

Sensory design for dementia care: 3 stories

Anke Jakob, Kingston University London

Helen Manchester, University of Bristol

Cathy Treadaway, Cardiff Metropolitan University

The three stories told here represent results of three research projects investigating design for dementia care and its impact. Each of these individual projects ('Tangible Memories', 'Sensor e-Textile'/LAUGH, 'Multi-Sensory Environments in dementia care') has been led by one of the three authors (see above) and received funding from the Arts & Humanity Research Council (AHRC) in UK.

With "Experimenting with sound" sociologist Helen Manchester reports on the impact of the 'immersive sound' rocking chair created together with experience designer Heidi Hinder and computer scientist Peter Bennett. The chair provides the experience of nature for people living with dementia who might find it difficult to go outside. Its design emerged from the 'Tangible Memories' research project (tangible-memories.com). The project has been working on co-designing a set of new digital tools and explores how tangible technologies might be developed in a co-design process to enhance democratic community building and to engage residents in care homes in multi-sensory experiences.

In "Bill and Elaine's story", designer Cathy Treadaway shares her experience of co-designing a sensory blanket for a person living with advanced dementia who was chair/bed bound, almost blind and without verbal communication, and his carer. The blanket, developed together with textile designer Helen Watkins and computer scientist Stephen Lindsay, is one of the outcomes from the 'Sensor e-Textile' project completed in 2016 which is now informing current LAUGH design research (laughproject.info). Within the later the research team is developing a number of playful objects that stimulate, engage, soothe and give pleasure to people living with the advanced stages of the disease. Methodologies involved include co-design and participatory Compassionate Design approaches.

"Paradise room" is a story about a care practitioner working in a care home in London which participated in research investigating the design and use of 'Sensory Rooms' - also called 'Multi-Sensory Environment' (MSE) - in dementia care. Designer Anke Jakob, together with occupational therapist Lesley Collier, explored how the performance and success of such spaces can be improved through design to the benefit of care home residents, especially people in late stages of dementia, their relatives and care givers. (kingston.ac.uk/sensoryroom). Based on the outcomes of the project's ethnographic study which included observations of environments and facilities on offer in 16 care homes and semi-structured conversation with care staff, the research team developed initial design guide lines on best practice regarding multi-sensory engagement of residents and sensory enriched spaces that meet the specific needs and preferences of people living with dementia, their families and the care homes they live in.

Experimenting with sound

by Helen Manchester

As an ethnographic researcher interested in lifelong learning, more tangible ways of knowing and stories I wanted our work to acknowledge the different material and immaterial prompts, responses and forms of sense making that older adults engage in through recognising our connections to 'things' as well as people, to the evocation possible through visits to places, through smells and through music. I wanted the team to appreciate and encourage the creative acts of cultural collection and production through which people make sense of their own lives and identities and make connections with the lives of others. Through our developing relationships we hoped to enhance opportunities for older adults in 'the fourth age' to share and make sense of their lives and their sense of self now and to think together about their possible future

lives, perhaps better coping with the often intense feelings of loss and instability that they may experience as they move into and live in care home settings.

In a facility for those with more advanced dementia we were often greeted by residents asking us to 'let them out' or by others walking along the corridors with coats on or over their arms, looking to leave at the first opportunity. This is, of course, partly a symptom of their illness but we also noticed a disconnect from the outdoors and nature for these residents, although these aspects of their previous lives were often discussed in conversations with us. For instance, Barry would discuss his cycling holidays and Enid her days out on the coast. As a result of these conversations and observations we worked alongside residents and staff to develop a prototype that enabled us to bring nature into the care setting, which we felt could be a therapeutic experience for those unable to get outside and experience nature firsthand. The prototype is an 'immersive sound' rocking chair that plays sounds from nature, music and poetry, played through speakers in the chair's headrests, and activated by the rocking motion. As the residents gently rock and listen to the dawn chorus, or to crickets singing on a summer's evening, their journeys of the imagination can rekindle past memories and help to assist story sharing.

Residents' reactions to our prototype chair were varied and left lasting impressions on all involved. Margaret, a former pilot, spent some time exploring the surface of the chair through touch, commenting that it reminded her of the cockpit of an aeroplane. Then, listening carefully to the different sounds emitting from the speakers embedded in the rocking chair's headrests, she identified a woodpecker and an owl's call among the chorus of birdsong, and she even cooed back to the owl in reply. As she heard the rhythmic sound of someone walking on snow, she lifted her legs up and down in time, keeping apace with them, and describing a vivid story to us about what was happening in her imagination: 'The farmer's on his way'. Jean, who usually doesn't speak or sing, sat in the chair and sang 'Rock a Bye baby' from beginning to end, causing an emotional response from the care staff present. Further testing of the immersive sound rocking chair in additional settings has suggested a positive therapeutic benefit for those living with more advanced dementia through sensory engagement with the natural world.



Bill and Elaine's story

by Cathy Treadaway

Bill and Elaine lived near Swansea in South Wales. Their shared pleasure had been to walk together in the grounds of Aberglasney House, an impressive historic building set in beautiful gardens. Even after Bill had been diagnosed with dementia their walks continued, until Bill became so disabled by the disease that he could no longer be taken out of the nursing home. The care staff in the home suggested to our

research team that Bill would benefit from a sensory object to help calm him. His wife Elaine spent several hours every day in the care home and was keen to tell us about Bill's preferences and provide a short biography to help inform the design process. In particular, she explained the pleasure Bill had walking with her in natural surroundings - particularly through the formal gardens at Aberglasney. He loved the trees and wildlife and Elaine longed to be able to take him back to the sensory experiences of nature that they had shared together.

Our research team focused on developing design concepts that would use embedded technology to provide highly personalised sensory experiences. Materials experts, computer scientists, engineers, textile designers, health professionals and carers were brought together in a series of co-design events in which the ideas were discussed, formulated and prototyped. Using the formal gardens as an inspiration for the layout of the surface pattern, fabric was selected with appropriate colour and stimulating texture and stitched to construct the base layer. The textile designer used specialist stitch and print skills to develop tactile embellishments including a stitched tactile fabric book, zippers, buttons and embroidered sections. Simple touch sensitive electronics were developed using a Touchboard microcontroller attached to metal clothing buttons to add nature sounds: birdsong, running water wind in the trees etc. A textile designer with some understanding of electronics used conductive stitch techniques and snap fasteners to integrate the electronics into the base textile. The electronics were positioned in a leatherette pouch that could be removed from the blanket and wiped clean using antibacterial wipes; the base textile was fully washable.

Bill and Elaine were given the blanket and within twenty minutes the research team observed that Bill was able to deliberately reach out and touch the buttons to operate the sound. Video recordings made at the time evidence that the textile immediately provided stimulation and interest. Elaine commented on how the blanket rekindled for the couple a sense of intimacy. Hand in hand they could go for a walk at Bill's bedside and once again experience nature sounds together. For Bill, the sensory experience provided in the moment pleasure and for Elaine reminiscence of good times walking together. Elaine treasured the blanket and chose not to leave it in the care home but to take it with her when she visited Bill every day. It became a special activity that she alone shared with her husband.

The design for the blanket fits with the key components of Compassionate Design; it is personalised, sensory and designed to stimulate connection between Bill and his wife. The pleasure experienced was shared and their enjoyment together continued until Bill's death. The textile remains as a treasured reminder to Elaine of their lives together and has become a memorial object that is helping her to come to terms with the death of her husband.



‘Paradise room’

by Anke Jakob

During my first visit, Lydia, in charge of coordinating and organising activities for the residents of a care home in London, took me around the place introducing me to other members of staff as well as to some residents. I immediately noticed her enthusiasm, empathy and passion for the residents she provided for and for her work. Proudly, she showed me the improvements she had achieved to make the communal areas more interesting and inspiring for the residents. However, she also voiced her frustration about numerous critical issues and the slow progress she was making in initiating change regarding the environment. She was particularly frustrated about the home’s ‘Sensory Room’ complaining about how this room had become nothing more than a ‘dumping space’ where unused furniture or other items were placed. Lydia knew that she and her colleagues would need to provide something better and talking to me seemed to have an inspiring as well as reassuring effect on her. Our lively conversation, a semi-structured interview using a questionnaire, about sensory enrichment and meaningful activities lasted more than 2 hours. It provided valuable insight, knowledge and data for our research. For Lydia, our meeting was the instigator to act - encouraging her to make this room an accessible and positive experience for her residents.

After 9 months Lydia invited me to visit again and view the newly transformed space what was previously the ‘Sensory Room’. During my first visit, the room was cluttered with furniture and various items, some broken or dysfunctional. Although a spacious and light room with direct access to the garden, its appearance was uninviting and confusing. Most of the time it was locked. The situation after the refurbishment had significantly changed to the better through few but effective implementations of suggestions regarding the spatial arrangement I had made during my previous visit. After decluttering, one side of the room was transformed into a pleasant lounge featuring wallpaper with a life size image of a 1950s kitchen and new, elegant furniture and curtains with colouring matching the colours in the image. As advised, a LED projector and a new sound system had been added replacing the low quality transportable CD player. Further, Lydia had plans to install a sensory enriched curtain for dividing the space and adding flexibility in terms of multiple use. The open door now invites the residents to stay and from here to stroll into the garden.

According to Lydia, feedback from residents has been very positive. Liked for its stimulating, yet calm and soft atmosphere a destination has been created regularly frequented by the residents as well as staff members and relatives. It is often used for relaxation helping to reduce agitation and stress. This applies not only to residents with dementia but also to residents with other mental health issues and Asperger’s Syndrome. Remarkably the new room is not called ‘Sensory Room’ by the residents, rather ‘quiet room’, ‘beautiful room’, ‘lovely room’ etc. Lydia was particularly pleased about a resident who used to express his distress by shouting and abusive behaviour, and who feels better and calm when spending time in the new space. One day she was particularly moved by his response to feeling overwhelmed and distressed as he said to her: “I cannot take it anymore; can I go to PARADISE ROOM now?”



