



COMPASSIONATE CREATIVITY: CO-DESIGN FOR ADVANCED DEMENTIA

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Abstract: One of the most pressing challenges facing designers today is how to create appropriate, useful and safe designs for people living with advanced dementia. Dementia is a complex disease that presents and progresses differently for each individual. This paper contends that co-design with experts, including people living with dementia and their carers, is essential to inform design. Compassionate Design principles are useful to guide the creative process and ensure that concepts are developed that maintain the dignity, personhood and wellbeing of the person living with dementia. The key themes of Compassionate Design are presented through examples of designs for playful objects created as part of the LAUGH design for dementia research.

Keywords: *Creativity, co-design, dementia*

1. Introduction and context

One of the most pressing problems facing society today concerns how to ‘live well’ through older age and until the end of life. In particular the World Health Organisation and Alzheimer’s International have identified the global increase in numbers of people living with dementia as a major challenge (WHO, 2012; Prince, Wimo et al., 2015). National and international policy makers are pressing for medical dementia research to be made a priority since there are huge economic and social benefits to finding a cure. Unfortunately, no cure for the disease is imminent and the numbers of people around the world living with, and caring for people living with dementia is predicted to increase significantly in the future.

Dementia is a syndrome, or collection of neurodegenerative diseases of the brain that impact upon behaviour, perception, cognition and communication. There are over 100 different forms of dementia and each one presents in different ways, with a variety of trajectories through the progression of the disease. How dementia unfolds for each individual is significantly different, making treatment and care particularly challenging. Since there is little imminent hope of finding a cure, it is vital to find ways of caring for people so that they may ‘live well’ with the disease and have a good quality of life for as long as possible. While the medical world searches for a solution, the design world has an opportunity to address these problems in order to help improve the lives of all those affected by the disease (Ógáin and Mountain, 2015).

In design terms, dementia can be described as a ‘wicked design problem’ (Rittel and Webber, 1973; Buchanan, 1992; Coyne, 2005) The problem is complex; the knowledge required to address the design issues cuts across a number of disciplines and subject expertise (Krippendorff, 2006). Involving participants with dementia in the design process is vital and their inclusion essential, if design solutions are to be appropriate, useful and meaningful. Participants living with dementia often have severe communication difficulties, are in a declining state of health (often rapidly) and there is high attrition from any study as people reach the end of their lives. Gaining ethics approval to include them in the creative process or have their input in evaluation or user studies is complicated. Memory impairment issues demand that gaining consent must be a constant and iterative process as a person may not remember the previous occasion they gave consent to be involved. Consequently there is currently a dearth of design research in the field involving people in the advanced stages of the disease, despite the enormous and growing need for better designed products, environments and services for this market sector (Ógáin and Mountain, 2015).

One project that has been undertaking design research with people living with advanced dementia is the LAUGH project, a three-year study based in Wales and funded by the UK Arts and Humanities Research Council. The aim of the investigation has been to understand how to design and develop playful objects to support the subjective wellbeing (happiness) of people living with advanced dementia. The goal of this paper is to present some of the findings from the study and explains how Compassionate Design approaches (www.compassionatedesign.org) can inform designs that have the potential to make a real difference to peoples’ lives in the context of advanced dementia.

1.1. Playfulness

LAUGH is an acronym: Ludic Artefacts Using Gesture and Haptics and the project is predicated on the understanding that playfulness, fun and laughter benefit wellbeing (Fredrickson, 2004; Killick, 2013; Tonkin and Whitaker, 2016). Hand-use has also been found to benefit positive thinking and lift depression (Lambert, 2008) and so the LAUGH research has specifically sought to develop concepts for hand held objects that stimulate positive emotions for people living with advanced dementia in residential care. Playfulness is particularly important for people living with advanced dementia since the disease compromises semantic and declarative memory (i.e. memories of events, places, names etc). In addition, perception can be altered (colours, shapes, sound) and the familiar often becomes unfamiliar (faces, objects and places). Playful play (ludic play) however is something that takes place in the moment and does not rely on memory of facts or events; it is not goal orientated, there is no right or wrong and it is very useful for stimulating fun and laughter (Woodyer, 2012). Playful play at its most complicated may involve imagination but can be as simple as fiddling, twiddling or ‘potching’ with the hands. For people who are chair or bed bound and unable to physically do very much, simple ludic activities can bring great satisfaction and generate pleasure. Although research has found that playful play benefits health and wellbeing (Rogerson, Treadaway et al., 2013), a negative attitude towards adults playing and having toys continues to be prevalent in society (Kane, 2005). Relatives often feel uncomfortable about seeing their loved one living in residential care playing with a doll or teddy bear and may feel that it infantilises them and denies their dignity (Mitchell and O'Donnell, 2013; Mitchell, 2016). LAUGH research has sought to understand how to overcome this negative preconception and examine the key issues concerning playful play, memory, hand-use and ways to elicit positive emotion in the context of the later stages of the disease (Treadaway, Prytherch et al., 2016). Working in collaboration with Pobl Group Gwalia Care, the research has endeavoured to keep people living with advanced dementia and their families at the heart of the research.

2. Research methodology

The LAUGH project has used a qualitative methodology and involved a great many people (n=81) as participants in the research. The participatory nature of the work has enabled an interdisciplinary group of stakeholders from a variety of backgrounds to inform the study, including people living with dementia. The participants have included health professionals, carers, care managers, representatives from dementia charities, technologists, artists, designers and academics. Each one has contributed their

expertise and professional experience through a series of six participatory creative workshops held over the first two years of the project (Treadaway, Kenning et al., 2016). Participants were invited to the workshops from a database of over 100 individuals who had expressed interest in the research or had been involved in previous CARIAD projects. In addition, the research team undertook a case study comprising a series of six semi-structured interviews with key individuals who had personal experience of caring for someone with advanced dementia. Interview candidates were people selected for their experience and expertise by the project team in conjunction with the LAUGH Advisory Group (comprising the project partner and representatives of dementia charities and government organisations). Both inductive and deductive approaches were used to analyse the data and draw out key themes that were later used to inform the design process. These were cross-referenced with themes emerging from the literature review and case study interviews as described in detail in Treadaway, Fennell et al. (2016), and on the LAUGH website www.laughproject.info. Creativity and playfulness was key to each of the six workshops. Participants were encouraged to make with materials, create concepts and capture them in sketches and words, tell stories, use props (such as dressing up) and play games. The discussion that emerged from these creative activities helped inform the design process. As physical concepts began to be developed, an iterative process of refinement and testing was undertaken, initially with workshop participants to ensure they were safe and then in a series of ‘live labs’ (Brankaert, den Ouden et al., 2015) with residents living with advanced dementia in conjunction with their families and carers.

2.1 Compassionate Design

Compassionate Design underpins the LAUGH design process (Figure 1.). This approach builds on Positive Design methodology (Desmet and Pohlmeier, 2013) and is specifically concerned with designing for positive affect in advanced dementia. It focuses on three vital components that are key when designing for people who are cognitively impaired: design that stimulates the senses, that is highly personalised and that helps to foster connections between people.

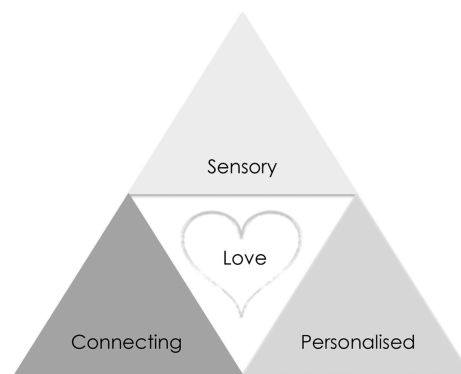


Figure 1. Compassionate Design (Treadaway 2015)

Compassionate Design places love at the heart of the design process, ensuring that design validates and maintains the dignity of the individual and provides them with sensory stimulation that connects them to others and the physical world around them (even when it is perceived differently by them and they may not be able to remember who they are). It was essential for the research team to work very closely with the individuals living with dementia, their daily professional carers and their families, in order to create highly appropriate personalised designs. Participants (n=8) were selected following recommendation by the partner organisation’s care home staff and managers. In several cases, despite requesting participants living with advanced dementia who had families willing to contribute to the research, staff proposed participants who had no family to visit them as they felt these people would benefit most from the objects being developed. In these cases the professional carers considered themselves surrogate family, as the residents had been so long in their care. For each resident, a profile

or ‘portrait’ was developed, detailing in words and images their preferences and elements of their life history and with potential to inform design concepts. Portrait information was subsequently used in the participatory design workshops to initiate ideas and guide emerging concepts. The following sections of the paper explain and provide examples of how Compassionate Design has been used to underpin the LAUGH creative process.

3. Technology

Although not all the playful objects designed for LAUGH contain embedded technology, most of them do. In nearly every case this is to extend the sensory properties of the object through sound, light or vibration or to include highly personal preferences such as music or sounds. Initially, simple microcontrollers and open source software was used to prototype ideas in order to maintain an emergent and agile design process, capable of including ideas from expert participants and others in the research team. The open-source Arduino platform has been used widely in the development of LAUGH playful objects. Third party adaptations, (Bare Conductive and Teensy platforms) have also been used to provide extended capabilities in sound and haptics, whilst still being programmable via the Arduino software. In particular the Teensy hardware has been used extensively for more advanced physical computing applications that required a dynamic audio output. All the objects with integrated technology are battery powered using lithium-polymer cells, allowing for good battery life, portability and recharging. Integration of electronics into the LAUGH objects has enabled the prototypes to be highly personalised. The following sections describe three of the LAUGH objects.

4. LAUGH Designs

4.1 Hug

Hug (Figure 2) was originally developed for a participant who died in the early stages of design development and before the concept had been prototyped. A second participant was sought who might benefit from the embryonic hug concept and whom the care professionals felt had similar background and preferences to the original lady. Another participant was selected who was in the advanced stage of the disease, withdrawn with little verbal communication; poor appetite, chair bound and with little ability to socialise with the other residents. She had been a resident in the care home for many years (10+) and rarely had a visitor or contact with her family. The care home manager and staff proposed themselves as surrogate family and provided life history details and personal preference information. The carers concluded that the most important thing that could be given to this resident was a hug.

A participatory design workshop scoped the concept and sketches of a long armed, soft cushion-like wearable object were proposed, that contained a beating heart and played music. The aim was to make a sensory object, using soft furry fabric that was comforting to touch, and to extend the sensory properties through the addition of a rhythmic heartbeat. The object was personalised through the addition of favourite music tracks activated by hugging or movement.

Several iterations of the design were prototyped by the LAUGH team, first in calico and then in a washable synthetic fur fabric. The arms and legs were extended to wrap around the body and the hands and feet weighted to replicate the sensation of a hug. A very simple floppy head with sleepy eyes, nose and mouth provided the soft shape with a baby doll effect without being specifically doll or teddy-like. The electronics were developed to go inside a small leather pouch contained within the object. These consisted of a Teensy 3.2, SD-card reader for storing sound files, an amplifier with miniature speakers and a vibration motor similar to those found in mobile phones for the heartbeat. A pair of mechanical tilt sensors connected to the Teensy activates ‘Hug’.



Figure 2. Hug

When the participant was first given 'Hug' she responded positively by holding it close, resting her head on it and closing her eyes as well as speaking a few words, to the amazement of the care staff. When the research team left and the resident returned to the dementia unit, her carer observed that she continued to hold it close and that when staff tried to remove it from her she cried and wanted it back. Three further live lab evaluation sessions (over a period of two months) in which the participant's facial expressions and body language were observed, confirm that she experienced comfort and pleasure from 'Hug'. The care professionals have provided further confirmation of this and report that her overall health has improved, falls have reduced, her appetite has returned and that she now speaks a little and socialises with other residents. Her carer confirmed this saying:

'I can see the difference and what's happened to her. She's come on so much better, she's happier, she's eating more, it's amazing!... You can see, she's so content in herself....We make sure she's got her 'Hug' and we know she's happy. We come back and she's smiling, and she hasn't gone to sleep so much. She's smiling and happy.'

4.2 Steering Wheel

One of the most significant findings from the early LAUGH research concerned the particularly negative affect of the diagnosis of dementia on men who found they were no longer able to drive a vehicle. This finding stimulated ideas around the development of a playful object that might bring back the positive emotions experienced through driving. The steering wheel is a stand-alone playful object that provides the haptic sensation of driving a car (Figure 3). It contains electronics that provide vibration (felt through holding the wheel as if an engine is running), has working indicators, dashboard with winking lights and a tune-in radio with bespoke music. The wheel was developed for a male resident who had worked as a car mechanic and loved driving throughout his life. The concept was scoped at a LAUGH participatory design workshop, informed by the participants 'portrait' information. Sketches and technical ideas were explored and captured, and the LAUGH team subsequently refined concepts and developed prototypes. The electronics were able to extend the sensory properties of the object and ensure it was personalised through inclusion of the participant's favourite music. The electronic design was again based around the Teensy 3.2 with an SD-card reader for accessing audio files. The radio works with the adjustment of a pair of potentiometers, one for volume and the other for tuning. The simulated radio tuning is, in reality, a fade between the selected music tracks and a recording of radio static. Switches and tilting activate the vibration and indicator LEDs of the Steering Wheel.



Figure 3. Steering wheel

On the first live lab evaluation the resident was recovering from surgery and reticent to hold the wheel or bring it close to his body. However, he did show interest in the object and was observed by the research team to become less agitated and stressed. On the second Live Lab evaluation day the resident's health was still very poor. Despite being told initially he was too unwell to participate, carers wheeled him through to the lounge area in a wheelchair with him holding the steering wheel as if he was in control of his vehicle. There followed a very playful session lasting about 20 minutes when two carers sat next to his wheelchair and play-acted a road trip to the seaside to buy ice cream. This included driving around bendy roads, parking the car, tuning-in the radio and driving home. The research team observed and noted the participant's body language and facial expressions and it was clear to all he was having a very good time. The care home manager reflected on this activity saying: *'We had a very personal journey, on a trip and he was driving us to Porthcawl. It was absolutely the most interaction I have ever seen from him. It was absolutely amazing... it was!'* The steering wheel has been used subsequently by the resident and carers and has continued to bring him pleasure.

4.3 Fidget Jewellery

Most of the LAUGH objects contain embedded technology; this enables them to be highly personalised and to extend the sensory properties. Some of the LAUGH objects however, have no embedded electronics and are very simple to make, using found and recycled materials. People living with advanced dementia often gain great pleasure from fiddling with physical objects (Tanner, 2017). The sensory properties are both satisfying and soothing and can help calm agitation. A series of simple hand-held decorative objects were designed for a resident who particularly liked jewellery and had enjoyed handcraft activities through her active life. This particular resident was in the final stages of the disease and, although she had a sunny disposition and was often smiling, she had limited verbal communication and interaction with others. Four pieces of jewellery were designed based around her love of beads, particularly pearls, and her previous interest in sewing and knitting. She particularly liked jewellery boxes and so the prototypes were presented to her in a wooden jewellery box.

The shell piece (Figure 4) comprised a series of threaded shells and pearls strung from a piece of honed driftwood. This wrapped around the base of the fingers and strands of beads and shells hung down into the palm of the hand where they could be looked at and manipulated with the fingers on the other hand. In the first live lab evaluation, the piece stimulated interest and, according to her carer, prompted her to speak the longest sentence she had spoken in many weeks. This was particularly significant because her response also indicated that the piece had prompted a memory from the past; this astounded the carers who were present. A carer reinforced interaction with the object during the

second live lab by singing seaside related songs and rhymes. For several minutes they were observed to be communicating and were intimately connected via interaction with the object.



Figure 4. Fidget jewellery

The jewellery pieces provide a good example of simple design solutions that are easy to make, personalise and cost very little. They provide sensory stimulation, are easily personalised and make it possible to connect and communicate with others in simple tactile ways even when the disease compromises speech and cognitive skills. Handholding and touch can provide great comfort for people living with advanced dementia. This study indicates how tactile objects, that encourage hand-use and interaction via the hands, are beneficial for both the person living with dementia and the carer.

5. Discussion

The three objects described in section 4 provide examples of ways in which Compassionate Design has informed the design process by prioritising *sensory stimulation*, *personalisation* and *connection* as key themes. Given the predicted increase in the numbers of people living with advanced dementia, there is clearly a growing market for innovations that assist their care. LAUGH research has revealed the complexities involved in addressing the needs of people living with advanced dementia through design. It has also validated interdisciplinary participatory approaches and co-design as useful ways of embedding expert knowledge within the creative process. Guided by Compassionate Design principles, the creative process has focused on addressing the vital requirements of people living with advanced dementia. Evaluation of LAUGH playful objects has found that this approach has helped to ensure that the design solutions are appropriate, sensitive and can help maintain the wellbeing, dignity and personhood of some of the most vulnerable people in society. It has also evidenced some of the fundamental difficulties in design research in this field, including participant attrition and ethical considerations, already mentioned in section 1. Participatory research involves a range of experts and although this can be both expensive and time consuming, it is vital, in order to embed professional knowledge and ensure safety of the designs. Evaluation and user testing can be problematic since end users often have communication and perceptual difficulties. Empathy and patience are required on the part of the researcher to observe and interpret the impact of the designed solutions in context. Integration of new products in dementia care requires health professionals' acceptance and endorsement; this can be difficult without quantitative measures and random controlled trials. Robust evaluation frameworks need to be developed that can illuminate the benefits of compassionately

designed innovations in the field. The goal of the paper has been to present findings from the LAUGH project and to contribute examples of design practice and Live Lab evaluation to this debate.

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