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686. Designing for playfulness through compassion: design for advanced dementia

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ABSTRACT The LAUGH project is a recently completed international three-year UK Arts & Humanities Research Council (AHRC) funded design research project. Outcomes from the research include a collection of playful objects designed to support the wellbeing of people living with advanced dementia that aim to provide comfort, pleasure and fun. These artefacts - a series of seven prototypes of playful objects, have recently been exhibited in London at the Royal Society of Arts, the Senedd in Cardiff and in Sydney, Australia. This visual essay provides an explanation of the research underpinning the designs and the Compassionate Design methodology that has informed the work.

Those in society who have the greatest need for excellent design are often the most vulnerable and may find it difficult or impossible to articulate what they want due to physical, sensory or memory impairment as a result of accident or disease. These people need innovative design solutions that are highly appropriate, customizable and sustainable. Finding ways to understand the challenges they face moment-by-moment and day-by-day is vital. Including them, and those who care for them, in a co-design process can provide rich insights into design requirements and result in better design solutions. LAUGH has involved key experts in dementia, including those living with the disease and their carers, at every stage in the research process.

Each of the LAUGH playful objects has been designed for a specific person living with advanced dementia. Most of them contain embedded electronics, are interactive, stimulate the senses and are highly personalized. The design narratives behind three of the playful objects will be explained in relation to the three key themes of Compassionate Design, which stress the importance of personalization, sensory stimulation and maintaining connections between people and the world.

Keywords: Dementia, design, qualitative research methods, compassion



Introduction

Over the last three years the LAUGH research team has been investigating how to design playful objects to help in the care of people living with advanced dementia (www.laughproject.info). Due to increasing numbers of those in the later stages of the disease, there is a need to find new ways to help people live *well*, and experience pleasure and fun until the end of life (Ógáin and Mountain 2015; Brooker 2007).

The LAUGH project has involved a collaboration between Cardiff Metropolitan University, University of Technology Sydney and Coventry University and a care provider: Pobl Gwalia Care and Support. It has included over 170 research participants representing more than 70 organizations.

Methodology

A qualitative and interpretivist research methodology was used to ensure the research was appropriate and informed by those who are 'dementia experts by personal experience' and those that care for them. Participatory and co-design methods, using creative and audio visual methods to gather data, have proved useful in previous research in this field, to reveal deep and complex issues (Hendriks et al. 2014). These approaches influenced the LAUGH research design process. The key methodological steps in the project involved knowledge gathering (step 1), analysis and reflection on the knowledge acquired (step 2) to inform an iterative process of design and prototype development (step 3). Evaluation was via a series of Live Labs (Brankaert et al. 2015), initially with health and care professionals to ensure safety and appropriateness of the objects and then with people living with dementia in two Pobl Gwalia Care and Support care homes in South Wales (step 4). The evaluation process is currently on-going and a larger 2-year study will include quantitative biomedical testing of the playful objects in collaboration with the NHS.

Compassionate Design principles guided the LAUGH design process (Treadaway et al. 2018) (Figure 1). These build on Positive Design (Desmet & Pohlmeyer 2013) and are informed by findings from a series of previous CARIAD design for dementia research projects. This approach advocates a person centered and relational ethos in which loving kindness for the person living with advanced dementia is placed at the heart of the design process (Kitwood 1997; Brooker 2007). The three core themes of personalization, sensory stimulation and connecting with others are key to designing for people living with advanced dementia, who frequently become withdrawn and detached from the world as a result of the progression of the disease.



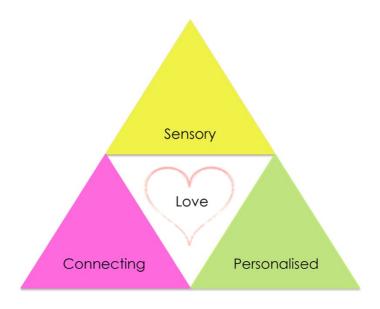


Figure 1: Compassionate Design

During the initial three LAUGH workshops, participants were encouraged to experience a number of playful and creative activities and use this to reflect on how people living with advanced dementia might experience similar activities. Participants (n=25) comprised dementia experts including carers, health and care professionals and charity representatives (Figure 2).



Figure 2: LAUGH participatory workshop: bread making to investigate hand-use



The workshops interrogated three themes in relation to advanced dementia: 1) playfulness and hand use; 2) positive emotions and emotional memory; and 3) craft activities and procedural memory. Guided by Compassionate Design principles, the design team worked directly with seven people living with advanced dementia with the assistance of family members and care professionals, to develop individual 'portraits' (personal histories and preferences) that were also used to inform design development. An analysis of the video recorded data and paper outputs from workshops 1-3 identified broad themes that were used along with the individual 'portraits' to inform subsequent co-design development workshops (n=2) (Treadaway et al. 2016).



Figure 3: (left) LAUGH Participatory workshops to develop broad themes: e.g. 'Nurturing' (right)

LAUGH Designs

The following sections explain the LAUGH design development process (step 3) of three of the playful objects.



Giggle Balls



Figure 3: Giggle Ball

Findings from the participatory workshops indicated that playful activities that induce laughter are highly beneficial to enhance wellbeing. Children's laughter, in particular, was considered likely to be infectious and engaging. In response to this, a set of six Giggle Balls were developed for a woman who had enjoyed being a bowling club member for many years (Figure 3). The balls are made of felt and contain a small tilt sensor, speakers and microcontroller containing sound files of children's laughter (Figure 4). When turned over in the hand the balls 'giggle'. Sadly, the participant passed away prior to the evaluation. However, the balls have proved particularly popular with care staff who have found them useful for changing the mood in stressful interactions with residents during the working day. One carer commented: 'If someone's sad you can cheer them up with a giggle ball.'

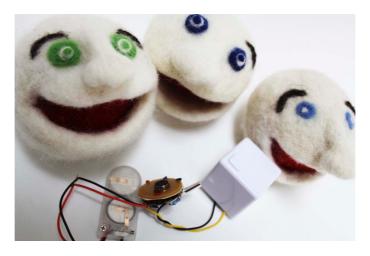


Figure 4: LAUGH Giggle Balls contain electronics that play sound files of children's laughter when moved



Steering Wheel

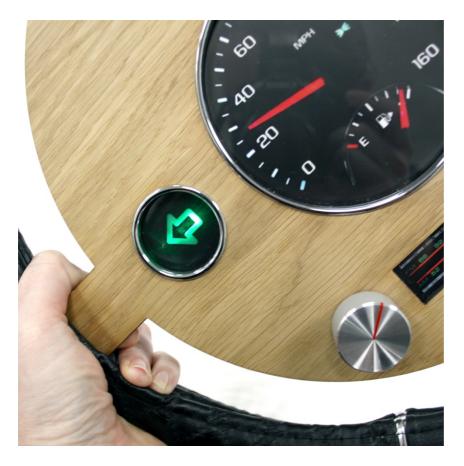


Figure 5: LAUGH Steering wheel

Data from the knowledge gathering phase of the LAUGH research identified two significant issues that led to the development of the LAUGH steering wheel. Firstly, people living with dementia find no longer being able to drive very depressing. This was highlighted in interviews with men living with early stage dementia who were part of an Alzheimer's Service User's Review Panel. Secondly, memories of emotional experience are retained later into the disease along with procedural memories. Rekindling the pleasurable act of driving was, therefore, used as inspiration for a design for a male resident with advanced dementia who had been a roadside recovery driver and motor mechanic. The steering wheel (Figure 5) provides haptic vibration to simulate the car engine running, has functioning indicators with lights and a 'tune-in' old fashioned radio. An embedded microcontroller enables a playlist of the person's favourite songs to be played. The Live Lab evaluation prompted a playful 30-minute activity in which the resident 'drove' into the lounge in his wheelchair and enacted an imaginary journey to the seaside to buy ice-cream with two carers at his side. The care home manager commented:

'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!'





Figure 6: Health professional testing the prototype steering wheel

Hug



Figure 7: LAUGH Hug - a soft wearable object

Finding ways to comfort and bring pleasure to people who are increasingly withdrawn and unable to communicate is challenging. Hug was a playful object made for a woman with advanced



dementia who was in bed for most of the day, had frequent falls, was no longer able to communicate verbally and had poor appetite and general health. Her carers suggested to the design team that the only thing she really needed was a hug. A soft cushion like wearable was designed that, when held, was reminiscent of nursing a small child. The body contains electronics that produce the sensation of a simulated beating heart and microcontroller with speakers, programmed to play her favourite music - a selection of soothing Vera Lynn songs. Hug is made from a soft washable fleece textile and is stuffed with a polyester filling.

The resident's response to hug was immediately observed to be positive and she cried when carers attempted to take it from her. Hug was left with her and the research team returned after a week, one-month and then three-month intervals to observe and evaluate. After three months with Hug, the benefits to her wellbeing were clearly evident. She was out of bed for most of the day, talking, eating better, her general health had improved, her hands were no longer stiff and contorted and significantly, she had no falls after being given Hug. According to reports by care staff and a close relative, improvements to her wellbeing could be attributed to Hug as no other significant changes to her care had taken place during the three-month period. One of the carers commented:

'She's come alive so much, whereas before she was sitting in her chair all day, not interacting with anyone, just laying there and then going to bed for most of the day. She's like a different lady now.... it's like a miracle in a way.'

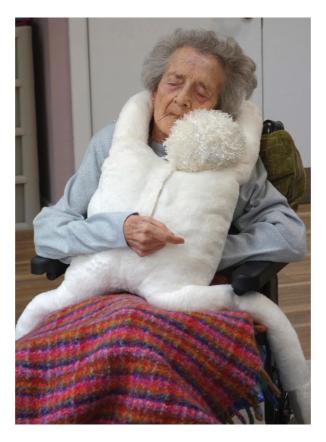


Figure 8: Live Lab evaluation of person living with advanced dementia with LAUGH Hug



A larger study is planned that will evaluate the impact of Hug on wellbeing, with a group of people living with dementia and Post Stroke Cognitive Impairment. The study will involve batch prototyping and triangulated qualitative and quantitative evaluation in collaboration with the NHS.

Conclusion

LAUGH researchers have used Compassionate Design methodology in order to focus design thinking on three key areas essential when designing for people with severely impaired mental capacity: personalization, sensory stimulation and connecting to others. As well as the three objects described in this paper: Giggle Balls, Steering Wheel and Hug, four more bespoke playful objects were designed for people living with advanced dementia. These are currently being evaluated for their benefits to health and wellbeing; early results from Live Lab evaluations indicate that they have provided pleasure, comfort and stimulation to the people living with advanced dementia that they were designed for. In addition, feedback from family members and carers reveals that they also help people to reconnect, stimulating conversation and providing non-verbal channels of communication and interaction.

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