

Compassionate Design for Dementia Care

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To cite this article: Cathy Treadaway, Aidan Taylor & Jac Fennell (2018): Compassionate design for dementia care, *International Journal of Design Creativity and Innovation*, DOI: 10.1080/21650349.2018.1501280

To link to this article: <https://doi.org/10.1080/21650349.2018.1501280>

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This work was supported by the Arts and Humanities Research Council under Grant: AH/M005607/1

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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. A qualitative participatory co-design research methodology is described along with findings informed by a Live Lab evaluation of the objects with people living with advanced dementia living in residential care.

Keywords: Creativity, co-design, dementia, Compassionate Design, care

1. Introduction and context

A key challenge facing society today concerns how to support people 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 (Prince et al., 2015; WHO, 2012). 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 near future (Livingston et al., 2017; Prince et al., 2015).

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 (AlzheimersResearch-UK, 2016). 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 & Mountain, 2015).

In design terms, dementia can be described as a 'wicked design problem' (Buchanan, 1992; Coyne 2005; Rittel & Webber, 1973). This is because 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; however, this is not without challenges.

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 & Mountain, 2015). Recent design research that has focused on people living with advanced dementia includes designs for sensory environments (Jakob, Manchester, & Treadaway, 2017), tangible and assistive technologies (B. Bennett et al., 2017; P. Bennett, Hinder, & Cater, 2016) and communication (Branco, Quental, & Ribeiro, 2017).

One recent design research project that has focused on designing to support the wellbeing of 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 the Compassionate Design methodology that has been developed (by the lead author) over the last five years, informed and tested by LAUGH research, and used to underpin the creative approach used in the development of the LAUGH playful objects. This paper explains and provides practical examples of how Compassionate Design

(www.compassionatedesign.org) can inform the development of products 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 & Whitaker, 2016). Hand-use has also been found to benefit positive thinking and lift depression (Lambert, 2008) and so the LAUGH research team have specifically developed concepts for hand-held objects to 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.) (Killick, 2013). 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, Lorimer, Billington, & Fyfe, 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, 2016; Mitchell & O'Donnell, 2013). 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 (C Treadaway, Prytherch, Kenning, & Fennell, 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 interpretivist methodology and involved a great many people (n=80+) as participants at different stages in the research with the end goal of designing playful objects for people living with advanced dementia. Action research and grounded theory approaches were used in which both verbal and non-verbal social interaction and engagement in activities were observed in detail (Craig & Tracy, 2014). Participatory workshops, visits and interviews in the care homes, a series of Live Lab evaluations and team reflections were used to gather data. Audio and video recording, collaborative creative worksheets capturing ideas and commentary, participant feedback sheets, still photography and research journals were used as research tools in the process.

The initial phase of the research involved a period of knowledge gathering via participatory workshops and case study interviews (step 1). This was followed by a period of reflection (step 2) leading to an iterative cycle of making (step 3) and testing involving Live Lab evaluations with people living with advanced dementia in residential care (step 4). This evaluation approach has been successfully used by other

design researchers working in the field (Brankaert, den Ouden, & Brombacher, 2015).

The LAUGH study is on-going and the evaluation process has yet to be completed.

This paper focuses on early findings and observations in relation to Compassionate Design.

Research process	Purpose	Methods	No.	Number of participants	Types of participants	Outcomes
Step 1	Knowledge Gathering	Participatory workshops	3	25 per workshop	Dementia experts, technologists, care professionals, family carers, designers	Knowledge to initiate and guide design concepts
		Case study interviews	6	5 x 1 1 x 8	Dementia experts, care professionals, family carers, SURP members	In-depth personal reflections and knowledge
Step 2	Reflection	Participatory workshop	1	25	Care professionals Dementia experts	Identification of key themes
		Data analysis from workshops		7	Research Team	Themes to inform design
		Development of 'Portrait' Information	7	7 + 15 (family members and carers)	People living with advanced dementia, carers and family members	'Portrait' personal information to inform designs
Step 3	Design & Prototyping	Co-design workshop	1	25	Dementia experts, technologists care professionals family carers designers	Initial broad concepts based on 'Portrait' information
		Creative design and prototyping		3	Research design team	Focused design development
Step 4	Test and evaluate	Participatory workshop	1	25	Dementia experts, technologists care professionals family carers designers	Testing and feedback on design prototypes
		Live Labs	4	6+	Care professionals Research team	Iterative process of feedback on designs and evaluation

Table 1. Research Process

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 (step 1). 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 (C. Treadaway, Kenning, Prytherch, & Fennell, 2016). Participants (n=25) 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 projects led by the LAUGH Principal Investigator. The goal of the initial 3 participatory workshops was to interrogate the themes of *playfulness*, *hand-use*, *memory and positive emotion* in the context of advanced dementia. 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. Participants included key experts on dementia who either lived with or cared for someone living with the disease. Their comments and reflections enabled the research team to understand the complex factors that influence ways in which people in the advanced stages of the disease experience the world and the implications for the development of playful objects to support their wellbeing.

In addition to the participatory group workshops, 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 (step 2) 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 (C. Treadaway, Fennell, Kenning, Prytherch, & A. Walters, 2016) and on the LAUGH website: www.laughproject.info. The six key themes that emerged resonate with universal human needs. These include 1). *Nurturing*: the desire to nurture and be nurtured 2). *Security*: to feel safe and secure 3). *Purposeful*: to have agency and a sense of purpose 4). *Movement*: to move and to interact with others 5). *Replay*: to be creative and playful 6). *Attention*: to attend to the moment.

The design research team worked intimately with seven people living with advanced dementia, their families and carers to develop concepts based on their personal preferences and life history. As prototype concepts began to be developed (step 3), an iterative process of refinement and testing was undertaken, initially with key experts in dementia care to (ensure they were safe and appropriate) and then in a series of ‘Live Labs’ (step 4) with residents living with advanced dementia in conjunction with their families and carers. The Live Labs took place over a period of five months, in two residential care homes in south Wales. Rich data comprising: audio and video recording, photography, carer feed back, researcher observations in situ and post hoc reflections, were fed into an evaluation matrix along with wellbeing assessments of each person living with dementia, completed by care staff before and after introduction of the objects. Design concepts were refined and adapted in light of the responses observed in the Live Lab evaluation in an iterative design development cycle. Evaluation of the impact of the LAUGH playful objects on participant

wellbeing will continue over the next two years, with the UK National Health Service, in a second phase of the research.

2.2 Compassionate Design

Compassionate Design underpins the LAUGH design process (Figure 1.). This approach builds on Positive Design methodology (Desmet & Pohlmeier, 2013) and is specifically concerned with designing for positive affect in advanced dementia.

Compassion is described as '*a sense of concern that arises when we are confronted with another's suffering and feel motivated to see that suffering relieved*', Thupten cited in Dali Lama, Tutu, & Abrams, (2016 pp. 252). It is a pro-active word that implies agency, action and suggests the need to 'get involved' and effect change. As a design approach, it assumes the designer to be an active participant in strategies to make a positive difference to the lives of others who are suffering. It demands the design researcher to be empathic and responsive to the person for whom they are designing and informed about the context in which they live and the challenges they face. Compassionate Design 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. It 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).

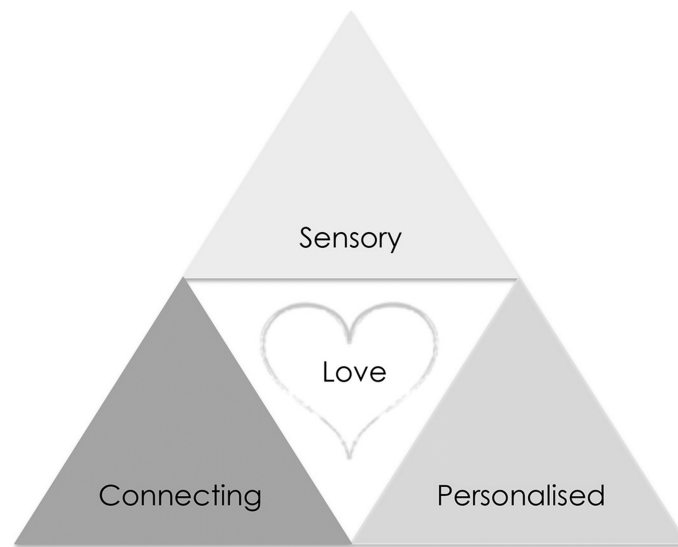


Figure 1. Compassionate Design

The LAUGH research team have tested this approach throughout the three-year project and have chosen to work very closely with individuals living with dementia, their daily professional carers and families, in order to create highly appropriate personalised designs. This has been demanding and emotionally challenging at times, requiring the researchers to embrace the difficulties of individuals living with advanced dementia and the inevitable loss and grief encountered by families and loved ones affected by the devastating disease.

People living with advanced dementia (n=7) were selected as participants for the LAUGH project (step2) following recommendation by care home staff and managers from the partner organisation. In several cases, despite a request for participants who had families willing to get involved and contribute to the research,

staff proposed participants who had no family to visit them. They felt these people were in greatest need of playful objects and would benefit most from the products being developed. In these cases the professional carers proposed themselves as surrogate family, since the residents had resided so long in their care and they knew them intimately. For each participant, a profile or ‘portrait’ was developed, detailing in words and images their preferences and elements of their life history with potential to inform design concepts. Participants attending the LAUGH participatory design workshops used this portrait information 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.

4. LAUGH Designs

The following sections describe four of the seven LAUGH objects developed and present observations acquired during the Live Lab evaluations (step 4). They provide insights into the participants' response to the prototype objects that were developed. They are informed by carer interviews, research team observations in situ, and post hoc analysis of video of participants interacting with the prototypes. Body language and emotional expression was noted by the researchers, and observations corroborated by family members and professional carers with intimate knowledge of the person living with advanced dementia.

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. The participant who was selected 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

Findings from the early qualitative LAUGH research (step 1) which involved interviews with a mixed gender Alzheimer’s Society Service Users Review Panel (people living with early stage dementia) (n=8) identified the particularly negative affect of the diagnosis of dementia on people, particularly men in this group, 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. The carer commented during the evaluation that:

‘[the fidget jewellery is] like a tool for a carer ... you can make conversation out of it and have it as a focus point, so for me, that’s like a tool for me to interact with her, which then impacts on her wellbeing.’



Figure 4. Fidget jewellery

The jewellery pieces provide a good example of simple design solutions that are easy to make 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. Hand-holding 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.

4.4 Giggle Balls

Giggle Balls are soft felt balls, in the shape of small smiling faces that giggle when held in the palm of the hand (Figure 5). This concept was developed for a participant who passed away in the early stages of the design development phase. The LAUGH team decided to continue to develop the idea but to make it a social activity to be used by several residents sitting together in the lounge. The concept emulates the idea of passing around a box of chocolates in a social gathering so that each person can select their choice from the box. The aim was to connect residents through a shared activity that generates laughter, as well as reinforcing their sense of autonomy by enabling them to choose their own ball. The experience of touching, holding and squeezing the felt material also provides sensory stimulation that is enhanced by the giggling sound.



Figure 5. Giggle Balls

The Giggle Balls are about the size of a tennis ball. Each one contains a small microcontroller and speaker with sound files of children giggling that are activated through a tilt switch via gentle hand movement. Laughter is contagious, particularly the sound of children's laughter, and so the embedded sound files were intended to stimulate spontaneous joy. The balls are soft, washable, robust, safe to throw and comforting to hold. The felt was made from lambs' wool and crafted by hand, using a combination of wet felting and needle felting. The open mouth contains a small felted inner pouch containing the electronics. This inner pouch is velcroed to the inside of the outer felt ball and is intentionally difficult to remove, to avoid becoming a choking hazard for a person living with dementia.

The response to the Giggle Balls from the residents living with dementia was mixed, however they proved to be unanimously popular with the carers. The role of caring for someone in the advanced stages of the disease can be very demanding and emotionally draining. Opportunities to laugh, in the midst of a difficult day, can be a huge relief and very beneficial for a carer. Prior to the Live Lab evaluation, carers and

health professionals had been asked to give their opinion about the potential of each of the LAUGH objects and the Giggle Balls were anticipated to be very successful with people living with dementia. However, during the evaluation some residents found them very funny but others violently disliked them, finding them disturbing and frightening. This polarisation of reaction validates the importance of personalisation and emphasises the need for designers to understand how each individual living with dementia has a unique experience of the world. During the evaluation interviews with care staff, one carer also made the following observation:

‘Everybody, even people without dementia experience different emotions throughout the day and I think the Giggle Balls could be used at certain points in the day when they’re feeling a certain way and that could affect anyone. But then the same person 10 minutes later might not like that Giggle Ball, you know. And it’s about having the tools there to try and change the moment for them, when you know, you have to be in that moment with them and by having these things just laying around casually, you can just use them as and when, do you know what I mean? I think that would be awesome and I think every care home that has dementia units should have things like that, I really do I think it would make a massive impact.’

5. Discussion

The four 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. The responses to the playful objects, by the people they were designed for and their carers, have been very positive. There is evidence that they have brought pleasure, stimulated interest, generated conversation and brought significant health benefits evidenced in reduction in the number of falls, increased appetite, physical activity and social interaction. Several carers commented on the positive impact the playful objects had in caring for

residents and felt they had helped to make their jobs easier and more rewarding:

‘I found for me, using these toys with the individuals makes me love my job more, it really makes me feel like it gives me time to connect and be in the moment and I just think it’s a beautiful thing really, you know, I really feel nice about it.’

One carer commented on the importance of embracing playful objects and activities in the care of people living with dementia:

‘It’s person centred care not just personal care and hygiene and food and all these things ‘cos there’s much more to a person’s happiness than the basic needs. And why should we stop there, you know, they live here, that’s it, they’re not going to go elsewhere, they stay here and why shouldn’t we provide that fuller care.

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. Live Lab 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. The project 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 therefore required on the part of the researcher, to observe and interpret the impact of the designed solutions in context and then iteratively refine the outcomes.

The aim of this paper has been to describe how Compassionate Design has informed the design outcomes from the LAUGH project and to present initial findings from the research, which it is hoped, will support much needed work in the field. Integration of new products in dementia care requires health professionals' acceptance and endorsement; this can be difficult to achieve without medical quantitative measures and random controlled trials. However, robust qualitative evaluation frameworks are being developed that can illuminate the benefits of compassionately designed innovations in the field. This paper aims to contribute examples of design practice to this debate and reveals the vital importance of including 'expert' participants in a co-design process when designing for advanced dementia care.

Acknowledgements

This research is supported by an AHRC Standard Grant Ref: AH/M005607/1; we would like to acknowledge and thank our project partner Pobl Gwalia Care, residents, families and carers; we are grateful for the support and participation of Alzheimer's Society, Dementia Positive, Age Cymru and Ageing Well in Wales, in this research.

References

AlzheimersResearch-UK. (2016). All about dementia. In A. S. Society (Ed.), (Vol. AAD-1114-1116, pp. 20). Cambridge: Alzheimer's Research UK.

- Bennett, Belinda, McDonald, Fiona, Beattie, Elizabeth, Carney, Terry, Freckelton, Ian, White, Ben, & Willmott, Lindy. (2017). Assistive technologies for people with dementia: ethical considerations. In W. H. Organisation (Ed.), *Bulletin of the World Health Organisation Policy and Practice* (Vol. 95, pp. 729-792): World Health Organisation.
- Bennett, P., Hinder, H., & Cater, K. (2016). *Rekindling Imagination in Dementia Care with the Resonant Interface Rocking Chair*. Paper presented at the CHI EA '16 Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems, San Jose, California, USA.
- Branco, Rita Maldonado, Quental, Joana, & Ribeiro, Óscar. (2017). Personalised participation: an approach to involve people with dementia and their families in a participatory design project. *CoDesign*, 13(2), 127-143. doi: 10.1080/15710882.2017.1310903
- Brankaert, R., den Ouden, E., & Brombacher, A. (2015). Innovate dementia: the development of a living lab protocol to evaluate interventions in context *info*, 17(4), 40-52.
- Buchanan, Richard. (1992). Wicked Problems in Design Thinking. *Design Issues*, 8(2), 5-21.
- Coyne, R. (2005). Wicked problems revisited. *Design Studies*, 26(1), 5-17. doi: doi.org/10.1016/j.destud.2004.06.005
- Craig, R.T., & Tracy, K. (2014). Building Grounded Practical Theory in Applied Communication Research: Introduction to the Special Issue. *Journal of Applied Communication Research*, 42(3), 229-243.
- Desmet, P.M.A., & Pohlmeier, A.E. (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.
- Jakob, A., Manchester, H., & Treadaway, C. (2017). *Design for Dementia Care: making a difference*. Paper presented at the Nordes 2017, 7th Nordic Design Research Conference, Oslo, Norway. <http://www.nordes.org/nordes2017>
- Kane, Patrick. (2005). *The play ethic: a manifesto for a different way of living*. London: Pan.
- Killick, J. (2013). *Playfulness and dementia: a practice guide*. London: Jessica Kingsley Publishers.
- Krippendorff, Klaus. (2006). *The semantic turn: a new foundation for design*. Boca Raton: CRC/Taylor & Francis.
- Lama, Dalai, Tutu, Demond, & Abrams, Douglas. (2016). *The Book of Joy*. London: Hutchinson.

- Lambert, Kelly. (2008). *Lifting depression: a neuroscientist's hands-on approach to activating your brain's healing power*. New York: Basic Books.
- Livingston, Gill, Sommerlad, Andrew, Orgeta, Vasiliki, Costafrada, Sergi G., Huntley, Jonathan, Ames, David, . . . Mukadam, Naaheed. (2017). Dementia prevention, intervention, and care. *The Lancet*. doi: 10.1016/S0140-6736(17)31363-6
- Mitchell, G. (2016). *Doll therapy in dementia care*. London: Jessica Kingsley.
- Mitchell, G., & O'Donnell, H. (2013). The therapeutic use of doll therapy in dementia. *British Journal of Nursing*, 22(6), 329-334.
- Ógáin, E. N , & Mountain, K. (2015). 'Remember me: Improving quality of life for people with dementia and their carers through impact investment.' NESTA.
- Prince, M., Wimo, A., Guerchet, M., Ali, G., Wu, Y., & Prina, M. (2015). World Alzheimer Report 2015: The Global Impact of Dementia - an anaysis of prevalence, incidence, cost and trend. London.
- Rittel, Horst, & Webber, Melvin. (1973). Dilemmas in General Theory of Planning. *Policy Sciences*, 4, 155-169.
- Rogerson, R., Treadaway, C., Lorimer, H., Billington, J., & Fyfe, H. (2013). Permission to Play: taking play seriously in adulthood *AHRC Connected Communities Reports* (pp. 11). Swindon: AHRC.
- Tanner, Luke. (2017). *Embracing Touch in Dementia Care*. London: Jessica Kingsley.
- Tonkin, Alison editor, & Whitaker, Julia editor. (2016). *Play in healthcare for adults: using play to promote health and wellbeing across the adult lifespan*. Abingdon, Oxon: Routledge.
- Treadaway, C., Prytherch, D., Kenning, G., & Fennell, J. (2016). *In the moment: designing for late stage dementia*. in: P. Lloyd & E. Bohemia, eds., Proceedings of DRS2016: Design + Research + Society - Future-Focused Thinking, Volume 4, pp 1442-1457, DOI: 10.21606/drs.2016.107 ISSN 2398-3132 Design Research Society Conference 2016, Brighton, June 27-30 2016
- Treadaway, C., Fennell, J., Kenning, G. , Prytherch, D., & A., Walters. (2016) *Designing for wellbeing in late stage dementia*. Proceedings of WELL-BEING 2016: Co-Creating Pathways to Well-Being, The Third International Conference Exploring the Multi-Dimensions of Well-Being, Birmingham City University, 5th- 6th September 2016
- Treadaway, C., Kenning, G., Prytherch, D., & Fennell, J. (2016) *LAUGH: designing to enhance positive emotion for people living with dementia*. Paper presented at the 10th International Conference on Design and Emotion, Amsterdam. in Desmet, P.M.A., Fokkinga S.F., Ludden, G.D.S., Cila, N., & Van Zuthem, H. (2016) (Eds.). Celebration & Contemplation: Proceedings of the Tenth International Conference on Design and Emotion, Amsterdam, September 27-

30, 2016. Amsterdam: The Design & Emotion Society. ISBN/EAN: 978-94-6186-725-4

WHO (2012). Dementia: A Public Health Priority. UK: World Health Organisation. Alzheimers Disease International.

Woodyer, T. (2012). Ludic Geographies: not merely child's play. *Geography Compass*, 6(6), 313-326.