

In the moment: designing for late stage dementia

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Abstract: This paper presents international multidisciplinary design research to support the wellbeing of people living with dementia. The LAUGH¹ project aims to develop playful artefacts that will contribute to non-pharmacological personalised approaches to caring for people living with late stage dementia in residential care. This paper presents the context for this research and explains the initial stages of the work currently in progress. An inclusive participatory methodology is described in which key experts including: health professionals, technologists, materials scientists and carers of people living with dementia are informing the development of design concepts. A positive design approach in which designing for pleasure, personal significance and virtue underpin the work. The initial stages of the research have identified the significance of: playfulness, sensory stimulation, hand use and emotional memory. This paper contends that designs should aim to promote 'in the moment' living in order to support subjective wellbeing of people living with late stage dementia.

Keywords: Inclusive design, dementia, wellbeing

1. Introduction

The World Health organisation has identified dementia as one of the greatest health challenges facing the world today (WHO, 2012). By 2050 it estimates there will be 115.4 million people with a diagnosis of dementia in the world. The rapid increase in numbers of people living with the disease will have a significant impact on individuals, families and society as a whole. There are currently very few products designed specifically to support the care of people living with late stage dementia who are often amongst the most marginalised and neglected members of our communities. New approaches to the design of

¹ LAUGH is an acronym for Ludic Artefacts Using Gesture and Haptics



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care services and ways of supporting their wellbeing are urgently needed (Zeisel, 2013; Design Council, 2012; Treadaway & Kenning, 2015; Treadaway, Kenning, & Coleman, 2015).

Dementia is a syndrome that encompasses a range of neurodegenerative diseases (including Alzheimer's) for which there is currently no cure. Caring for people with late stage dementia is demanding due to their complex needs and often what are perceived as challenging behaviours. Additionally, there can be great variation in the way the disease presents itself, and it is widely known that 'one person's journey through dementia is one person's journey through dementia'; there can be no 'one size fits all' when considering how to design for this demographic. Seeing the individual living with the disease and being mindful of their personhood and life experiences is vital when they can no longer communicate their identity for themselves (Zeisel, 2011).

There are both economic and social benefits to be gained from designing specifically to support the wellbeing of people living with dementia. According to a report by the King's Fund, total UK annual spending on dementia is projected to reach £35 billion in 2026². The cost to families is both economic and emotional; unrecognised informal carers looking after a family member with dementia shoulder the majority of care responsibilities. In residential care many residents are given expensive anti-depressant and anti-psychotic drugs in order to manage perceived challenging behaviour however, according to Alzheimer's Society, the use of these drugs as a first resort, for two thirds of these people, is inappropriate³. Research shows that happy people take less medication, suffer fewer falls and hospital admissions (Huppert, Baylis, & Keverne, 2005). There are therefore, significant economic advantages to increasing subjective wellbeing⁴ for people living with dementia and designing specifically to promote their positive emotions.

Fredrickson (2004) identifies the ten most common positive emotions as *joy, gratitude, serenity, interest, hope, pride, amusement, inspiration, awe* and *love*. Positive emotions have been shown to have enormous health benefits; laughter can reduce stress, lower blood pressure, decrease pain, boost the immune system and is better than any anti depressant (Sternberg, 2009). The brain's emotional systems have evolved to ensure human survival (Damasio, 2000; Goleman, 2004). Negative emotions such as fear and hate automatically stimulate the body's flight or fight response. The impact is felt via changes in the body such as quickened heart rate, sweaty palms etc. and is capable of hijacking conscious rational thought (Damasio, 2000). Positive emotions such as happiness, joy and peace have evolved to help us seek opportunity, be creative and connect with each other (Fredrickson, 2004). Laughter is contagious and smiles often elicit smiles from others: they are socially

² <http://tinyurl.com/hgxfmpm>

³ <http://tinyurl.com/jgbgz6v>

⁴ <http://tinyurl.com/h6t67h3>

connecting mechanisms with a universally understood language that does not rely on spoken words or rational thought. Fredrickson's research has shown that the natural bias of human emotion is more negative than positive and that in order to flourish there is a need to experience more positive emotions than negative ones.

There are, therefore, good reasons to investigate ways to develop and sustain positive emotion, particularly for people living with dementia for whom life is limited, often sedentary and lacking in hope. As the disease progresses it affects explicit memory (recall of experiences and information) and perception, resulting in confusion, altered sense of self and relationships with others. New approaches are needed to create opportunities for 'in the moment experience' in which the senses are stimulated and savoured. Playful activities that draw on a lifetime's accrued procedural memory have the potential to bring ludic pleasure and fun. New ways to tap into emotional memories through personalisation are needed to stimulate a sense of 'self' and retain a person's identity. These are the challenges that the LAUGH research is addressing in order to develop new types of playful objects (ludic artefacts) to support the wellbeing of people with late stage dementia.

2. Memory and emotion

2.1 The brain and dementia

Dementia is caused by a range of progressive neurodegenerative diseases of the brain resulting in memory loss and cognitive dysfunction. The disease causes the brain to shrink; the hippocampus, the primary region of the brain associated with memory, is significantly affected and reduces in size⁵. The result is the gradual loss of autobiographical or episodic memory of the experiences that punctuate life. The biological purpose of memory is to inform *present* and *future* action and so it is not surprising that impaired memory leads not only to amnesia but also confusion and frustration in the present. Recent research in neuroscience imaging is illuminating ways in which the hippocampus is instrumental in making and remembering memories. Researchers at the Wellcome Trust Centre for Neuroimaging, University College London, have found that damage to the hippocampus affects 'spatial coherence': the way in which the world is perceived and remembered in 'scenes'. Without this function the brain is unable to recall spatial memories such as locations or sets of objects within a scenario. It is also impossible to imagine, dream, predict or navigate spatial scenes (Zeidman, Mullally, & Maguire, 2015). Nevertheless, other types of memories are able to persist into the later stages of the disease; these include emotional (affective) memories and procedural memories (learnt physical activities that have become automatic i.e. tacit or muscle memory)(Zeisel, 2011). Examples of these include the ability to sing and remember the words of songs when the facility to construct sentences in everyday

⁵ <http://tinyurl.com/jr5jt8a>

language is lost and the ability to knit, although not the ability to follow a printed pattern. Neither of these memory systems seems to be affected by spatial fragmentation as a result of hippocampal damage.

2.2 Emotional memory

Emotions are hugely significant in the laying down of memory. According to LeDoux, there is no one emotional system in the brain but a series of systems which give rise to different kinds of emotions (LeDoux, 1998). These have developed for specific evolutionary purposes and control the basic emotions (fear, pleasure, anger) and drives (hunger, sex, dominance, care of offspring). Since they have developed to ensure human survival they are low level, preconscious response mechanisms that affect and control the physiology of the body. For example fear stimulates the fight or flight response preempting action through the release of chemicals, raising heart rate and focusing attention in the brain. It is only after the body has entered the 'alert' state that it is possible to reflect on the biofeedback and consciously become aware of the resulting 'feeling'. Memories of emotion are therefore experienced pre-consciously and only subsequently reflected upon and rationalized as feelings.

The brain has two regions that have been shown to be significant in the processing of memories: the hippocampus and the amygdala. As explained in the previous section 5.1, the hippocampus is concerned with the episodic memories that punctuate experience. These *explicit* memories involve events and facts, logic and reason. By contrast the amygdala is concerned with *implicit* emotional memories. In traumatic events, both memory systems function in parallel (LeDoux, 1998). This accounts for the rekindling of the emotional feelings and sometimes also bodily responses, such as increased heart rate, when these memories are consciously remembered.

In the later stages of dementia both logical and emotional memory systems are damaged, however emotional memories remain intact for much longer and are used to help make sense of the world. Consequently a person may not remember who someone is, but they will remember how they *feel* about them. This also applies to objects and situations encountered in daily living. Objects may retain important emotional significance and stimulate moments of clarity when past memories are revived. Attachment to personal possessions, clothing, pieces of furniture and places, result from their emotional value and significance to the person living with dementia.

The heightened sensitivity to emotions of people with dementia can lead to communication that is largely receptive and dependent on the moods of others (Logsdon, McCurry, & Teri, 2007). Although emotions are felt, there is difficulty in expressing them verbally. The design implications from this include the need for alternative forms of communication and interpretation that encourage non-verbal emotional expression as a way of sharing, understanding and building on positive feelings of happiness and comfort.

2.3 Procedural memory

Another implicit memory system linked with the amygdala is procedural memory. This can be described as hard-wired body knowledge that is tacit resulting from years of repetitive action. Skills that have been practiced consistently until they have become automatic such as playing a musical instrument, practicing a craft or folding a napkin are retained as implicit procedural memories. According to Sennett it takes 10,000 hours of practice for a skill to become automatic (Sennett, 2008) but once it becomes implicit, the skill can provide pleasure by inducing states of flow, competence and absorption.

Designs for people with late stage dementia need to focus on ways of rekindling implicit memories, both emotional and procedural, and avoid placing cognitive demands on the user. By understanding a person's lived experience and focusing on their attachments to objects and activities, it is possible to enable pleasurable 'in the moment' experiences that reinforce positive emotions. Dexterous skills learnt throughout life by a person with dementia may provide insights into developing new ways of interacting with playful objects, building on procedural competencies using gesture and haptic touch.

3. Hand use and Haptics

Recent studies of hand-based activities with people in the later stages of dementia show that whilst their cognitive capabilities may decline, tactual sensory input remains effective and rewarding, (Ballesteros & Reales, 2000). Engagement in the physical activities of daily living develops tactual skills and emotional preferences that are hard wired into brain structures and neurological pathways from birth (Csikzentmihaly, M, 2001; Duchaine, Cosmides and Tooby, 2001; Wilcock, A., 1993). Evidence has shown that tactual hand based motor control remains 'comparatively spared', even in advanced cases of dementia, (Thompson et al, 2003) subject to other medical conditions that may be present.

Motivation and the ability to *perform* activities are interconnected (Kielhofner & Burke, 1980). White's 'Competence Theory' (White, 1959) states that "an intrinsic need to deal with the environment seems to exist and satisfaction (the feeling of efficacy) is derived from it". Ryan & Deci's (2000) 'Self-determination Theory', states that every person has an innate drive i.e. an internal or self-motivation to become good (competent) at something, which when achieved, enhances our subjective wellbeing and increases the intrinsic motivation to repeat this task. This is further enhanced when a person's "human tendency towards learning and creativity" is capitalised (Ryan & Deci, 2000). As ability/competence to successfully complete a particular task/activity decreases, there is a need to strive to become good at another activity. Therefore, to ensure the psychological wellbeing of people with advanced dementia, activities that are achievable and appropriate for them are needed. Those that foster and utilise these fundamental biological drives of motivation and reward have the potential to re-channel the negative agitated behaviour frequently seen in

people with dementia into a more positive, emotionally rewarding and playful activity (Cosmides & Tooby, 2000).

A meditative approach that focuses the person living with dementia's attention on the immediate moment of haptic experience and tactual sensation are more appropriate than those that involve cognitive stimulation. Previous studies have observed improving feelings of wellbeing through haptic experiential pleasure, which appears to foster increased attentional focus (Prytherch, D. & Jerrard, R. 2003) and in particular for people living with dementia (Treadaway and Kenning 2015). If the activity is shared, this may also assist the development of a deeper person centred relationship between people living with dementia and their carers, and peers.

Agitated behaviour exhibited by people living with dementia is often a consequence of a lack of stimulation and meaningful activity (Brooker & Duce, 2000). Kong, Evans & Guevara (2009) carried out a systematic review and meta-analysis of non-pharmacological interventions for people with dementia who have agitated behaviours. This review included data from sensory interventions, social contact, activities, environmental modification, caregiver training, combination therapy and behavioural therapy and found that only sensory interventions had a statistically significant effect on reducing agitation. Woods, Beck & Sinha (2009), suggested that therapeutic touch was beneficial both for symptoms of motor-restlessness and for stress reduction.

Woods et al (2009) were unable to suggest a mechanism to explain why therapeutic touch was beneficial. It is evident however, that therapies that tap into sensory and motor functioning are most effective, and indicative of a biological basis. A study by Thompson et al. (2003) monitored the loss of grey matter in the brain as Alzheimer's disease progresses. Their findings reveal losses occur in the temporal and parietal regions and limbic cortices, spreading to the frontal cortex as the disease advances. Findings from the study indicate that primary motor and sensory areas are "comparatively spared" even in advanced Alzheimer's disease. This suggests that therapies/activities for people with advanced dementia are more likely to be beneficial if they utilise motor and sensory functions of the brain.

In summary, well-designed products for people with late stage dementia require limited cognitive effort, provide: fun, playfulness and surprises, the facility to easily choose whether or not to engage in the activity, and if so for how long. A repetitive touch activity incorporated into designs, in order to channel motor-restlessness behaviour, would encourage and reward 'in the moment' activity thereby fulfilling the innate need for occupation, self-determination and competence via play.

4. Playfulness and sensory stimulation

Activities that stimulate positive emotions are creative, open and playful. They bring pleasure by reducing stress; they are without fixed goals or rewards and encourage 'in the moment living'. It is 'playful' or 'ludic' playing that is open ended and fun-filled, that stimulates positive emotion and enhances subjective wellbeing (Woodyer, 2012). Playful play, however, is all too often considered to be the preserve of children and as life progresses, both the opportunities to play and the self-granting of permission to play diminish (Rogerson et al 2013). When ludic play stimulates positive emotion it is evidenced extrinsically in behaviours that contribute to sociability, such as smiling and laughter. These acts of reciprocity are hardwired in the brain for the purpose of establishing social connectedness, affiliation and friendship (Dissanayake, 2000).

Opportunities for socially acceptable ludic play can be limited in adult life. Play is often viewed negatively as 'larking around' and 'childish' and adults who engage in silly or frivolous behaviours are often considered socially irresponsible (Kane, 2005). This negative bias towards adult playfulness is reflected in the reluctance to accept the notion of 'play' or concept of 'toys' for people with dementia. The use of the term 'toy' may be contentious due to its association with childhood, or considered infantilizing and detrimental to the dignity of a person with dementia. Despite the negative connotations, there is a growing body of research evidence to indicate that playful objects, such as dolls and soft toys, bring much pleasure and are able to comfort and soothe people living with late stage dementia (Mitchell & O'Donnell, 2013). All too frequently it is the carers and family members who are most resistant to the idea of play and the use of toys in residential care. This attitude is beginning to change as their therapeutic benefits are recognised by those working in the sector. Nevertheless, there is little published empirical data to support those carers who have witnessed the positive affect of playful objects on people living with dementia, including reduction in the need for medication, fewer falls and less agitated behaviour. There are also currently no published guidelines endorsed by government (Mitchell 2015). The LAUGH research discussed in this paper aims to contribute new playful objects and evaluate their potential to provide a non-pharmacological approach to the care of people with late stage dementia.

Previous research by the authors has already identified the benefits of playful textile artefacts in the care of people with late stage dementia (Treadaway et al., 2015). These textiles have been designed specifically to encourage 'in the moment' haptic experience with interesting textures, fabrics and threads, as well as buttons, zips and poppers designed specifically for ludic fiddling and fidgeting (Fig. 1). Each textile is bespoke, designed around an individual person with dementia's life history and personal preferences. The addition of embedded electronics has enabled further personalisation, for example the inclusion of an embedded MP3 player containing favourite music. Simple intuitive haptic electronic interfaces also facilitate extended sensory functions. For example, in one of the textiles

simple metal (clothes) buttons function as controllers to playfully select a variety of birdsong audio files which are played through a small speaker embedded in the textile.



Figure 1 Textile for 'in the moment' tactile stimulation designed to support the wellbeing of a person with late stage dementia.

Evaluation of the textiles indicates that they are able to reduce stress, promote positive emotion and encourage social play (Treadaway & Kenning, 2015). The significant aspect of these objects is that they are concerned with 'in the moment' experience. No cognitive skill is required to activate them and their carefully designed material properties stimulate a variety of senses including sight, touch, sound and smell. As objects to share, they are able to broker non-verbal interaction and emotional communications between people living with dementia and their carers when verbal communication is difficult or has been lost due to the progression of the disease.

5. Methodology

Over the last three years a series of funded research projects - 'Making a Difference', 'Dementia Aprons' and 'Sensor e-Textiles' - have been undertaken by CARIAD⁶ researchers in order to scope the need for the LAUGH research and to develop networks of experts to participate in it (Treadaway, Kenning, & Coleman, 2014). Partnered by Gwalia Cyf, one of the leading providers in South Wales of residential care for people living with dementia, and supported by three leading charities: Alzheimer's Society, Age Cymru and Dementia Positive, the LAUGH project now has a database of over 90 participants including health professionals, carers, family members of people living with dementia, materials experts,

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computer scientists, designers and engineers who are contributing their time and expertise to the project. The CARIAD team is joined by academics from University of Technology Sydney and Birmingham City University with expertise in creativity, craft, technology and haptics.

The research methodology is largely qualitative, participatory and inclusive (Blessing & Chakrabarti, 2009; Krippendorff, 2006). Data is gathered from a series of case studies, semi structured interviews, practical participatory workshops and post-hoc expert review. Participants include researchers who observe, journal and reflect on their experiences and the experiences of the other participants. The workshops are video and audio recorded simultaneously on four video cameras in the User Centred Design Lab at the National Centre for Product Design in Cardiff, UK. Video material is later analysed using Noldus Observer XT software and aligned to themes identified from previous research and current literature in the field. In addition, the recordings are analysed for emergent themes arising from each workshop.

This paper focuses on one component of the broader research reporting on findings from one of three participatory workshops that will inform the design development stage of the work. The subsequent iterative prototyping and 'live lab' evaluation phases of the research will include people living with dementia in Gwalia residential care.

5.1 Person centred and positive design

The approach to the design of highly customised ludic artefacts for people with dementia in this work aligns with the person-centred approaches prevalent in the theory and practice of care for persons with dementia (Chenoweth et al., 2014; Chenoweth et al., 2009). These approaches recognise the personhood of each individual (Kitwood, 1997), as social beings to be treated with dignity and respect, and the need to design to promote positive emotion. Importantly, such approaches recognise that to be effective, designing for the individual must also take into account the community of stakeholders involved in the care; family members, caregivers, health care staff. By taking a participatory and inclusive approach each participant can make a valuable contribution to inform the design of artefacts for people with late-stage dementia (Hughes, 2014). Positive Design, an approach that focuses specifically on designing to promote positive emotions, underpins the LAUGH research (Desmet & Pohlmeier, 2013). This design methodology, rooted in Positive Psychology, identifies three key constituents when designing to support positive emotion: pleasure, personal significance and virtue.

5.2 Data collection and analysis

A total of 25 participants comprising: experts in dementia care, occupational therapists, managers, dementia nurses, representatives from Alzheimer's Society and Age Cymru, designers, and technologists were brought together for a participatory workshop to explore hand use and playfulness in relation to dementia (Fig. 2). The three-hour workshop was

divided into three one-hour sessions, each with a practical activity followed by a group discussion. Activities including bread making, clapping games and simple crafts were used to stimulate discussion around the themes and enabled participants to share their expert knowledge in caring for people with late stage dementia. These particular activities were selected in order to focus participants' attention on manual dexterity, haptic responses and playfulness as these had been identified as significant areas for interrogation from the authors' previous research and contextual review (Treadaway and Kenning 2015; Treadaway et al 2014; Killick, 2013). A different member of the research team led each part of the workshop and participants were encouraged to share their thoughts whilst engaging in the practical activities. The discussions were video recorded and participants were also given simple digital cube cameras to document the session themselves. From this data, recurrent themes were identified and tagged to provide a framework used later for thematic analysis of the audio transcription.



Figure 2 Bread making, LAUGH Workshop 1

6. LAUGH workshop

The participatory workshop provided insights and practical knowledge about dementia care through an experiential reflective process of involvement in practical activities. Participants were experts who either work directly with people with late stage dementia or are closely connected with their care. Activities (bread making, clapping games and making simple toys) were selected for their potential to reveal insights about manual dexterity, haptic touch and the implications of memory impairment on hand use for people living with late stage dementia, who are often sedentary or bed bound. Participants' reflections on the activities took place during and after each session in a round table discussion.

6.1 Bread making

The participants were guided through the practical activity of making bread in order to elicit personal reflections on hand use and haptics (Fig. 2). The feel of the flour in the bowl, the smell of the dough once the water had been added, the warmth experienced during the kneading process all contributed to a feeling of pleasure from the sensory experience. The kneading process quickly became repetitive and rhythmic as participants stopped chatting and became absorbed in the task. Comments from the participants during the activity highlighted the ways in which the activity stimulated pleasurable memories – some long past. Others commented on how the kneading process was a tacit skill and they were able to continue happily whilst thinking about other things. Researchers observed that the activity became more energetic once participants had their own piece of dough and became intrinsically motivated to complete the activity. Key findings from this workshop session indicate the importance of designing for immersive⁷ occupation, self-determination in the choice of activity and competence in undertaking the playful experience. Dexterous activities provide rhythmic, calming and soothing engagement that is absorbing and distracting; the senses are stimulated and the focus of attention is ‘in the moment’. During the discussion participants contributed anecdotes concerning their positive experiences of undertaking cooking activities with people living with dementia.

6.2 Clapping Games

During this part of the workshop music was played and participants were encouraged to respond with clapping games (Fig. 3). Some participants consciously drew on their memories of games played as children with associated rules of engagement (e.g. who should take the lead); most instinctively began clapping and moving to the rhythms co-operatively with their partners, drawing on memories through doing the activity rather than thinking about it. Although there was some discussion, most people simply got involved in the activity. There was a great deal of laughter and smiling amongst the majority of those involved. One participant was reluctant to participate and removed himself from the group. Gender differences were observed in the approaches taken to the activity. The male participants were slower to engage, maintaining that only girls played clapping games as children. Nevertheless, they began to play a more aggressive and competitive clapping game remembered from childhood called ‘Crocodiles’. The music played during the activity was found to be energizing and helped to stimulate a sense of immersion and flow. Physical movements inspired childhood memories and the need to follow a partner produced bodily attunement resulting in social connection that was evidenced in smiling and laughter. This activity highlighted several important design considerations including: the potential for both inclusivity and exclusion, the significance of music and rhythm and the role of pre-defined rules in shortcutting access to fun and play.

⁷ deeply involving the senses



Figure 3 Clapping games

6.3 Simple toy making

The final part of the workshop was devoted to making simple toys: a paper fortune-teller, a whizzy disk and simple card-weaving spiral. The crafting process required basic skills of folding and cutting and everyday familiar materials: paper, wool and cardboard (Fig. 4).

Participants immediately began to reminisce about childhood games and, although they were unable to remember the names, they were able to describe the activities using hand gestures. Memories of how to construct the toys evolved through the making process - by *doing* rather than thinking and planning. Participants also expressed particular enjoyment derived from the combined activity of making the object then playing with it.

Discussion following this session indicated the need to consider designing for the social aspects of play. The activity highlighted the intrinsic reward gained from making a toy individually and then being able to share the game socially and enjoy the 'in the moment experience' of play. Hand use, gesture and haptics were again shown to be significant in this activity and memories were rekindled through procedural rather than semantic memory.



Figure 4 A fortune-teller paper toy

7. Discussion and future work

The key findings from this workshop were that participants:

- Were able to recognise what ‘in the moment’ fun and joy felt like as a result of personally engaging in activities that were fun and involved hand-use;
- Recognised the importance of ‘in the moment’ activities that are playful and engage the senses;
- Were able to translate their own experiences of exploring memory, hand-use and playfulness through their knowledge of working with people with dementia into information that can directly inform design considerations when designing for people living with late stage dementia.

Workshop participants’ personal and professional experiences confirmed that ‘in the moment’ activities that are: playful, involve hand use and engage the senses, contribute to building positive emotions. The round table discussion - following the activities, confirmed the theory that the three key themes: memory, hand-use and playfulness, are significant design considerations when designing for people living with late stage dementia.

Subsequent planned participatory research will examine positive emotion and emotional memory in greater depth. This will help to inform ways of designing to personalise designs in order to stimulate a stronger sense of ‘self’ for a person living with late stage dementia and communicate their personhood to others. Focus on emotional memory, which is retained even in the later stages of the disease, may provide significant design opportunities. A

greater understanding of how to stimulate emotional memories that are positive and engaging for a person living with late stage dementia will be required.

Fun, pleasure and playfulness in relation to *emotional* memory, and crafting and making in relation to *procedural* memory, will be explored in the next stage of the research via two further participatory workshops. This will be followed by a series of iterative design development workshops that will explore appropriate forms, materials and technologies. People living with dementia will be involved in the development and evaluation of the design prototypes through a series of 'live labs' involving residents in the project partner's care homes. Due to the vulnerability and communication challenges of people living with late stage dementia, care staff, health professionals and family members will contribute their expertise throughout the design development and evaluation phases of the research.

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