

# Introducing a Designing Attitude in Dementia Care

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**Abstract:** This paper discusses how design can enhance the wellbeing of people living with dementia, their carers and caregivers. It refers to two examples of recent design research that focus on supporting the provision and facilitation of appropriate activities and environments for individuals with advanced dementia in residential care. The projects use interdisciplinary co-design approaches and ethnographic methods to establish new knowledge and develop user-centred design solutions to improve care. Questioning how to REDO design research to create a sustainable impact on the lives of those affected by dementia, the paper concludes that active involvement and continued participation of users, carers and care practitioners in the design process is essential. Training on design skills and making will enable carers to adapt a designing attitude. Exploring how such training can be delivered is a chance for the design community, in collaboration with experts from health care, to take the lead in solving this problem.

**Keywords:** dementia, sensory, co-design, design sustainability, older people

## 1. Introduction

The paper discusses the growing role of design for dementia enhancing the wellbeing of people living with the disease, their carers and caregivers. It refers to examples of recent design research that focus on supporting some of the most important aspects in dementia care - the provision and facilitation of appropriate multi-sensory experiences and activities, including non-pharmacological, person-centred interventions ameliorating behavioural symptoms. The paper raises the question of how to REDO design research and practice for dementia so a long-lasting, widespread and sustainable impact on the quality of care and the lives of those affected by dementia can be created.

## 2. Context

According to the World Alzheimer Report 2016, there are 47 million people living with dementia worldwide today, and it is expected that this number will have risen to more than 131 million by 2050 (Prince et al., 2016). Dementia is a process of cognitive decline that impacts a person's ability to cope with and adjust to their environment, to interact with others and to meet their own needs (Cohen-Mansfield et al., 2015). The term 'dementia' includes several disorders, such as Alzheimer's disease, vascular dementia and dementia with Lewy bodies. Apart from memory loss these conditions present problems with behaviour and the capacity to take part in everyday activities. Behavioural symptoms (i.e. apathy, challenging behaviour, depression) are often an expression of confusion or frustration resulting from limited abilities to communicate and interact, loneliness, need for meaningful activity, too much or too little stimulation, and discomfort (Cohen-Mansfield et al., 2015).

As there is currently no cure for dementia, recent treatment and care methods focus on optimising living conditions for people with dementia fostering a sense of wellbeing. The rapid rise of people affected by dementia as mentioned above has brought an urgent need for effective interventions in supporting dementia care. Particularly in later stages of dementia, care practice needs to support these individuals in maintaining quality of life, dignity and comfort by alleviating behavioural and psychological changes without resorting to antipsychotic medication (Strom et al., 2016).

## 3. Design for dementia

Increasingly, design research and practice has been responding to this need by developing artefacts, environments and initiatives aiming to support individuals living with dementia to re-connect with people and places, maintain their dignity, and re-gain a sense of belonging, purpose and accomplishment - subsequently improving their quality of life and the life of their carers and caregivers. A range of successful products providing meaningful activities for people in early to mid-stage dementia are now commercially available (i.e. [active-minds.org](http://active-minds.org)). Online resources offer information on recent initiatives regarding design interventions for dementia and ageing (i.e. [ageinginnovators.org](http://ageinginnovators.org)). In recent years, numerous projects with high-quality outcomes have emerged from international academic research into the design for dementia, with a focus on improving the provision of personalised stimulation and activities meaningful to the individual as well as improved every-day experiences such as eating and dressing (i.e. [dementialab.com](http://dementialab.com), [designingfordementia.eu](http://designingfordementia.eu)).

Because of the participatory nature of most design interventions and projects in this area, they often generate a high impact already during the project or immediately after. They are very well received and supported by the health care sector, the care-home, the carer and caregiver recognising the beneficial effect. However, after the designer's departure, the impact is not always sustained (the design intervention fails to be embedded in care practice) or the desired ripple effect is not achieved (the design intervention does not spread across the sector / organisation / home).

This observation has now started a debate within the design community as well as interdisciplinary, about how designers can ensure their efforts create a long-lasting, widespread and sustainable impact, improving the lives of as many people affected by dementia as possible.

### 3.1 Sensory enriched environments in dementia care

Within this context, recent interdisciplinary research evolved investigating the quality of multi-sensory experiences currently provided in care-homes in UK (Jakob & Collier, 2017).

People with dementia are often at risk of sensory deprivation as they are limited in their ability to access meaningful and suitable activities. On the other hand, they might be exposed to sensory overstimulation, for example in a care-home environment where common living areas can be very noisy with too many things going on. Both situations present a significant challenge to wellbeing and health potentially aggravating behavioural symptoms. Facilitating appropriate multi-sensory experiences tailored to the needs of the individual (either providing stimulation or helping to relax) is particularly important for people in later stages of dementia as this might be the only activity they can enjoy (rather than occupations requiring a certain level of cognitive abilities, i.e. puzzle). In an attempt to provide a solution, the concept of the Multi-Sensory Environment (MSE) – also referred to as Sensory Room or Snoezelen – was introduced in dementia care. Many MSEs were established in UK care-homes over the last decade as a resource for meaningful engagement reducing agitation and improving functional performance (Maseda et al., 2014; Collier et al., 2010). However, it had been reported that the facilitation of sensory stimulation and the use of such spaces in practice have been inconsistent and limited (Andrews, 2015; Anderson et al., 2011), and anticipated benefits of MSEs for residents has not been achieved. Consequently, staff have become discouraged, perceiving the space of little value, resulting in the rooms themselves becoming abandoned (Dalke & Corso, 2011).

Establishing more evidence, an ethnographic study examining existing facilities and their use was carried out in 16 participating care-homes in London and South England. The results from this critical survey confirmed that most MSEs in care-home settings do not reach their full potential in providing multi-sensory enrichment for their residents (Collier & Jakob, 2016). This was due to the impact of aesthetically and functionally inappropriate design and set-up, the limited range of sensory accessories and equipment available, and a lack of attention to how these spaces are meant to be used, the findings revealed. An important issue was that in the absence of sufficient information and guidance for care practitioners, facilitation of sensory enriched environments and multi-sensory activities for residents with dementia by staff was often very poor.

Following the results from this study, design criteria for creating sensory spaces that maximise the benefit for the users, and that support the daily work of carers and caregivers, needed to be identified and established. The features that emerged from this process as most important were identified as: comfortable and safe; meaningful and familiar; multi-sensory experience; stimulation and relaxation; control and interaction; age-appropriate and usable; flexible and cost-effective (Jakob & Collier, 2017). Based on this design brief, design recommendations for setting up a successful and effective MSE for people with dementia were developed considering aspects such as lighting, accessibility, material, use of technology, climate, and maintenance.

In response to the findings from the study in respect to lack of information and knowledge amongst care practitioners, the research team made these design guidelines and recommendations unlimited available through an online hand book, the first of its kind, titled 'How to make a Sensory Room for people living with

dementia' (Jakob & Collier, 2014). The guide book is accessible via [kingston.ac.uk/sensoryroom](http://kingston.ac.uk/sensoryroom). This was also motivated by the gained understanding of the increasing economic challenges care-homes face today. The guide book aims to enable carers and staff in care-homes to set up a multi-sensory space which are tailored towards the specific requirements and preferences of individuals living with dementia without necessarily the need for cost-intensive input from design experts and consultants.



Figure 1. Examples of sensory enriched environments for people living with dementia. (Photos Anke Jakob)

### 3.2 Co-designing playful objects and sensory textiles for dementia

Many people living with dementia in residential care have little to do, lack purposeful activity and are often bored (Chenoweth et al., 2009), which can lead to an increase in agitation and perceived challenging behaviours making day-to-day care difficult. By providing multi-sensory experiences through playful objects that can interest, distract, comfort and soothe them, there is a reduced need for the use of medication to alleviate these symptoms (Zeisel, 2011). The result is an increased wellbeing of the person living with dementia and a reduced cost, both economic and emotional, to the care provider (Treadaway et al., 2015). Although some dementia care facilities use playful objects, their use is not accepted wholeheartedly and continues to be considered by some to be stigmatising and infantilising to the person living with dementia (Mitchel & O'Donnell, 2013). Consequently, although playful objects and sensory textiles maybe enjoyed by people living with dementia, unless the family members, carers and medical professionals are supportive, these objects may remain in a cupboard or left in a pile in the corner of a room. Where the management and care professionals are supportive of their use, improved wellbeing and enhanced relationships can be achieved and non-verbal communication for both the carer and recipient of care created (Treadaway & Kenning, 2016).

CARIAD researchers have undertaken a series of projects investigating the benefits to wellbeing of playful objects and textiles ([cariadresearchgroup.cariadinteractive.com](http://cariadresearchgroup.cariadinteractive.com)). The LAUGH project is currently

developing playful hand-held objects for people living with advanced dementia in residential care (Treadaway et al., 2016). This work builds on four previous CARIAD textile design research projects revealing the ways in which people with dementia can benefit from experiencing playful artefacts: *Making a difference*, *Dementia Aprons*, *Hand i Pockets* and *Sensor e-Textiles* (Treadaway et al., 2014). Each of these projects used interdisciplinary participatory co-design approaches to develop bespoke textiles, garments and blankets for people living with advanced dementia (Treadaway & Kenning, 2016). Health professionals, carers, family members and people living with dementia participated in the design process through a series of practical hands-on creative design workshops with materials scientists, computer scientists, artists and designers. Further detail, photographs and descriptions of activities undertaken during these workshops can be found on the project website [laughproject.info](http://laughproject.info). Workshop participants were considered an 'expert group', who were not only able to contribute novel ideas in the design process, but also helped to shape the design requirements; they advised on suitability of their use with vulnerable people and any potential dangers. By adopting this inclusive approach to the design process, the research impact became embedded in the care practice of those professionals and family members involved; changing attitudes and building confidence in the use of playful objects and sensory textiles with people living with advanced dementia.

The attitude of management and ethos of the organisations involved have been found to be key to successful adoption of the designed objects in care. Where the management has been interested and supportive, it has been possible to work closely with family members and professional carers to ensure beneficial use of the artefacts with the people they were designed for.



Figure 2. Sensory textile 'dementia aprons' (Photo Cathy Treadaway)

## 4. Introducing a designing attitude

Two important aspects emerged from both research projects in respect to achieving sustainable impact: 1) the active involvement and continued participation of users, carers and care practitioners in the design process (co-design) is essential, and 2) carers and caregivers need to be provided with skills,

tools and methods that enable them to continue designing after the designer has left.

Co-design / participatory design is not only a valuable method of addressing the complex needs of people with dementia when developing designs to support their wellbeing, but also vital for skill and knowledge transfer and dissemination. As the LAUGH project proves, the inclusive approach causes a change in views and attitudes fostering an appreciation of the potential impact of design on improved care methods. Co-design paves the way for creating an environment where adapting a designing attitude and developing a sensibility for appropriate design solutions becomes possible.

Ensuring long-lasting and widespread impact of design interventions, carers and care professionals need to be actively and continuously involved as creators / co-creators. Evidence-based design guidelines, such as the guide book for setting up MSEs for dementia care, are only a first step to provide the means of enabling carers and care providers to facilitate conditions that promote wellbeing. It is important that people who care for individuals living with dementia are offered training and education on design skills and design making - empowering them by mobilising their creativity and helping to adapt a designing attitude in their care practice. Exploring how such knowledge should be conveyed and training delivered is a chance for the design community, in collaboration with experts from health care, to show ways forward taking the lead in solving this problem.

## References

- Anderson, K., Bird, M., MacPherson, S., McDonough, V., & Davis, T. (2011). Findings from a Pilot Investigation of the Effectiveness of a Snoezelen Room in Residential Care: Should We Be Engaging with Our Residents More? *Geriatric Nursing*, 32 (3), 166-177.
- Andrews, J. (2015). *Dementia: The One-Stop Guide - Practical advice for families, professionals, and people living with dementia and Alzheimer's Disease*. London: Profile Books Ltd.
- Chenoweth, L., King, M. T., Jeon, Y. H., et al. (2009). Caring for aged dementia care resident study (CADRES) of person-centred care, dementia-care mapping and usual care. *Lancet Neural*, 8, 317-325.
- Cohen-Mansfield, J., Dakheel-Ali, M., Marx, M. S., Thein, K., & Regier, N. G. (2015). Which unmet needs contribute to behavior problems in persons with advanced dementia? *Psychiatry Research*, 228 (1), 59-64.
- Collier, L. & Jakob, A. (2016) The Multisensory Environment (MSE) in Dementia Care: Examining its Role and Quality from a User Perspective. *Health Environments Research & Design Journal*, doi:10.1177/1937586716683508
- Collier, L., McPherson, K., Ellis-Hill, C., Staal, J., & Bucks, R. (2010). Multisensory Stimulation to Improve Functional Performance in Moderate to Severe Dementia - Interim Results. *American Journal of Alzheimer's Disease and Other Dementias*, 25 (8), 698-703.
- Dalke, H. & Corso, A. (2011). *Living with dementia: Can design make a difference?* London: Kingston University.
- Jakob, A. & Collier, L. (2014). *How to make a Sensory Room for people with dementia - a Guide Book*. Retrieved February 08, 2017, from [www.kingston.ac.uk/sensoryroom](http://www.kingston.ac.uk/sensoryroom)
- Jakob, A. & Collier, L. (2017), Sensory enrichment for people living with dementia: increasing the benefits of Multisensory Environments in dementia care through design. *Design for Health*, 1 (1), 115-133.
- Maseda, A., Sanchez, A., Pilar Marante, M., Gonzalez-Abraldes, I., Bujan, A., Millan-Calenti, J.C. (2014). Effects of Multisensory Stimulation on a Sample of Institutionalized Elderly

- People With Dementia Diagnosis: A Controlled Longitudinal Trial. *American Journal of Alzheimer's Disease and other Dementias*, 29 (5), 463-473.
- Mitchell, G., & O'Donnell, H. (2013). The therapeutic use of doll therapy in dementia. *British Journal of Nursing*, 22 (6), 329-334.
- Prince, M., Comas-Herrera, A., Knapp, M., Guerchet, M., Karagiannidou, M. (2016). *World Alzheimer Report 2016: Improving healthcare for people living with dementia - Coverage, Quality and Costs now and in the future*. London: Alzheimer's Disease International (ADI)
- Strøm, B. S., Ytrehus, S., Grov, E.K. (2016). Sensory stimulation for persons with dementia: a review of the literature. *Journal of Clinical Nursing*, 25 (13-14), 1805-1834.
- Treadaway, C., Kenning, G., Coleman, S. (2014). Designing for Positive Emotion: ludic artefacts to support wellbeing for people with dementia. In *Colors of Care: 9th International Conference on Design and Emotion Bogota*, edited by J. Salamanca, P. Desmet, A. Burbano, et al. Columbia: Design and Emotion Society; Universidad de Los Andes.
- Treadaway, C., Kenning, G., Coleman, S. (2015). Sensor e-Textiles: designing for persons with late stage dementia. In *Proceedings of the 3rd European Conference on Design4Health*, edited by K Christer. Sheffield: Sheffield Halam University
- Treadaway, C. & Kenning, G. (2016). Sensor e-textiles: person centered co-design for people with late stage dementia. *Working with Older People*, 20 (2), 76-85
- Treadaway, C., Kenning, G., Prytherch, D., Fennell, J. (2016). LAUGH: Designing to enhance positive emotion for people living with dementia. In *Celebration & Contemplation: Proceedings of the Tenth International Conference on Design and Emotion*, edited by in P. Desmet, S. F. Fokkinga, G. D. S. Ludden, N. Cila, and H. Van Zuthem. Amsterdam: The Design & Emotion Society.
- Zeisel, J. (2011) *I'm Still Here: Creating a better life for a loved one living with Alzheimer's* London: Piatkus.

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