COMPASSIONATE DESIGN

HOW TO DESIGN FOR ADVANCED DEMENTIA

A toolkit for designers

LAUGH

LAUGH (Ludic Artefacts Using Gesture and Haptics) is a three-year international design research project investigating playful objects for people living with advanced dementia. The research is led by Professor Cathy Treadaway, CARIAD Cardiff Metropolitan University.

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We acknowledge contributions from Ageing Well in Wales, Office of the Older People's Commissioner for Wales, My Home Life Cymru, Alzheimer's Society, Age Cymru, Ty Hapus and Dementia Positive.

We kindly thank all workshop participants and the staff and residents of Pobl: Gwalia Care and Support.

LAUGH is funded by the UK Arts and Humanities Research Council grant ref: AH/M005607/1 (2015 - 2018)

www.laughproject.info
www.compassionatedesign.org

First printed 2018
Cardiff Met Press, Cardiff Metropolitan University, UK
ISBN 978-0-9929482-8-3

Arts & Humanities Research Council

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LAUGH

Compassionate Design: How to design for advanced dementia

INTRODUCTION

One of the major challenges facing the world today is how to care for the increasing numbers of older people in society and help them to live well, right until the end of their lives. The World Health Organisation and Alzheimer's International have identified the increase in numbers of people living with dementia as a particular challenge. Globally, about 47 million people were living with dementia in 2015, and this number is projected to triple by 2050. Designers need to be well informed if they are to create new products, services and environments to help meet the complex care needs of older people, particularly those living with dementia.

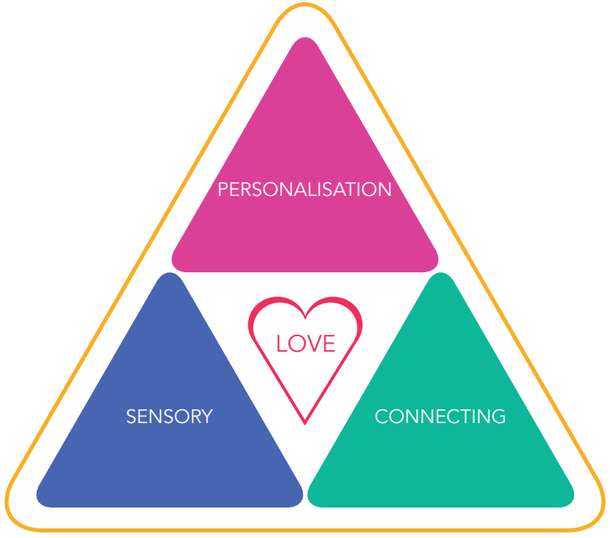
Those in society who have the greatest need for good design are often the most vulnerable; those who find it difficult or impossible to articulate what they want due to physical, sensory or memory impairment as a result of accident or disease. These people need innovative design solutions that are highly appropriate, customizable and sustainable. Finding ways to understand the challenges these people 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.

This book presents Compassionate Design. It has evolved directly from our experience of designing for people living with advanced dementia and is underpinned by international research from a number of disciplines including psychology, neuroscience and design. Our aim in this publication is to present the Compassionate Design approach and provide examples of designs that have been guided by its themes. Each design story illustrates a design solution for someone living with advanced dementia and explains its relationship to the three key themes of Compassionate Design: Personalised, Sensory and Connecting.

Using Compassionate Design, we believe we can begin to design a better world in which individuals living with severe cognitive impairment feel valued, retain their dignity and can experience loving connections with others. We know this is just the beginning of the story – there is more to do, learn and improve - but we have already found this approach useful and wish to share it with you.

Professor Cathy Treadaway, 2018

WHAT IS COMPASSIONATE DESIGN?



Compassionate Design has been developed directly from our research that has investigated how to design for the complex requirements of people living with advanced dementia. It has been influenced by research in the field of Positive Psychology, notably the work of Barbara Frederickson in the USA; and Positive Design methodology by Pieter Desmet and Anna Pohlmeyer in the Netherlands.

Compassion has been described as 'a sense of concern that arises when we are confronted with another's suffering and feel motivated to see that suffering relieved'[1]. It is a pro-active word that implies agency 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 loving-kindness 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 no longer be able to remember who they are.

1. Thupten Jinpa (2015) pp.xx A Fearless Heart Pub. Hudson St Press, New York

CONTEXT

Our design research has involved designing playful objects to support people living with advanced dementia and for the last five years we have been developing bespoke sensory objects that aim to connect people, make visiting easier and bring some fun back into their lives.

Dementia is the name given to a collection of neurodegenerative diseases of the brain for which there is currently no cure. Dementia presents in many different forms and impacts on memory, perception, cognition and behaviour. Each person has a different story to tell about the effect of the disease on their lives and its progression. For this reason, it is very difficult to generalize and to design one-size-fits-all solutions.

In our design research we have examined those aspects of brain function that are often least detrimentally affected by dementia, such as emotional and procedural memory. This includes ability to perform activities that are so embodied that they can be carried out automatically with little conscious thought. These skills or actions are often hard-wired through many years of lived experience or many hours of repetitive learning. When stimulated, these tacit skills can bring pleasure and connection to someone who might normally be considered withdrawn or disengaged from the world.

Reminiscence and memory objects are useful for stimulating and connecting people in the earlier stages of dementia. For those with advanced dementia however, it can be much more difficult to access the explicit memories of events, people or words. Language is often detrimentally affected making communication challenging. Memories are a vital component of who we are and help us to define our relationship with the world. Without our memories we loose our identity, self worth and have difficulty maintaining relationships. Design solutions that directly reference a person's lived experience can help communicate their identity to those with whom they interact - even if they can no longer remember who they are themselves.

POSITIVE EMOTION & WELLBEING

Everybody has the right to live well and experience happiness and pleasure until the end of life. Ensuring that people living with dementia have the potential to live well with the disease, experiencing pleasure, fun and laughter is vitally important. Good design can make a difference to the moment-by-moment interactions and everyday experiences of people living with dementia. It can help to shift attention away from the distressing negative effects of the disease, provide pleasure and stimulate joyful connection with others.

Dementia is a complex condition; each person's experience and symptoms are different and the progression of the disease is individual and unique. Although many people with a diagnosis of dementia experience memory problems, not everyone experiences the same level of impairment. A number of different memory systems exist in the brain and, even when memory is affected by dementia, not all of these are compromised. Even people living with the advanced stages of the disease may retain memories of activities and actions that have been practiced frequently throughout life so that they have become automatic (procedural memory). For example, someone who has practiced a craft skill, such as knitting, may continue to be able to do so although they may no longer be able to follow a pattern; or they may play a musical instrument but no longer be able to read the music.

In the later stages of dementia both logical and autobiographic memory systems are affected, however implicit emotional memories remain intact for much longer. For example, a person may not remember the identity of a loved one, but they will remember how they feel about them; or they may have feelings associated with an event, rather than the facts about what happened at that point in time. Objects can retain important emotional significance for a person and stimulate moments of clarity when past memories are revived and re-experienced.

People living in residential dementia care often suffer from boredom and depression; their lives are limited, often sedentary and lacking in hope. Design that stimulates emotionally positive implicit memories can help to lift someone living with dementia out of depression. Research shows that happy people take less medication, suffer fewer falls and hospital admissions and so there are significant personal and economic advantages to designing specifically to promote positive emotions from past experiences.

Designs can support the wellbeing of an individual living with advanced dementia by rekindling implicit memories that have the potential to make a person feel good. To design for positive 'in the moment' experiences it is important to understand the life story of an individual and focus on their positive attachments to objects and activities that bring them pleasure.

HAND-USE, HAPTICS & TOUCH

Hands become the primary means of interacting with the world beyond the body when a person's mobility and speech is challenged as a result of dementia. Hands and fingers can act as a conduit; exploring and translating experience of the world through the sense of touch and then responding to it outwardly from the body through gesture and finger movement. The hands contain a vast number of sensory receptors that detect texture, shape, pressure, temperature and pain. These are controlled via an area of the brain that is disproportionately large compared to those corresponding to other parts of the body. This signifies the importance of the hands in acquiring and responding to sensory knowledge. People living with dementia may experience confusing or contradictory sensory perceptions of the world around them as a result of the disease. However, touch appears to remain constant into the final stages, maintaining an individual's sense of familiar reality and providing comfort, security and sensory pleasure.

People living with the advanced stages of dementia are often chair or bed-bound and their experience of the world becomes largely confined to their immediate vicinity. Things to touch, handle and hold are increasingly important, providing sensory stimulation and purposeful activity. Agitation and anxiety can be relieved through having something to hold onto, provide a refocus of attention or relieve boredom. Touch can also trigger deep emotional and procedural memories. Different materials, surfaces and textures can trigger familiar sensations and provide comfort; for example, soft fur fabric can stimulate memories of stroking a favourite pet or wood and sandpaper stimulate happy memories of crafting in the garden shed.

Haptic touch, experienced through handling objects, can also stimulate sensory reawakening when a person living with advanced dementia has become withdrawn from the world. The brain's capacity to 're-wire' itself (neuroplasticity) can be encouraged by sensory touch via the hands. This can lead to surprising moments of clarity as different pathways in the brain are activated, providing access to aspects of a person's memory or language that had previously been perceived to be lost.

Research has shown that hand-use benefits emotional wellbeing. The effort-driven reward circuit, which is crucial in maintaining emotional resilience and avoiding depression, is activated in purposeful hand-based activities. Its activation results in the secretion of neurochemicals such as dopamine and serotonin, which contribute to the stimulation of positive emotions. In addition, having a sense of autonomy to determine whether or not to engage in an activity, and having the motivation to undertake it, are also vital for wellbeing. Activities that are hand-held, simple to accomplish, familiar and pleasant to touch can be comforting and rewarding for someone living with advanced dementia.

PLAYFULNESS

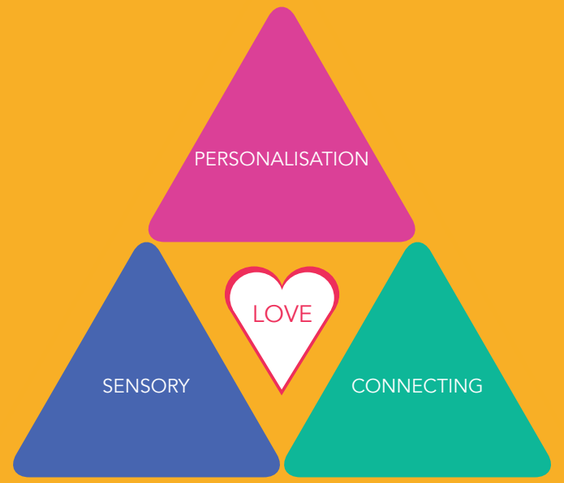
Play is really good for us. Playful or 'ludic' play has many benefits for our health and sense of wellbeing right through life, from cradle to the grave. Despite its acknowledged health benefits, play is frequently frowned upon in adult life unless it is goal driven and competitive. Playful play however has no goals and is not competitive – it is impossible for someone to be forced to be playful or it is no longer play.

Laughter and smiles are often generated in playful play and have many positive health benefits. Research has shown that laughter can lower blood pressure and boost the immune system. Smiling encourages positive connections between people; it is a signal that we want to belong. Laughter, smiles and giggles should be part of our experience throughout our life - right to the end. Designing ways to encourage this is particularly important for people living with advanced dementia since the progression of the disease makes communicating with others difficult, often resulting in a sense of isolation.

Playful activities make living in the moment much easier. They are great ways to connect people when conversation is difficult and so can make visiting times much more enjoyable and light hearted for all involved. Many people living with advanced dementia are chair and bed-bound but can still enjoy simple playful sensory activities, particularly those involving touch, gesture and sound. Hand-held objects are particularly attractive for someone who is frail and chair or bed-bound. Although dexterity may be compromised through other conditions (such as arthritis) the sense of touch is usually retained to the end of life. Designs for people living with advanced dementia can exploit the sensory pleasure of touch and the satisfying haptic stimulation received from activities that involve stroking, fiddling and fidgeting.

Playful objects can generate pleasure through their sensory and material properties and objects can become mediators between the person living with dementia, their carers and loved ones. They provide an alternative focus away from the deficit and loss that characterizes the disease. A person's attention can be directed towards a tangible thing, with physical material properties, that can be handled and discussed in conversation. Objects can also hold clues to the identity and past life of the person living with dementia and so can stimulate story-telling and reminiscence. They can do this on multiple levels at the same time. Each person brings to the object their own perception and related narrative; this may be based on sensory experience in the moment for the person living with dementia but highly charged with past experience and deep memories for the carer or loved one.

COMPASSIONATE DESIGN



Compassionate Design places loving-kindness for others at the heart of the design process.
It aims specifically to prioritise three constituent elements in the design process:

Personalised – *design to retain a person's sense of self and maintain dignity*
Sensory – *design to keep in the present moment and not rely on past or future*
Connecting – *design to encourage moments of high quality connection with others*

PERSONALISATION

One of the three key themes of Compassionate Design is Personalisation. To design appropriately for someone living with dementia it is essential to see the person and not the disease. By placing the needs and preferences of the individual at the heart of the design process it is possible to develop bespoke design solutions that can make a real difference to someone's life. A person-centered approach to design takes account of the difficulties they may encounter day by day as a result of living with the disease. It includes their personal preferences as well as information about their life history, including significant relationships and cultural background. A designer can obtain this through empathic observation; by engaging them in conversation (if they have capacity) and via life story information supplied by carers and loved ones. Past experiences that someone living with dementia may no longer recall for him or herself, nevertheless contributes to the person as they are now. By focusing on the individual in the context of their lived experience it is possible to design to help maintain their sense of identity and retain their dignity.

The inclusion of autobiographical themes within designs, such as references to a person's job or carer, their culture or family, can help to stimulate emotional memories for someone living in the advanced stages of the disease. They may not be able to remember explicitly what is being referenced but the sense of familiarity and associated feelings can be stimulating and pleasurable. Equally it is important to know whether there are subjects to be avoided, or themes that a person will find emotionally uncomfortable.

Designing for dementia is complex. The disease can affect a person's perception of shapes and tonal relationships. Lines and colours can 'misbehave' by normal design rules and design can be perceived as over or under-stimulating. Perceptual difficulties can also change as the disease progresses and there are no fixed points or certainties. A person living with the disease can experience a spectrum of constant variation from hour to hour. This highlights the importance of understanding and keeping the individual needs of the person central to the design process.

Music has been found to be particularly stimulating for people living with advanced dementia. Personalised playlists can quickly transport an individual back in time and provide an emotional release or lift a low mood. Finding the right musical choices is imperative, but when identified and integrated into designs, can bring extraordinary moments of reawakening for people in the later stages of the disease.

In the LAUGH project we have worked with family members, carers and the person living with dementia to develop a profile of their preferences, lifestyle choices, favourite music, colours, favourite smells and family histories. We call these 'portraits' and these have been used as the starting point for design ideas.

SENSORY

Our senses help us to perceive the world around us and can keep us ‘in the moment’; they can also help trigger emotional memories of past experience. Sounds and smells in particular can evoke a sense of place and time almost instantaneously and music can transport a person back to how they felt at a particular moment in their life. Design that specifically engages one or more of the senses can provide vital stimulation for someone living with advanced dementia. Our research has shown that sensory re-awakening can stimulate moments of lucid remembering and trigger verbal accounts of memory from those who were considered no longer able to communicate verbally. It can also enhance positive emotion, provide comfort and relieve stress.

The sense of touch is particularly important for those who have restricted mobility and are confined to a chair or bed. Exploring through touch, fiddling and fidgeting can be a way of relieving boredom, agitation and frustration for people living with cognitive impairment. By incorporating tactile surfaces, interesting textures and materials it is possible to specifically design positive opportunities for sensory touch to relieve stress and enhance pleasure.

Many older people living with dementia also have age related sensory impairments such as hearing loss or poor vision. Dementia can also impact on the interpretation of sound and visual perception resulting in hearing problems and disturbing visual effects. For some people, an overload of sensory stimulation can result in distress, while others need stimulation and benefit from it. When designing for people living with advanced dementia, appreciating a person’s sensory strengths and limitations is vital.

Music can have a particularly profound impact on people living with advanced dementia. Rhythmic sound can help stimulate movement and exercise. It can influence and enhance mood, lift spirits and sometimes enable a person living with advanced dementia to remember words when singing, even when speech is lost. Designs that incorporate playlists of favourite music or provide rhythmic vibration or sound can provide deep emotional comfort and soothe people who are agitated, in pain or distressed.

Our senses keep us ‘in the moment’ and don’t rely on past or anticipated future experiences, making them vitally important for those with impaired memory. Sensory communication is visceral and beyond words; it can reach into the emotional depths of human experience. When sensory designs work well for a person they ‘just feel good’ and can bring simple pleasure and contentment.

CONNECTING

Our connections with other people are fundamental to our health and wellbeing. Research has shown that we are interdependent beings and need social interaction to thrive. Loneliness and isolation have been found to have huge negative impacts on health and can lead to depression and other medical conditions; we need high quality relationships with others to flourish and live well. People living with advanced dementia become increasingly disconnected from others and the world around them as the disease progresses. Finding ways to keep these connections alive is vitally important which is why the theme of 'connecting' is one of the three key elements of Compassionate Design.

Maintaining relationships is difficult for people living in the advanced stages of dementia. As the disease progresses they may no longer recognise loved ones, the people who care for them or even remember their own identity. This can be very confusing and frightening. Finding ways to stimulate positive emotion that can help re-establish a sense of connection between people is vitally important. Smiles and laughter help us to connect socially; the touch of a caring hand or gentle embrace in a hug can lift the spirit and diffuse anxiety, agitation and distress.

Visiting someone living with advanced dementia can be very distressing for a loved one especially when they sense the person is withdrawing from the world and is unable to communicate as they once did. Finding things to do together, objects to share and activities to participate in can stimulate verbal and non-verbal communication that helps maintain the connections between people and sustain relationships. Research has shown that positive eye contact and close physical proximity can synchronize patterns of brain activity leading to empathy and mutuality. It is the eye-to-eye contact and loving touch of a hand that can produce the micro moments of love that give purpose to life and help a person living with dementia to live well with the disease.

Social activities can help people living with advanced dementia maintain positive connections with others. Objects designed for individual use can also stimulate conversation, both verbal and non-verbal with carers or visitors. Designs can incorporate aspects of a person's life story, family interests, cultural motifs and familiar places to help generate positive and affirming emotional memories on which conversations can be based.

Objects are also vital for maintaining an outward connection from the body into the world. They provide a person with a sense of autonomy, opportunity for interaction and a self-determined choice about whether to respond or not. These activities, although small, can be highly significant for maintaining the person-hood of someone with severely impaired mental capacity.

INTRODUCTION TO THE SIX THEMES

During the course of the LAUGH project we have worked with over 170 experts from 70 different organisations, finding out the fundamental issues that need to be considered when designing for someone living with advanced dementia. Using participatory and co-design workshops we have engaged our experts in playful and creative experiences and asked them to reflect on these activities in relation to caring for someone living with advanced dementia.

Through the insights gained from these workshops, we have identified six key themes we consider vitally important when designing for people with advanced dementia. They include:

- Nurturing
- Security
- Attention
- Purposeful
- Replay
- Movement

In the following sections we explain each theme in more detail and present a LAUGH design story reflecting this theme. Each story also explains how the design has been guided by the three key themes of Compassionate Design.

NURTURING

Human beings have an innate need to nurture and be nurtured. This instinctive desire is fundamental to the survival of the species; we need to provide for each other's basic human needs and give and receive love and companionship. We are not designed to be alone and research has revealed the negative impact of loneliness and isolation on health. Our nurturing instinct leads to activity that has a physiological impact on our bodies. When we give and receive love via hugs and cuddles, hormones in our brains such as oxytocin are released that reduce stress, boost our immune system and help build affiliative bonds that promote mutuality and attachment. Our first experience of this is from our mothers where we experience the soft touch of skin-to-skin; warmth, food and safety are provided within moments of birth while we are wrapped in her arms. It is no wonder then, that these deeply embodied memories are fundamental to who we are. They stay with us as positive feelings that we experience when someone gently holds our hand or by touching soft materials or being wrapped in a warm towel.

Many people living with dementia have nurtured families, raised children and grandchildren and lived busy lives involving caring for others. Activities that stimulate positive feelings associated with these important life roles can provide purpose and pleasure and help them to redefine to themselves their sense of humanity. Visits from families with children and babies can provide huge pleasure for a person who has enjoyed family life. Young children experience life in the moment and often have huge rapport with people living with dementia, for whom life is also best experienced in that way. They bring activity, movement, smiling faces, laughter and a sense of simple fun. Dolls, teddy bears and soft toys can also provide substitute experiences to nursing a baby or caring for a small child as well as stimulate interaction with young visitors.

Our desire to nurture others is expressed in many different activities that are not all human focused. Many people express their nurturing instinct through keeping a pet, looking after animals or feeding the birds. Some care homes have resident pets and visitors are often encouraged to bring animals that can be stroked by residents. Soft furry fabric can also provide comfort to someone who has kept a pet or who likes contact with animals.

Nurturing activities can be extended to plants and nature. Research has shown that even the simple task of caring for a pot plant can benefit a person's health and wellbeing. Many people have taken pleasure in outside activities throughout their lives and so objects and activities that reference gardening, plants, flowers and trees can stimulate positive nurturing emotions.

Hug

Hug is a soft wearable textile object. It has extended arms and legs that are weighted in order to wrap around the body and provide the physical sensation of a hug. It contains embedded electronics with small speakers that can be programmed to play a selected playlist of a person's favourite music. It has a beating heart that is activated through movement via a small electronic sensor inside the body cavity.

Hug was designed for a lady with advanced dementia who was bed-bound, had frequent falls, poor appetite, little verbal communication and limited hand and finger movement. Her carers considered that what she needed most of all was a hug.

Hug is cushion-like but also reminiscent of a soft toy or doll. It is highly personalised and plays her favourite music - a selection of Vera Lynn songs. The outer casing is made from a velvet pile polyester fleece that is washable and stuffed with a polyester fibre. The electronics are rechargeable and easily removed to enable Hug to be washed.

When Hug was given to the lady for the first time she responded positively by holding it close as if she were nursing a small child. 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, most significant of all, she had no falls after being given Hug.

SECURITY

Like nurturing, feeling safe and secure is another fundamental human need. We are hard wired for danger and our body's emotional response system is automatically primed for 'flight or fight'. A series of physiological responses are triggered when we sense danger or feel insecure resulting in the release of cortisol, a hormone that can have damaging implications for health if produced in excess over a period of time. Having a sense of security is therefore vital for maintaining wellbeing. Objects and environments that enhance a person's perception of being safe or reference things that help make them feel secure are very important.

Many people living with dementia are no longer able to care for themselves in their own home and enter residential care 'homes'. Without familiar things around them and in a new environment that can be disorientating they can feel very confused, insecure and often try and leave to go 'home'. Finding ways to evoke the positive associations of what has constituted home for a person living with dementia can reduce stress and help a person feel more relaxed and 'at home'; familiar objects, possessions, clothing and furniture in a person's room can help. Their favourite armchair, a family photograph, familiar jewellery can elicit positive emotional memories and help them feel safe.

Objects and personal possessions that we have around us everyday help to maintain our sense of personal identity. These things can speak to others about our lived life, past experiences and current preferences. For a person with advanced dementia who has difficulty communicating verbally, personal possessions can help convey who they are, their values and interests. Keeping personal objects and possessions safe when living with the confusion of the disease and in an unfamiliar environment, can become a reasonable concern. Boxes, bags, pockets handbags, wallets, purses, pens, key rings and money often become a preoccupation for a person living with dementia in their desire to keep their possessions safe. Having familiar things such as these to touch and hold can be very comforting.

When mobility is limited, the armchair or bed may become the person's immediate world and so designs need to be manageable in the space and accommodate how someone might use them seated, without requiring extended reach. Objects that are on the body, can be held in the hand or sit in the lap, with the potential to be explored with the hands or held close to the body, can give a person living with dementia a sense of ownership, autonomy and security.

Fidget Jewellery

A jewellery box was designed in response to this theme. It contains three pieces of simple personalized jewellery designed to rest in the palm of the hand and provide something to fiddle with and touch. Each one contains a series of strung beads and similar small objects that reference the hobbies and preferences of the person for whom it was made. The beads are strung on extra strong thread spun with a wire core and can be slid up and down or rattled to make a noise. The jewellery is handmade and designed so that it can be easily replicated and personalized by anyone using simple craft skills.

This jewellery box was made for a lady of 92 who was particularly fond of beads and pearls. She was able to hold the box in her lap and determine for herself who she would permit to look inside. The jewellery pieces are designed to stimulate the senses and are highly personalised. The jewellery included a seaside themed piece containing pearls, shells and driftwood and another referencing textile crafts she had once practiced as hobbies, with threaded buttons, lace and embroidery. The pieces are designed to rest gently over the fingers and dangle into the palm of one hand where they can be manipulated by the fingers of the other hand.

When given the box for the first time, the lady it was designed for chose the shell themed piece, which she touched gently and then spoke a full sentence for the first time in many weeks: ‘I used to like going to the beach,’ to the amazement of her carers. The jewellery was subsequently used by her carers to stimulate conversation and share songs and rhymes together.

REPLAY

Objects, environments and activities that reference past life experiences can stimulate positive emotional memories and bring pleasure to people living with dementia. Reminiscence objects can also help increase opportunities for playfulness, creativity and imagination. Playfulness however, is often inhibited by carers and family members, due to the perception that a person must conform socially in order to maintain dignity and self-worth. Playful objects and collections of things that are personally meaningful can be used to help give a person living with dementia the self-permission to be playful.

Reminiscence is an excellent way of stimulating memory and conversation when people are living with the early to mid-stages of dementia. Rummage boxes containing memorabilia that reference a person's lived history have been shown to be pleasurable and highly effective in stimulating interest and conversation. However, in the more advanced stages of the disease, when autobiographical memories are impaired, reminiscence is less about remembering experience, but rather to evoke pleasurable emotional memories. The secret is finding the kinds of forms, shapes, materials, images, sounds or activities that can trigger positive emotional memories for an individual.

Music has been found to be one of the most significant and easiest ways to help someone to reconnect to good times in their lives. A particular genre of music or favourite song can instantly affect mood and take us back in time to particular people, places and things. Discovering what kind of music a person living with advanced dementia is engaged by and incorporating favourite playlists into designs, can help bring immense pleasure and be used to help soothe, engage or stimulate them.

Many people living with dementia have a different perception of what constitutes reality as a consequence of the disease. Their individual experiences have unique psychological validity and are no longer framed in the same way as those around them, often leading to misunderstanding and confusion. A compassionate approach looks for opportunities to enter the perceived reality of the person and find ways of supporting them through their experiences. Humour, fun and playfulness are excellent ways of doing this. Objects that are designed to create open and imaginative experiences, full of sensory experience to keep the activity in the moment, can bring a person living with advanced dementia joy, fun and laughter.

It is possible to incorporate a wide range of sensory and reminiscence cues into designs using embedded electronics and digital technologies in order to make them highly personalized and deeply meaningful for the user.

Telephone

The wooden box contains a retro telephone with a dial mechanism and handset. When switched on it rings spontaneously and following the traditional dialling tone sound, plays a random music track from a pre-programmed favourite playlist. The sprung dial mechanism, operated by inserting a finger, is designed to prompt procedural memories through haptic touch and is reminiscent of analogue telephones that existed prior to the advent of press or touch button devices. A number can be dialled to randomly select a favourite music track and any combination of numbers will work. The hand-set containing the speakers is attached to the box via a coiled cable.

The telephone was initially developed for a lady who had grown up in Spain and whose first language was Spanish. People living with dementia often revert to their original mother tongue in the advanced stages of the disease. Hearing that language spoken or sung can be very comforting and reaffirming.

On the first iteration of the telephone design, dialling any combination of numbers selected sounds files containing pre-recorded Spanish conversation and music. However, the telephone proved to be popular as a social activity amongst other residents and stimulated conversation, singing, laughter and smiles. The sound files were re-programmed to contain culturally relevant music familiar to those people who were sharing the device.

ATTENTION

People living with advanced dementia can become agitated, stressed, anxious and confused as a result of memory impairment and the perceptual challenges as a result of the disease. Finding ways to refocus attention and keep activities 'in the moment' has huge benefits not only for the person who is experiencing the distress but also the person caring for them.

Many routine activities of daily life can become daunting for a person living with profound memory impairment. Intimate activities like washing and dressing, with the help of a carer who may feel like a complete stranger, can be very distressing. Distractions that are positive can reframe a potentially stressful situation and provide comfort and pleasure. The 'Attention' theme is all about bringing someone back to being 'in the moment'. One of the quickest ways to do this is through humour. Laughter and smiles forge reconnections with a person who is anxious and agitated and helps them to appreciate that they are loved, accepted and safe.

Attention is a socially oriented theme and incorporates the idea of mutuality, sharing and inclusion. Someone with declining ability to communicate verbally will inevitably begin to withdraw from the world around them; finding ways to grab their attention and reconnect with them is essential if they are to feel loved and valued.

Boredom and lack of purpose can lead to depression and apathy. Providing objects or activities that stimulate the senses can engage a person and give them something to do. Touching sensory textiles and manipulating objects with moving parts, wind chimes or kinetic mobiles can provide a focus of attention for someone who is sedentary or bed-bound.

Music is often a great way of gaining attention, changing a mood and diffusing stress. Singing, beating rhythms and clapping to music can quickly engage and absorb a person living with dementia. Adding music and rhythm to an activity, for example singing simple songs or reciting rhymes and poems, can add motivation to complete a task or redirect attention away from what might have been a stressful situation.

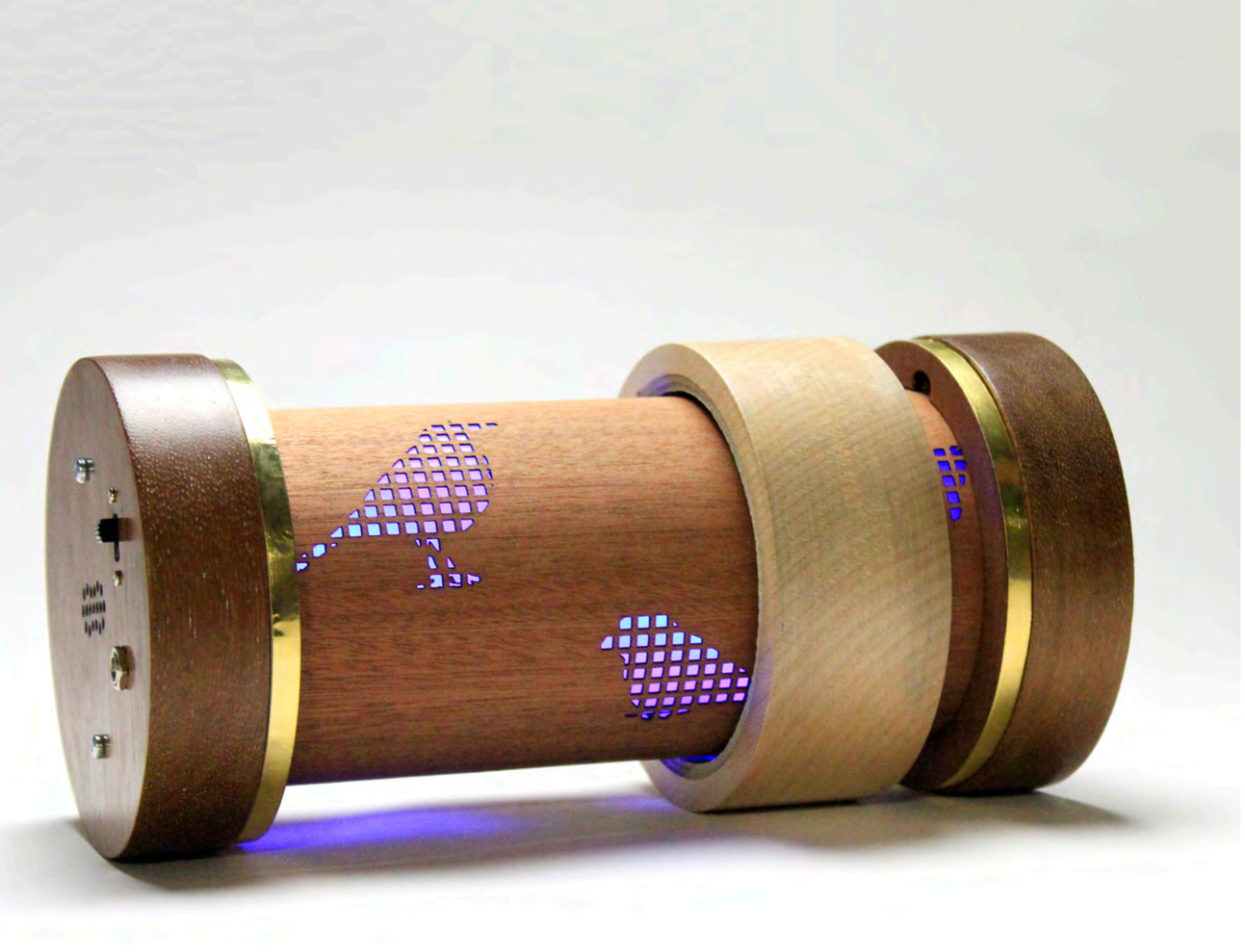
Giggle Balls

A set of small hand-held felt ‘Giggle Balls’ were developed in response to this theme. Each ball has a simple laughing face and contains embedded electronics that when activated produce the sound of a laughing child. Each ball has a different face and a different laugh. The balls are soft, warm to touch and rest easily in the palm of the hand. They can be washed and the electronics are contained in a small removable pouch attached to the inside of the Giggle Ball.

The balls were originally designed for a lady of 96 who had enjoyed playing bowls; she had a large family and loved children. The three balls contained in a box were designed as a social activity to stimulate fun and laughter between people sitting together in a lounge. The box can be passed around and a Giggle Ball selected, held in the hand and shaken to activate the giggling.

The reaction to the Giggle Balls has been mixed. Some residents found them amusing but others were disturbed by them. The carers, however have found them very useful and use them to relieve moments of stress, change a difficult mood and stimulate laughter.

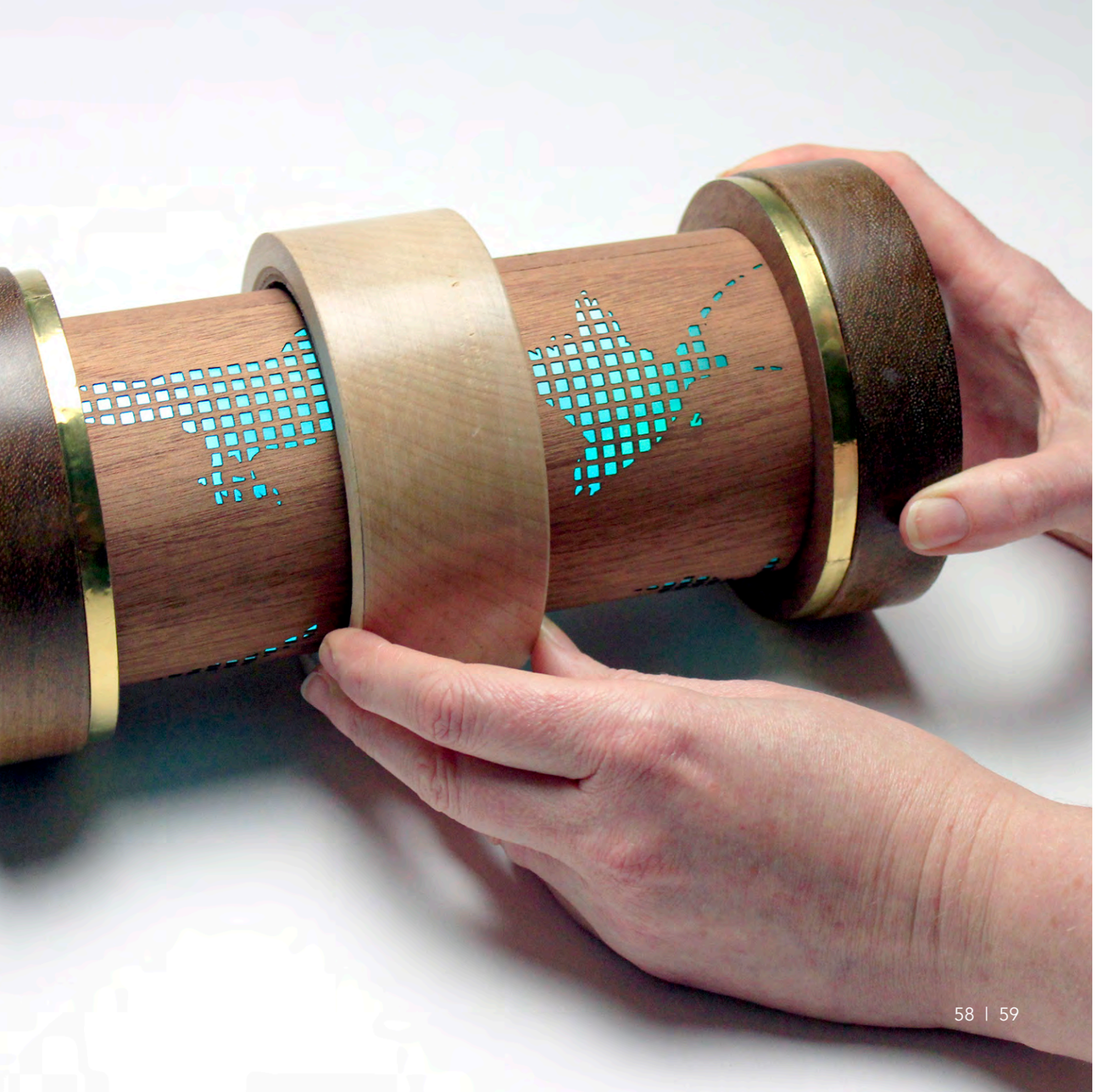
PURPOSEFUL



Having a purpose to life is another fundamental human need. Often ‘purpose’ is acquired as a result of a job, skill or profession and helps to define the identity of a person. As dementia progresses, a person’s sense of competency diminishes and activities that were once meaningful and engaging may become frustrating, reinforcing the sense of loss of self they may feel. To be purposeful an activity needs to motivate a person’s intrinsic desire – they have to want to engage in the activity for themselves and derive some pleasure in doing so. Any activity that is too complicated, or places a high cognitive load on the person living with dementia, is likely to reinforce their awareness of lost skills and undermine their self-confidence. Finding just the right level of interest and challenge is not always easy. Understanding the person, how the disease is affecting them at that moment in time and what motivates them is the key.

Often, when people move into residential care or hospital, everything is done for them and this can result in a lack of purpose in life. They feel they can no longer contribute to their own care and give up doing some things they were quite capable of doing for themselves. Finding ways of providing opportunities for them to continue to engage in domestic activities or contributing their own care can help provide a purpose to keeping going with life. Simple yet meaningful activities such as helping to fold napkins and clothing, dusting, laying the table and washing up can deliver the rewards of social appreciation and sense of achievement. As dementia progresses, finding ways to reframe activities so that they can be achieved without a sense of failure and reinforce a practiced skill are important. One step activities, for example, sanding a piece of wood or untying knots on a length of string, can provide simple purposeful satisfaction.

The experts that helped inform this research noted that there are subtle gender differences in the kinds of purposeful activities that are found to be rewarding. They noted that men often like to take things apart whereas women are more likely to enjoy repetitive tasks. Although these are generalisations, cultural upbringing, employment roles and societal attitudes may contribute to very different perceptions and experience of what may be considered purposeful to a person living with advanced dementia.

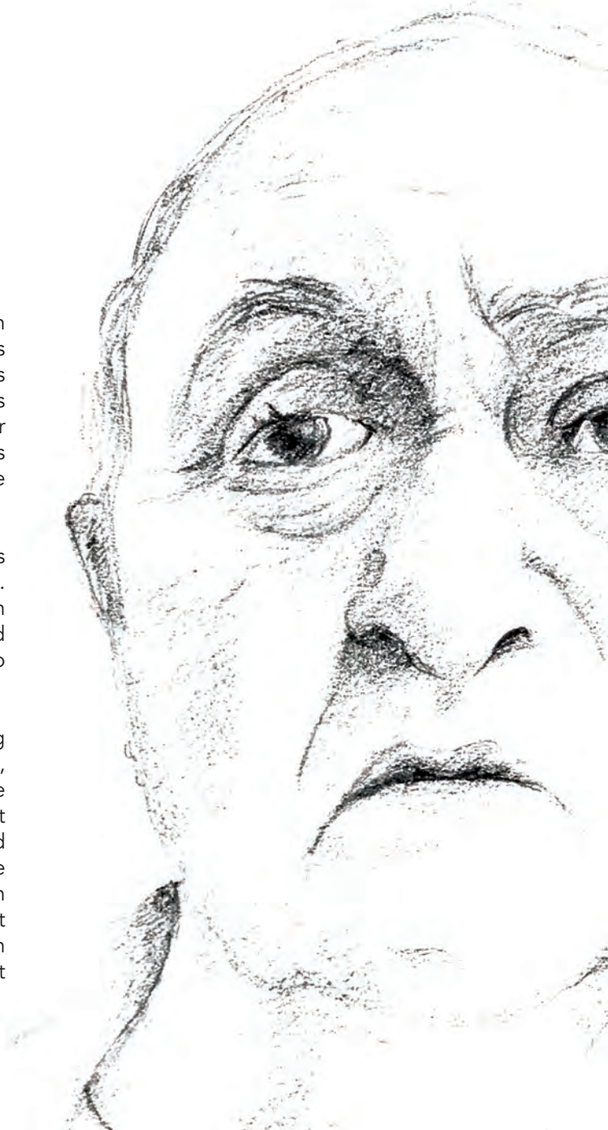


LUMA

Luma is an interactive hand-held crafted wooden object. When activated, a central tube that is decorated with laser cut garden bird silhouettes is illuminated. As the outer turned wooden ring slides along the tube, the internal lights change colour and bird song sounds are activated. Small speakers are contained in the two wooden end pieces. The object is rechargeable.

LUMA combines digital and hand craft processes including laser cutting, CNC cutting and 3D printing. It was developed in collaboration with craftsmen from Squirrel's Nest Men's Shed Tondu who turned the wooden rings and the LAUGH design team who used digital fabrication technologies.

The object was designed for a gentleman living with dementia who had become very withdrawn, apathetic and bored. LUMA was designed to be pleasing to hold and aimed to stimulate his interest via the potential to modify light, colour and sound with ease. This object was developed in response to this resident's lack of interest in objects for which there was no apparent purpose. The design concept was stimulated by the idea of feeding the birds in the garden and references the shape of a peanut bird feeder.



MOVEMENT

People living with dementia often have declining ability to perform purposive actions, to move and keep their balance. As the disease progresses they are likely to become increasingly sedentary and perhaps eventually bed-bound. Poor posture and unsteady movement can also be indicators of depression and finding ways to motivate a person to move can have multiple health benefits. Movement provides much needed exercise that oxygenates the blood, stimulates the brain, reduces agitation, improves sleep, boosts the immune system, decreases stress and so promotes well-being and self-confidence.

From birth we have an instinctive desire to move and often this is stimulated by music and rhythm. Dance has been found to improve mood and body awareness, increase social interactions and physical capability for people living with dementia. When people living with the advanced stages of the disease are no longer able to walk or dance, they may be still capable of moving their upper body, arms and hands. Movement can bring them sensory pleasure and help keep them connected to others through gesture and body language that can convey deeper emotional information than simple words. Research has shown that music accompanying movement is able to arouse emotional memories and can sometimes stimulate lucid moments of reawakening in people considered unable to communicate.

Movement, however small can stimulate ‘in the moment’ sensory pleasure. Repetitive motions such as rocking can be very comforting and soothing, especially as a response to music. Hand movement, which might include finger tapping, folding, picking, fiddling and fidgeting can provide important sensory stimulation for someone living with advanced dementia who is no longer capable of moving around themselves.

Design can be used to rekindle the sense of movement and the associated pleasurable feelings. When a person is confined to a bed or chair for many hours each day, finding ways to stimulate the sensation of being outside, walking in nature, or to be able to re-experience the joy of driving a car or bicycle can be really important. The sensory pleasures derived from these activities are not just visual; haptic and auditory cues, such as vibration and sound help to stimulate positive emotional memories of movement.

Steering Wheel

Steering Wheel is a hand-held object designed to replicate the sensory activity of driving a car. It has embedded electronics that provide vibration, flashing indicator lights and a simulated retro tune-in radio (complete with white noise) that plays a pre-programmed playlist of favourite songs. The dashboard has a speedometer and fuel gauge. Once activated, the steering wheel provides haptic stimulation via the hands through small vibration motors. These are embedded in the leather casing of the steering wheel to give the sensation of a running engine and feel of a quality motor car.

The steering wheel is highly personalised through the favourite music play list. It provides opportunities for a person living with dementia to connect with carers and family by encouraging reminiscence about road trips, holidays or types of vehicles that the person has owned or driven. It helps stimulate hand-use and upper body exercise and can rekindle emotional memories of movement for a person who might be chair or bed bound.

The loss of permission and opportunity to drive has been shown in our research to be particularly distressing for men living with dementia. This object was designed for a man who missed being able to drive his car and who had worked as a motor mechanic for a road-side assistance organisation. When given the steering wheel, he was visibly delighted. He ‘drove’ his wheelchair into the lounge and then took an imaginary a road trip to the seaside. His carers encouraged him to experience the sensation of going around bends and parking the car by moving in tandem with him.

COMPASSIONATE DESIGN MANIFESTO

Together we can design a better world for people living with dementia

We believe that compassion helps us to see the person and not the disease and that moments of positive connection can inspire loving relationships

We are committed to designing products, places and services that stimulate the senses, bring pleasure and reconnect people living with dementia with carers and loved ones

We believe that there is no simple solution, no one size fits all, no single answer to the problem of living with the disease but that we can design for positive experiences, moment-by-moment and day-by-day.

Our aim is to design with compassion, share with joy, communicate with sincerity and make a contribution to building a dementia friendly world.

www.compassionatedesign.org

Compassionate Design: How to design for advanced dementia

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LAUGH is funded by the UK Arts and Humanities Research Council grant ref: AH/M005607/1 (2015 - 2018)

First printed 2018
Cardiff Met Press, Cardiff Metropolitan University, UK
ISBN 978-0-9929482-8-3

Arts & Humanities Research Council

Cardiff Metropolitan University | Prifysgol Metropolitan Caerdydd

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People living with advanced dementia become increasingly withdrawn, isolated and 'locked-in'. Since there is currently no cure for the devastating disease, finding new ways to improve a person's quality of life and help them live well with the disease are urgently needed.

This book aims to help designers understand how to design for advanced dementia by using a Compassionate Design approach. The book provides examples of design solutions that have been designed for people living with dementia using the three key themes of Compassionate Design: Personalised, Sensory and Connecting. Using this approach, the book shows designers how they can begin to design a better world in which individuals living with severe cognitive impairment feel valued, retain their dignity and can experience loving connections with others.

For more information about Compassionate Design visit:
www.laughproject.info
www.compassionatedesign.org

ISBN 978-0-9929482-8-3