LAUGH: co-design for people living with advanced dementia

Researchers in Australia and the UK have been working with people living with advanced dementia to develop a collection of sensory objects to engage, comfort and bring pleasure and fun to their lives. **Gail Kenning** tells the story behind the designs

While dementia impacts physical and cognitive functioning, emotional memory is retained and people living with dementia, even in the advanced stages, are still able feel joy, have fun, and laugh.

This article reports on a collaborative UK-Australian design research project, funded by the Arts and Humanities Research Council (AHRC grant AH/M005607/1) in the UK, to encourage people living with advanced dementia to engage playfully, have fun, and to promote social connection. The *LAUGH: Ludic Artefacts Using Gesture and Haptics* co-design project was led by Professor Cathy Treadaway of Cardiff Metropolitan University in Wales, in collaboration with Dr Jac Fennell, Aidan Tayler, Dr Amie Prior and Professor Andy Walters (Cardiff Metropolitan University), myself (Dr Gail Kenning, University of Technology Sydney, Australia), and Dr David Prytherch (Coventry University, England). The aim of the project was to research and design hand-held 'ludic artefacts' (playful objects), to encourage spontaneous fun and 'playful playing' – that is play that is not goal or outcome driven, but just feels good to do.

Objects, toolkit

The analysis and findings from a series of workshops held during the project, together with information from a review of existing projects and the input of people living with dementia, led to the development of a series of objects made for six people living with advanced dementia, and a toolkit to support designers. The toolkit, *Compassionate design: how to design for advanced dementia*, is freely available from the LAUGH website: www.laughproject.info/home-2/toolkit-for-designers/. In addition, a small number of hard copies are also available on request.

Play and wellbeing

In response to our ageing population, resources are increasingly being channelled into exploring how to support

'Hug' is a soft cushion-like object made for Thelma during the LAUGH project. When she was first given 'hug', Thelma remained in a state of quiet contentment, relaxed, but not smiling or engaging with others

people to not only have a long life, but also a good quality of life. However, this is an area that's not supported well in relation to people living with advanced stages of dementia. Karn Nelson, Executive General Manager of Strategy at The Whiddon Group in Australia, recently commented "there are many projects for people at early and mid stages of dementia, but so little for people with advanced dementia".

Research is increasingly showing that quality of life can be improved for people living with dementia when they have opportunities for social engagement and to engage in meaningful activities. Activities that engage multiple senses are particularly effective for connecting with people living with advanced dementia and fun activities that include 'playful playing' can contribute to positive wellbeing. However, play is often associated with children and discouraged in adults, and may be viewed as infantilising of older people and people living with dementia. The LAUGH

project shows that playful objects can be designed that promote dignity and respect, through personalisation, by offering sensory experiences, and by encouraging connection.

What is considered meaningful, fun or enjoyable is highly personal and varies from individual to individual. This is no less so for people living with advanced dementia. But understanding what they find meaningful, enjoyable and fun is complex because they may be non-verbal and unable to communicate needs, wants and desires. Asking family members for information may be unreliable as what a parent or spouse liked to do before having dementia may be no longer applicable or appropriate. Care staff may know the person through a care context and not necessarily have a holistic view of them or their life.

Another challenge in working with a personalised approach to design for playfulness is that people living with advanced dementia in care homes are part of a larger community that includes staff, family members and other residents. This can impact on what is made, why, and the response to the designs. For example, research shows that objects and activities that might be fun, comforting, occupy and entertain a person living with dementia may be perceived as infantilising by care staff, family members, or other residents. It is important to understand that what may be perceived as fun, playful or 'being silly' to one person (clowning, pulling faces, dressing up, or making up stories) may be considered childish or embarrassing to others. Similarly, while it may be accepted that an adult may take comfort in holding objects (ie clothing, jewellery) that belong(ed) to loved ones, taking comfort in dolls, blankets, or soft toys may be frowned upon. So, this raises questions with regards to how we can design to support personhood and enable individuals to experience a wide range of emotions, and be playful, and have fun, without undermining their dignity.

After having 'hug' for three months there was noticeable change in Thelma's condition

Multisensory engagement

The LAUGH project drew on research that shows the importance of multisensory engagement for people living with advanced dementia, particularly for those who may no longer be mobile or able to communicate through speech. At this stage people interact with the world through touch, and may be more responsive to objects and activities that are also accompanied by sound, highly contrasting colours or lights, and smell. Sensory materials can also generate playfulness, humour and pleasure and can relieve stress and tension.

Research showed that projects that explored fun and playfulness were, for the most part, performative; they used poetry, music, storytelling and aspects of theatre and dance (Hafford-Letchfield 2012, Killick 2013; Low et al 2013). These types of projects needed to be significantly adapted for people living with advanced dementia. While a number of projects focused on sensory experiences using sensory materials and creating sensory rooms, few explored the impact of self-contained hand-held objects that could be used with minimal supervision.

Personalised design

Researchers on the LAUGH project engaged with over 170 experts in ageing and dementia in 70 organisations, including psychologists, dementia care management and staff working directly

with people with advanced dementia, occupational therapists, and activities specialists, alongside designers and technologists.

The project was partnered by Pobl Gwalia Care, one of the largest providers of residential social care in South Wales. An advisory team included experts such as John Killick (Killick 2013) and Dr Jane Mullins, author of *Finding the Light in Dementia* (Mullins & Fawcett 2017). The project also brought together experts from ageing and dementia organisations such as Age Cymru and Alzheimer's Society.

Participants attended a series of co-design workshops to contribute to the research and development of a series of objects made for six residents of two care homes. Workshop participants were given

This hand-held steering wheel was designed for a man who had worked for a vehicle breakdown service and loved driving

'personas' of each resident and asked to think about how they would design highly personalised objects and activities to promote positive wellbeing. The personas were developed from information provided by the care facility, family members and care staff, including the person's age, cultural background, previous occupations and likes and dislikes around music, activities or hobbies.

Six workshops were held over one year. In each, participants were given tasks that required them to think about fun and laughter and to reflect on their own responses to various stimuli. They were also asked to draw on their knowledge and experience of engaging with people with dementia in their professional or caregiver capacity, and to explore what materials, situations and activities might be considered fun. One workshop focused on hand use, exploring bread making and playfulness such as clapping games. Another focused on procedural memory and craft activities, looking at how we use tools. A design prototype brainstorming session asked participants to create a playful object for a person living with dementia from a range of craft materials. They 'played' with materials, made playful objects, played games and then were asked to report back on their own feelings and responses.

Data was collected during each of the workshops; they included the objects, comments and notes made by participants and researchers, and audio and video recordings.

People with an early diagnosis of dementia and people living with advanced dementia were consulted as experts and advisors and provided feedback on the prototypes produced. People with advanced dementia contributed through verbal and non-verbal responses to materials, prototypes and objects in various stages of production. People living with an earlier diagnosis took part in interviews and provided insights into their journey of living with dementia.

The involvement of people with dementia, as with all participants, needed to be handled with great sensitivity. People living with advanced dementia had specific access requirements for mobility, communication and engagement and needed to participate in smaller groups and in quieter venues. It was also recognised that people living with the earlier stages of the disease might find it stressful to think about what happens in the more advanced stages. Therefore, because of the content of the workshops, the number of people involved, and the
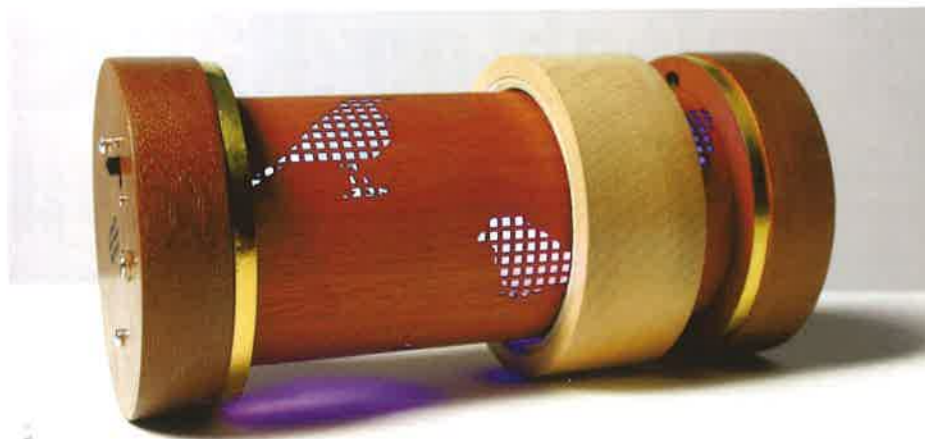
LUMA is an interactive hand-held crafted wooden object designed to stimulate interest through changing light, colour and sound

venue, it was decided that to enable all participants to contribute from a position of strength it was not possible for all experts to attend the same workshops.

Compassionate design

From the outset the LAUGH project focused on positivity and potential rather than viewing ageing and dementia through a lens of deficit. We developed a compassionate design approach (www.compassionatedesign.com) which focuses on the importance of designing with compassion to stimulate the senses, facilitating personalised experiences and encouraging connections between people. Within this overall framework six key themes were identified from the data collected during the first three workshops:

- Nurturing: the need for people to reflect on caring tendencies through objects.
- Security: the importance of feeling safe.
- Attention: how objects and activities can be used to redirect focus and change mood.
- Purposeful: the need to feel that an activity is meaningful.
- Replay: the importance of familiarity and how objects can draw on existing knowledge and skills and re-present them in a new form.
- Movement: to both stimulate and calm.

In the final stages of the LAUGH project a core team of design researchers worked with all findings from the workshops to explore what types of objects could be made in response to these themes and produced a series of highly personalised objects for the six residents. The prototypes were examined and critiqued by the advisory group and care staff and management of the two care homes with regard to safety, security, robustness and infection control. After the 'all clear' the objects were tested and evaluated with the six people for whom they had been

designed. Researchers evaluated the response to the objects, how they were introduced, the types of engagement, interaction and social connection they encouraged, and for frequent or intense responses.

The objects

The objects produced included:
- A telephone that plays music and the sound of people speaking Spanish, for a woman who had lived in Wales most of her life, but had grown up in Spain and liked hearing the Spanish language.
- A set of giggle balls – soft palm-sized felt balls, with a smiling face and embedded electronics that, when tilted, make the sounds of children laughing.
- A hand-held steering wheel for a man who had worked for a vehicle breakdown service, who loved driving. The steering wheel has inbuilt

electronics so the 'radio' plays his favourite music and the indicators can be switched on or off.
- LUMA, an interactive crafted wooden object, based on a garden bird feeder. When activated, images of garden birds are illuminated. An outer wooden ring slides along the tube to change the colour of the lights and activate the sounds of bird song. It was made to stimulate a man who had become withdrawn, apathetic and bored.
- Fidget jewellery – simple, personalised jewellery designed to rest in the palm of the hand and provide something to fiddle with and touch.
- A soft cat with embedded electronics that makes purring noises, for a woman who had a white cat.
- A 'hug'– a soft cushion-like object with long arms and legs that can be wrapped around the body, with embedded electronics that plays personalised music and has an electronic heartbeat. This was made for a woman called Thelma.

Thelma and her 'hug'

Thelma's 'hug' built on the theme of nurturing identified during the workshops, and was made in response to care staff who explained that Thelma was moving into end-of-life care and what she needed most was a hug. Thelma's response to 'hug' was immediate. She was brought into a bright, airy day room in a wheelchair, where members of the research team and care staff were sitting. Thelma's eyes were closed, although she was not asleep. The care staff commented that it was not a good time of day for her
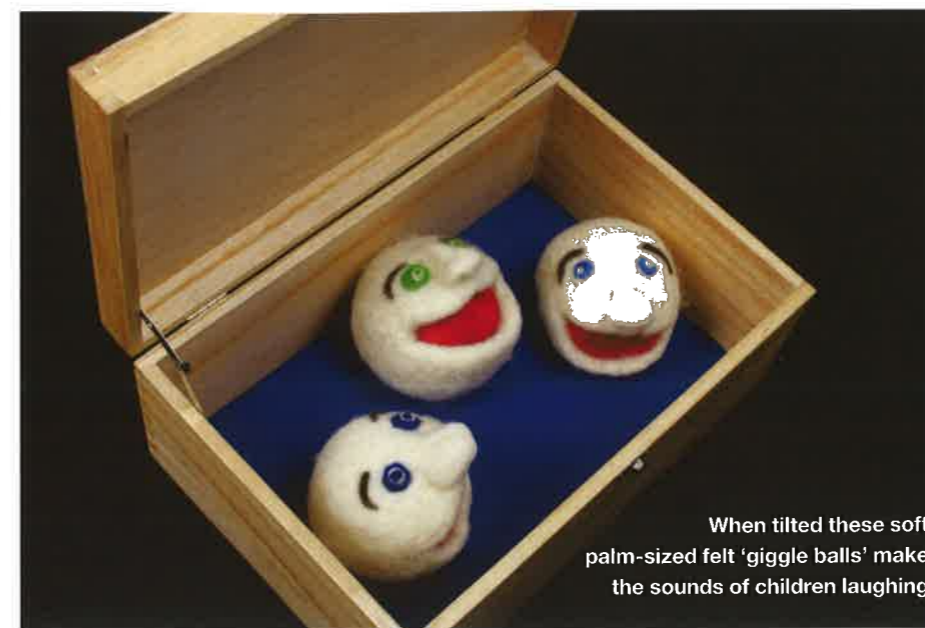

This telephone plays music and the sound of Spanish-speaking voices. It was designed for a woman who had grown up in Spain and loved hearing the Spanish language

When tilted these soft palm-sized felt 'giggle balls' make the sounds of children laughing

and that they thought she might be in pain.

They said "look, Thelma, these people are here to see you". She responded with an inaudible comment, keeping her eyes closed, not showing any sign of interest or concern. 'Hug' was placed on Thelma's lap and the arms and legs wrapped gently around her. Researchers observed as one of the care staff placed Thelma's hand on the back of 'hug' so that she could feel the heartbeat. There was the beginning of a smile, as she seemed to 'settle in' with her head cwtching* the hug. Thelma sighed audibly and began to gently stroke the back of 'hug'. Her hands were closed tightly and she had little dexterity. Care staff asked questions of Thelma as she sat with 'hug'. "Thelma, do you like that?" She replied each time with one or two words, softly whispered, "hmmmmm" or "yes". Thelma's eyes remained closed and her hands retained the tight closed position as they had when she entered the room, but she voluntarily moved her hands as she held on to 'hug'. Thelma remained in a state of quiet contentment, relaxed, but not smiling or engaging with others (see photo p22).

'Hug' was left with Thelma to interact with and after three weeks care staff were interviewed and asked to comment on Thelma's engagement with 'hug'. One carer reflected that when she first met Thelma "she was just a bundle of laughs", but her health had deteriorated and "she [now] spent a lot of time doing nothing". She then suggested that 'hug' had brought back glimpses of the Thelma they had

known. The care facility manager commented: "'hug' has been life changing…I don't think anyone would believe the transformation". When researchers then saw Thelma she was holding 'hug' on her lap with the arms wrapped around her. It was noticeable that Thelma's eyes were open, she appeared clearly more engaged with the world and the people around her, and her hands were no longer held in a tight closed position; they were much more open and she was able to use them with greater ease.

After having 'hug' for three months there was noticeable change in Thelma's condition (see photo p23). While she remained frail, she spent more time out of bed and out of her room, her eyes were open most of the time and she was awake

for longer, she would speak a few words occasionally, her hands were no longer as stiff, and importantly she had not had any falls since being introduced to 'hug'. The care staff and manager were highly enthusiastic about 'hug' and suggested that the changes were due to the relaxing impact that 'hug' had on Thelma, and how it encouraged other people to engage and interact with her, as they asked questions about 'hug'. For the time being, Thelma had been taken off end-of-life care.

Thelma's story also had an important impact on the wellbeing of the care staff working in the homes. Staff commented on how 'hug' gave them peace of mind because Thelma was 'settled'. Thelma's response to 'hug' also encouraged staff to start thinking about what could be made for other residents in the care home.

Project impact

Researchers observed moments of connection and engagement between residents, staff, with researchers, and with the objects. The qualitative evaluation of the objects took into account the reporting from care staff and management, reporting by doctors and clinical care staff visiting the homes' residents, observation by the researchers, and the interviews with care staff and family members. Further details of these findings will be published in due course.

An unexpected outcome of the project was the extent to which the workshop participants revisited some of the ideas and concepts during their day-to-day lives working in the care homes. For example, Karen, a manager at one of the homes, showed researchers a range of objects and activities that she and her staff

Fidget jewellery is simple, personalised jewellery designed to rest in the palm of the hand and provide something to fiddle with and touch

* Cwtching is a Welsh word describing an action somewhere between hugging and cuddling

had made for residents in their care based on ideas from the workshops. The objects included sensory textiles, kinetic mobiles, and decorative objects placed in and around the care home.

The LAUGH project also highlighted the importance of care staff being involved in this type of research. Researchers found that it is important for designers to gain the trust of all participants, to focus on both individual and relational experiences, and to work with a thorough understanding of the individuals and the broader social and cultural context in which they live and work. Without the active engagement of busy care staff, it is all too easy for the importance and potential impact of objects and activities to get lost.

Furthermore, how people living with advanced dementia are introduced to and given access to objects and activities is key to how they respond. Without the active support of care staff, objects and activities may be left to sit in cupboards, or out of reach of the people who need them most. We're now carrying out research to determine how care staff can receive training to engage through creative activities and objects. (Anyone interested in taking part in this project can contact the author for more details).

LAUGH exhibitions

The LAUGH project concluded in Wales in April 2018 with an event at the Senydd in Cardiff and an exhibition of copies of the objects at the Royal Society of Arts in London. In Australia a LAUGH Symposium was held at the Art Gallery of NSW in April where Professor Cathy Treadaway, myself and Dr Jac Fennell presented the findings from the three-year

The LAUGH objects on display in Sydney in April

project. The objects were also exhibited at a Sydney gallery.

Distribution

The LAUGH team is now seeking further research and investment funding to explore how the objects can be reproduced and distributed, how the process in which the objects were made can be scaled to reach more people, and whether it is possible to distribute details and information to enable Do-It-Yourself versions of these highly personalised objects to be made.

For details about our ongoing projects in relation to improving the quality of life of people living with dementia contact me (Dr Gail Kenning) gail@gailkenning.com in Sydney or Professor Cathy Treadaway ctreadaway@cardiffmet.ac.uk in the UK. ■

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In March this year we released a report of our research project detailing the effects of regulation on aged care services for people with cognitive decline. *The organisation of risk: how do dementia care providers adapt to regulation* (Carr & Biggs 2018) presents findings at the system, organisation and practice levels, and suggests a series of recommendations.

The project was funded by the NHMRC Cognitive Decline Partnership Centre and carried out between 2014 and 2017. Throughout we worked with three aged care providers – Brightwater Care Group, HammondCare and Helping Hand Aged Care –as well as Dementia Australia's National Consumer Network. Research also took place through the Brotherhood of St Laurence's Research and Policy Centre.

The research involved literature and policy reviews, interviews with stakeholder groups, mapping the aged care system and care pathways, and interviews with three levels of organisation – senior managers (17), facility managers (13), and care workers (30), which were PCA or equivalent. Interviews were also conducted with care users (10 in total), including people living with dementia in the community and care partners (see box p28).

The report suggests a need to move beyond debates about good versus bad, more versus less regulation to develop a deeper understanding about how aged care organisations and their employees respond to the pressures of various, overlapping and often competing regulatory demands. While there has been limited recent research in this area, such a focus demonstrates the different ways organisations and care workers seek to balance innovative care practice with regulatory compliance.

In this article we outline key findings at the system and organisation levels, followed by a more in-depth discussion of the effects of regulation on daily practice and the ways in which care workers respond to regulation in residential care.

Aged care regulation in Australia

Many of the care and support services that people living with dementia use are located within the aged care system. The regulatory system designed to govern aged care is complex with duplication and overlap occurring at the Commonwealth, state and local government levels and between different regulatory agencies.

Whilst moves have been made to reduce red tape and promote light touch

Balancing compliance and care in dementia practice

Simon Biggs and **Ashley Carr** discuss the strategies used by aged care organisations and care workers to manage the demands of dementia care within a regulated environment. How they do this, while still allowing room for innovation, is of interest to aged care providers, care practitioners, care-users, policy makers and regulators

approaches to regulation, measures have also been proposed to increase regulation and focus regulatory attention towards care activities and facilities considered higher risk. Much of the latter emerged as a consequence of the Oakden Report and the subsequent independent *Review of National Aged Care Quality Regulatory Processes*, conducted by Kate Carnell and Professor Ron Paterson, and released by the Australian Government in October 2017. A key outcome of the review was that for residential care facilities in particular the market alone proved "an inadequate mechanism to ensure the safety and wellbeing of highly vulnerable residents". The report argues that government regulation, including a rigorous accreditation process, should remain, as a means to ensure quality care standards and the protection of residents.

The Aged Care Act 1997 sits at the centre of Australia's regulatory system, and includes 17 principles covering areas such as care standards, requirements for approval, allocation of care places, fees and payments, sanctions, record-keeping, prudential requirements and care recipient rights. State legislation deals with other areas related to care, such as building certification, medication management and aspects of food provision. There are currently more than six independent or semi-independent regulatory agencies, including the Aged Care Complaints Commissioner, the Australian Aged Care Quality Agency (see box p29), the Aged Care Funding Authority, as well as national and state authorities covering food, building and training/skills. State and federal courts of law provide another source of regulatory influence.

Our policy and literature reviews found very few regulations specific to dementia within the Act and other relevant regulations. As a result, the implementation of formal regulatory
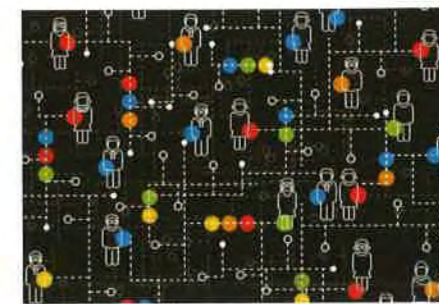
Australia's aged care regulatory system is complex, with duplication and overlap occurring at the Commonwealth, state and local government levels and between different regulatory agencies

requirements within organisational settings, and their integration within daily dementia care emerged as an area of critical concern. We began by examining 'soft' regulation, which is one means by which 'hard' forms of regulation, such as laws and legislation, are implemented within organisational and care settings. These soft forms of regulation, which include guidelines, organisational policies, practices and procedures, and care protocols, are what providers and professionals use to help translate legislation into everyday compliance (Heimer 2013).

The process of translating hard regulation into everyday practice via soft regulation suggested a middle ground, which leaves significant room for flexibility and manoeuvre (Huising & Silbey 2011). It also means that standardised regulatory controls can be adapted to the specific care needs of people living with dementia, though this was an ongoing challenge for care providers.

Regulation 'clusters'

We found that the distribution of regulation throughout the system and in care settings was uneven. From this we

developed the idea of 'regulatory clusters' to show how regulation tended to collect around particular points along a care pathway, for example, at care transition points, such as the move into residential care. This type of clustering suggests where additional support services might be needed to assist care users negotiating multiple regulatory demands, including eligibility requirements, care assessments and income/financial assessments.

Another form of clustering was used to show how regulation collects around particular daily care activities of residential care and not others. A continuum of regulation was proposed, indicating how activities like medication management are subject to high levels of regulatory control and prescriptive rules, whereas morning routines appear the least affected by regulation.

As our report states: "Care workers are able to exercise flexibility around certain care activities, but may be more constrained around others. Once these clusters of risk and control are understood, it is much easier to identify areas where innovation can be quickly achieved and where regulation may create a risk-averse response." We identified an ongoing need for organisations to provide support and guidance to help care workers balance discretion, best practice and caring relationships amidst regulatory control.

Organisational responses to regulation

We found that care providers adopted particular strategies as a way to cope with regulation. These proved important for balancing care principles, such as the creation of a homelike environment or the promotion of resident choice, with different regulatory demands, some of which were experienced as intrusive.

We categorised the strategies, all of