

Compassionate Design: a methodology for advanced dementia

Cathy Treadaway, Jac Fennell, Aidan Taylor
Cardiff Metropolitan University, UK

Treadaway, C. Fennell, J. and Taylor, A. (2020) 'Compassionate Design: a methodology for advanced dementia'. Pp. 667 in Proceedings of the 6th European Conference on Design4Health, 1st-3rd July 2020. Amsterdam Eds. Christer K. Craig C. and Chamberlain P., 2020. ISBN: 978-1-8381117-0-0

<https://research.shu.ac.uk/design4health/wp-content/uploads/2020/06/D4H-Proceedings-2020-Vol-4-Final.pdf>

ABSTRACT Predicted increases in the numbers of people living into the advanced stages of dementia pose a significant problem for health and care providers around the world. Finding ways to ameliorate the distressing dementia symptoms of anxiety and depression and assist people to live well into the advanced stages of the disease, is vitally important. There are currently few products available for people living in the later stages and understanding the complex needs of individuals on a unique dementia journey, is vitally important for designers of products and services.

This paper will propose that Compassionate Design provides an effective and tested methodology to help ensure that designs are appropriate and meaningful to users living with advanced dementia, or other forms of cognitive impairment as a result of accident or disease. The approach places loving kindness for the individual at the heart of the design process and focuses on three vital aspects of design: sensory stimulation, personalisation and connections with others and the environment.

This paper provides a case study from LAUGH EMPOWERED, a collaboration with UK NHS and an international residential care home company. It evidences how Compassionate Design methodology has informed the development and evaluation of HUG by LAUGH®, a new product designed to bring comfort and reduce anxiety for people living with advanced dementia. HUG® is a soft soothing object that contains embedded technology that provides personalised music and a beating heart. The study is evaluating design, safety and effectiveness of HUG® to support the wellbeing of people living with advanced dementia. Data is collected via the Pool Activity Level (PAL) tool and Bradford Dementia Wellbeing Scale, as well as interviews with caregivers, health professionals and family members. Early findings from the study indicate that HUG® helps to reduce patient anxiety and enhances communication with caregivers.

Keywords: dementia, design, wellbeing

Introduction and Context

This paper presents a design approach: 'Compassionate Design', which has been developed over the last ten years from academic design research for people living with advanced dementia. It has been refined and evaluated in design practice through two funded research projects: LAUGH and LAUGH EMPOWERED. The methodology has been found to be useful in guiding design priorities and evaluating the use of outputs designed to support the wellbeing of those living with cognitive impairment as a result of dementia, disability or disease.

There are currently very few products designed specifically for people living with advanced dementia, despite a huge predicted increase in the numbers of people likely to be living with the disease over the next 30 years. The World Health Organisation estimate that there will be over 152 million people living with dementia globally by 2050ⁱ. Increasing life expectancy means that more people than ever are likely to live into the advanced stages of the degenerative disease in which activities of daily living become impossible without assistance and verbal communication is eventually lost. Finding ways to design appropriate products, services and activities for people to enable them to 'live well' through the final stages of life, is vitally important.

Design Approaches

Wellbeing is defined by the Oxford English Dictionary as 'the state of being comfortable, healthy, or happy'ⁱⁱ. However, wellbeing is generally considered a much broader concept than moment-to-moment happiness and includes an estimation of how satisfied people consider their life as a whole, as well as their sense of purpose and autonomy. A report by the New Economics Foundation for the UK Government, published in 2008, proposed the following 5 themes as being essential for wellbeing: Connect, Give, Take Notice, Keep Learning and Be Active (Aked et al. 2008). These five themes have influenced government policy in the UK and are routinely used as foundations for wellbeing programmes in the UK National Health Service (NHS) healthcare system. Research into wellbeing by positive psychologists have revealed the link between the experience of positive emotion and its impact on physical and mental health (Seligman 2011, Fredrickson 2004). Laughter has been shown to have proven therapeutic benefit to physical health; pleasure, gratitude and hope all help to contribute to greater engagement with life and deepen social connections (Fredrickson 2004). Human beings are social beings and lack of physical contact with others is detrimental to our physical and mental health. Research has shown that physical intimacy, social touch and comforting experiences are vitally important to wellbeing (Tanner 2017).

It is crucial for designers to understand the influence of design on user experience, especially if their aim is to enhance wellbeing. There are a number of design approaches that are routinely used by design practitioners to inform the creation of successful and appropriate designs that help improve a person's quality of life. Experience Design developed out of the work of Donald Norman in the 1980s (Norman 1988). He emphasised the need for designers to focus on 'user experience' leading to user centred design, interaction design and UX design. These design approaches are concerned with emotional, aesthetic and functional attributes of a design as perceived by the user. Positive Design (Desmet and Pohlmeier 2013) developed from Positive Psychology and advocates that designers should focus on three key themes of pleasure, personalisation and virtue in order to

successfully design to support a person's wellbeing. While these approaches enable designers to focus on ways of designing for positive experiences and quality of life, they are not tailored to the specific needs of those who lack cognitive skills or for whom life is severely limited by disability and disease. These people may not be able to experience pleasure in the same way as others, comprehend virtuous acts or be able to define personal preferences themselves. Compassionate Design (Treadaway et al. 2018) is an alternative approach that fills this knowledge gap (Fig1).

Compassionate design

Compassionate Design places loving-kindness for the person at the heart of the design process. It aims specifically to prioritise three key elements in the design process: *Personalised* – design to retain a person's sense of self and maintain their dignity; *Sensory* – design to keep in the present moment and not rely on past or future; *Connecting* – design to encourage moments of high quality connection with others.

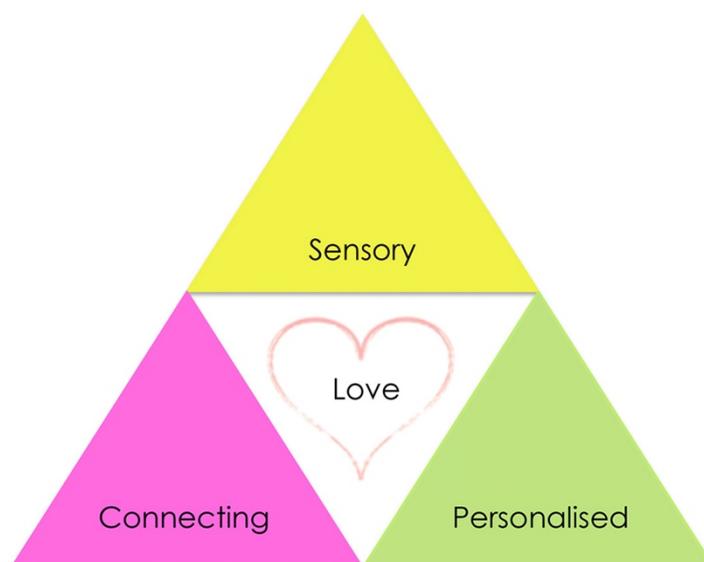


Figure 1: Compassionate Design © C. Treadaway 2016

Personalised

One of the three key themes of Compassionate Design is personalisation. By placing the needs and preferences of the individual at the heart of the design process it is possible to develop bespoke design solutions that can make a real difference to someone's life. A person-centred approach to design takes account of the difficulties they may encounter day by day as a result of living with a disease or disability. It includes their personal preferences as well as information about their life history, including significant relationships and cultural background. A designer can obtain this through empathic observation; by engaging them in conversation (if they have capacity) and via

life story information supplied by carers and loved ones. Past experiences that someone may no longer recall, nevertheless contributes to the person they are now. By focusing on the individual in the context of their lived experience it is possible to design to help maintain their sense of identity and retain their dignity.

The inclusion of autobiographical themes within designs, such as references to a person's job or career, their culture or family, can help to stimulate emotional memories. They may not be able to remember explicitly what is being referenced but the sense of familiarity and associated feelings can be stimulating and pleasurable. Equally, it is important to know whether there are subjects to be avoided, or themes that a person will find emotionally uncomfortable.

Music has been found to be particularly stimulating for people with cognitive impairment and those living with advanced dementia. Personalised playlists can quickly transport an individual back in time and provide an emotional release or lift a low mood. Finding the right musical choices is imperative, but when identified and integrated into designs, can bring extraordinary moments of reawakening.

Sensory

Our moment by moment experience of life is perceived via our senses which can also help trigger emotional memories of past experience. Even when memory is severely compromised, sounds and smells can evoke a sense of place and time instantaneously, and music can transport a person back to how they felt at a particular moment in their life. Sensory re-awakening can stimulate moments of lucid remembering and trigger verbal accounts of memory from those who were considered no longer able to remember or communicate verbally. It can also enhance positive emotion, provide comfort and relieve stress.

The sense of touch is particularly important for those who have restricted mobility and are confined to a chair or bed. Exploring through touch, fiddling and fidgeting can be a way of relieving boredom, agitation and frustration for people living with cognitive impairment. By incorporating tactile surfaces, interesting textures and materials it is possible to specifically design positive opportunities for sensory touch, to relieve stress and enhance pleasure.

Many older people living with dementia also have age related sensory impairments such as hearing loss or poor vision. Dementia can also impact on the interpretation of sound and visual perception resulting in hearing problems and disturbing visual effects. For some people, an overload of sensory stimulation can result in distress, while others need stimulation and benefit from it. When designing for people living with advanced dementia and cognitive impairment, appreciating a person's sensory strengths and limitations is vital. Music can have a particularly profound impact on people living with advanced dementia. Rhythmic sound can help stimulate movement and exercise. It can influence and enhance mood, lift spirits and sometimes enable a person living with advanced dementia to remember words when singing, even when speech is lost. Designs that incorporate playlists of favourite music or provide rhythmic vibration or sound can provide deep emotional comfort and soothe people who are agitated, in pain or distressed.

Connecting

Connections with other people are fundamental to happiness. Research has shown that we are interdependent beings and need high quality relationships with others to flourish and live well (Fredrickson 2014). Loneliness and isolation have huge negative impacts on health and can lead to depression and other medical conditions. One of the distressing impacts of advanced dementia is that people become increasingly disconnected from others and the world around them as the disease progresses. Maintaining relationships is difficult since they may no longer recognise loved ones, the people who care for them or even remember their own identity. This can be very confusing and frightening. Finding ways to stimulate positive emotion and re-establish a sense of connection between people is vitally important. Smiles and laughter help us to connect socially; the touch of a caring hand or gentle embrace, can lift the spirit and diffuse anxiety, agitation and distress.

Social activities can also help people living with advanced dementia maintain positive connections with others. Objects designed for individual use can stimulate conversation, both verbal and non-verbal with carers or visitors. Designs can incorporate aspects of a person's life story, family interests, cultural motifs and familiar places to help rekindle positive and affirming emotional memories on which conversations can be based.

Objects are also vital for maintaining an outward connection from the body into the world. They provide a person with a sense of autonomy, opportunity for interaction and a self-determined choice about whether to respond. These activities, although small, can be highly significant for maintaining the personhood of someone with severely impaired mental capacity.

HUG by LAUGH

Compassionate Design was developed and tested through LAUGH research, a design research project that investigated ways to support the wellbeing of people living with advanced dementia through the development of playful objects. This three-year international interdisciplinary research brought together a team of researchers from three universities, in UK and Australia, and involved over 170 participants representing 70 organisations, including people living with dementia.

LAUGH research

LAUGH research sought to understand how playfulness, positive emotion and hand-use contribute to a sense of wellbeing for people in the advanced stages of dementia. Using participatory and co-design approaches underpinned by Compassionate Design, a set of 6 key themes were developed that were later used to shape six bespoke handheld playful objects designed for residents living in specialist dementia facilities in two Pobl Gwalia Care homes in South Wales (Treadaway, Taylor, and Fennell 2019). Personal profiles (called 'Portraits') were developed to collect information about resident's individual preferences, lifestyle choices, favourite music, colours, favourite smells and family histories using qualitative interviews with

family members, carers and the person living with dementia. The portraits were used as the starting point for design concepts. The 6 key themes identified from data analysis of the participatory workshops with health and care professionals, relatives of people living with dementia, also informed each design concept.

LAUGH playful objects were evaluated via a process of deep observation by researchers and carers. Each person who received an object was in the advanced stages of dementia and unable to communicate verbally. They were visited by the research team on three occasions over the three-month period during the evaluation. The analysis also included qualitative interviews with professional carers, who knew the residents well, and could observe them every day. These interviews were used to corroborate the observational data from the evaluation.

One particular prototype design was found to have a significant positive impact on the health and wellbeing of the person it was designed for. HUG by LAUGH® is a soft wearable doll-like object that is designed to soothe and reduce anxiety (Fig. 2). It was created in response to the theme '*Nurturing*', one of the six key themes that had emerged from the participatory design workshops. HUG® is designed to nurture the user via the experience of its weighted limbs (that provide a hugging sensation), while simultaneously providing an opportunity for the user to cuddle (nurture) the object. HUG® contains electronics, which provide a simulated beating heart and can also be programmed with a playlist of a person's favourite music.

LAUGH EMPOWERED

HUG by LAUGH® was designed for Thelma, a person living with advanced dementia who was on end of life care. She could no longer communicate verbally, was bedbound, unable to socialise and constantly fell when out of bed. At the end of the three-month evaluation, there was a significant improvement in her general health and quality of life. She began to speak again, was no longer in bed all day, her appetite returned and, after being given HUG, she had no further falls. Her carers considered that Thelma believed she had a child to care for and so a purpose to continue to live.

Interest from NHS in Thelma's story led to follow-on research (funded by Welsh Government ERDF), to evaluate HUG® via a larger study, in both hospital and residential care home settings. The LAUGH EMPOWERED PSCI is currently on-going and includes qualitative evaluation using the Pool Activity Level (PAL) tool and Bradford Dementia Wellbeing Scale and involves 40 participants. The early findings from the study corroborate the earlier LAUGH research evaluation with Thelma and shows significant positive benefit of using HUG for people living with cognitive impairment. HUG by LAUGH is currently in the early stages of manufacture and is being developed via partnering with Alzheimer's Society through their Accelerator Programme.



Figure 2: HUG by LAUGH®

Discussion

Compassionate Design methodology was used to underpin the design of HUG by LAUGH® and the three key themes of *sensory*, *personalised* and *connecting* were prioritised in its development. Textiles were used to provide a variety of tactile experiences and materials selected that were soft and comforting to touch; the music and rhythmic heartbeat contribute to HUG's® *sensory* qualities. The potential to upload a person's favourite playlist onto the magic box enables HUG to be *personalised*. It *connects* with the person physically on the body and also provides opportunities to stimulate conversations with others and so connect the person socially to those around them. The LAUGH and LAUGH EMPOWERED projects have tested Compassionate Design methodology in design practice, through concept development to manufacture. It has resulted in a product that is having a significant positive impact on the quality of life of people living with dementia and cognitive impairment, both in hospital and living in residential care. The methodology is now part of the design curriculum, being taught to undergraduate and post-graduate students at Cardiff School of Art and Design, Cardiff Metropolitan University.

Acknowledgements

We would like to acknowledge our funders Arts and Humanities Research Council (Grant reference AH/M005607/1), Welsh Government ERDF (Grant reference 2018/COL/012/80839) and Alzheimer's Society Accelerator Programme partnership. We would also like to thank our project partners Pobl Group Gwalia Care, Sunrise Senior Living Ltd. and NHS Llandough Hospital, CAVUHB staff, patients and residents.

References

- Aked, Jody, Nic Marks, Corrina Cordon and Sam Thompson. 2008. 5 Ways to Wellbeing: A report presented to the Foresight Project on communicating the evidence base for improving people's well-being. The New Economics Foundation.
- Desmet, P.M.A. and A.E. Pohlmeier. 2013. "Positive design: An introduction to design for subjective well-being." *International Journal of Design*, 7 (3): 5-19.

Fredrickson, B. L. 2004. "The broaden and build theory of positive emotions." *The Philosophical Transactions of the Royal Society* 359:1367-1377.

Fredrickson, B. L. 2014. *Love 2.0: Creating Happiness and Health in Moments of Connection*. New York: Penguin Group.

Norman, Donald, A. 1988. *The psychology of everyday things*. New York: Basic Books.

Seligman, Martin E. P. 2011. *Flourish: a new understanding of happiness and well-being - and how to achieve them*. London: Nicholas Brealey Publishing.

Tanner, Luke. 2017. *Embracing Touch in Dementia Care*. London: Jessica Kingsley.

Treadaway, C., J. Fennell, D. Prytherch, G. Kenning, A. Prior, and A. Walters. 2018. *Compassionate Design: How to Design for Advanced Dementia* Cardiff: Cardiff Metropolitan University. Research output AHRC Grant AH/M005607/1.

Treadaway, Cathy, Aidan Taylor, and Jac Fennell. 2019. "Compassionate design for dementia care." *International Journal of Design Creativity and Innovation* 7 (3):144-157. doi: 10.1080/21650349.2018.1501280.

ⁱ <https://www.who.int/features/factfiles/dementia/en/>

ⁱⁱ https://www.lexico.com/definition/well_being

ⁱⁱⁱ See: www.laughproject.info