicinalized', meaning that testing methods become more systematic. However, things like beauty, joy, feeling are hard to assess. It is important from a design perspective to keep articulating our values and not to succumb to this medicinalized view of healthcare.

John: Up to now, universities do not rank among the dementia-friendly communities (as opposed to some retailers, cafés, transportation companies). Universities should become more proactive and open up to a wider range of disabilities.
Jayne: In order to get care involved in design we need to stimulate reciprocality. Invite caregivers to your labs and let them play with the technology. Form networks of people who want to make things better.

Niels: There seems to be a conflict between the culture of research and the culture of care. Research should adapt to the latter by lowering the tresholds.
Helma: It is not only a question of going to a care facility and carrying out a given assignment, potentially it might benefit the mutual relations if we stimulated the facilities to come to us with their questions.

In closing that the event itself seemed to, in a sense, speak to the already converted. Those in attendance were already familiar with common challenges attached to working with people with dementia. This doesn't mean that the event was irrelevant, it actually means that the focus is maturing. This maturing is precisely what allows for critical reflection and the asking of questions about evaluation methods and academic rigour. This furthers the Dementia Lab's idea that there is a need for defining a formal network in which designer-researchers as well as carers will feel comfortable enough to ask questions, share failures as well as successes and reflect on methodology; with the person with dementia and his/her experience and needs at the core of its values. Regardless of how it continues to progress, this initial Dementia Lab event was a good point at which to begin these discussions.

Biographies



Niels Hendriks
Inter-Actions; Social Spaces Research Group
LUCA School of Arts, University of Leuven, Belgium

Niels' interest domains are in participatory design and design for health. During the last years he has worked in research projects together with different industry players, cultural organisations & the social profit sector. He has experience in working in several dementia and design projects both in residential care and home care settings. As a lecturer Niels teaches in the Interaction Design program and in a faculty-wide master course on participatory design and dementia at the LUCA School of Arts (Belgium).

Niels is working on a PhD research at the University of Leuven focussing on involving persons with dementia in the design process (Supervisor Dr Karin Slegers). He is part of the program committee of the Participatory Design Conferen 2016 in Aarhus, Denmark and has been working in Hong Kong (HKDI DESIS Lab for Social Design Research) and in Denmark (IT University and The Royal Danish Academy of Fine Arts Schools of Architecture, Design and Conservation, Copenhagen).



Rita Maldonado Branco
PhD Design, University of Porto, Portugal

Rita is a communication designer currently undertaking a PhD in Design at the University of Porto. She has worked as a graphic designer for Francisco Providência Design Studio in Porto, and for the Design Against Crime Research Centre and Minus 9 Design Studio in London. Rita completed her degree in Design at the University of Aveiro (2008) and graduated with distinction in MA Communication Design from Central Saint Martins, University of the Arts London (2012) with a project that explored communication design contributions to dementia. Having two people in the family living with Alzheimer's disease, Rita proposed informative and more empathetic ways of representing dementia, as well as tools to mediate and facilitate the communication between her grandparents and her family. She is now taking this research forward through her PhD, focusing on how design can support the maintenance of social relationships and communication with people with dementia. Strongly influenced by the values of care, it explores how communication design can enable people with dementia and their close social circle to develop personalised strategies to communicate, with a special focus on leisure and entertainment.



Dr. Catherine Stones
School of Design
University of Leeds, UK

Catherine is a lecturer in Graphic Design. She teaches a variety of subjects including information design, digital design and visual communications in general. She is currently Programme Manager for the BA Hons Graphic Design and Visual Communication. She supervises PhD students working in the area of health communication and graphic design as well as projects related to participatory design and information design. She is an AHRC Design Fellow and was Principal Investigator on an AHRC funded project with Public Health England about the use of infographics in engaging public audiences. She also has an interest in illustration and its use in the telling of personal narratives.



Dr. John Vines
School of Computing Science
Newcastle University, UK

John's training is in product design but his research sits somewhere at the intersections of interaction design, human-computer interaction, gerontology, participatory research, public service design, and philosophy of mind and science and technology studies. Since 2004, he has been conducting design research on the topic of technology for later life and transitions across the life course. This has involved working on a range of projects designing digital technologies and services for and with older people – such as developing tangible and physical interfaces for 'information appliances' for later life socialisation, designing banking technologies for those who rely on others to help them with their shopping, and exploring intergenerational voluntary care services with groups of young and old caregivers and recipients.

www.johnvines.eu



Dr. Helma van Rijn
Founder of LINKX-app

Helma is fascinated by design for difficult-to-reach user groups. As designer, she does creative user research and meaningful design for healthcare and (special) education. She performed various design projects for people with dementia and children with autism. In her projects, she builds a creative understanding of the user group and their (social) context from close contact. In this way, she ensures that the people, pleasure, and usefulness take a central role in design.

In 2012, she defended her dissertation 'Meaningful Encounters' at the TU Delft (supervisors prof. dr. Pieter Jan Stappers, prof. Dr. Ina van Berckelaer-Onnes, dr. ir. Froukje Sleewijk Visser). In her PhD project, she researched how designers can learn from encounters with children with autism and their caregivers. This contact serves as source of information and inspiration for the design process.

In 2007, she was awarded as best graduate TU Delft with her design LINKX to help children with autism to expand their vocabulary. Her social startup LINKX-app, founded in 2015, aims to bring this further. LINKX consists of interactive wooden tags and an app, that allows you to learn to name anything around you!



Dr. Jayne Wallace
Craft Futures
Northumbria University, UK

Dr Jayne Wallace is Reader in Craft Futures at Northumbria University, UK. Her work spans digital craft, interaction design and Human-Computer Interaction, focusing on co-creative design practice and the development of physical-digital devices that have social and personal meaning to support wellbeing and sense of self. The ways in which our bodies and the objects that we associate with them (such as jewellery) represent different things about who we are and our relationships with other people have long been a fascination and she makes digital jewellery to explore how we can make things that are personal, beautiful and digitally enabled to give us new ways to understand ourselves and others. In recent years a key focus has been sense of self in dementia and she has worked closely with people who are living with dementia as well as specialist adult mental health units in the National Health Service, UK. She is co-founder (with Joyce Yee) of Praxis and Poetics: Research Through Design conference – an experimental, discursive conference format physically foregrounding the artefacts stemming from design research.



Andrea Wilkinson
LUCA School of Arts, Inter-Actions Research Group, Belgium
PhD Student: University of Leeds, School of Design, UK

Originally from the American Midwest, since 2001 Andrea's research has lived under a banner she terms 'The Response(Ability) of a Designer', which explores the use of design research and methodology to enable designers to respond to problems/issues/opportunities regardless of domain or media. For nearly 6 years she worked as Senior Lecturer in Design and Graphic Design Coordinator for the School of Media Arts at the Waikato Institute of Technology in Hamilton, New Zealand before taking up a teaching and research position at LUCA School of Arts in Genk, Belgium where she teaches across the design curriculum and researches within the Interactions/Social Spaces Research Group. She is primarily involved in location-based storytelling and combining design with healthcare contexts, one-to-one design and specifically how design can support people with dementia.

Andrea is currently doing her PhD at the University of Leeds, investigating how designing with individuals can enrich the graphic design practice.

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The stories come from presentations done by Helma Van Rijn, Nina Pillen, John Vines, Jayne Wallace, Tommy Dykes, Stefanie Schwarz, Rita Maldonado Branco, Lasse Rosenfeld, Niels Hendriks and Andrea Wilkinson. For reference, please refer to the contributor's name.

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