

Conversations at the Edge of Play: Media, communication and cultural intersections with dementia.

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Conversation at the Edge of Play: Media, communication and cultural intersections with dementia discourse

The mean age of the global population is increasing significantly. Incidences of dementia are also predicted to rise and this will impact society as a whole as well as individuals, who will find they are primary carers for one or more family members with the disease. Dementia carries a stigma and is not openly discussed. Discourse continues to be led by bio-medical approaches that focus on the need to ‘fight’ the disease and often leaves individuals feeling ill prepared and powerless to act.

This paper reports on an innovative approach that engages with material culture production; it uses textiles as media to encourage people to share their personal experiences of dementia. The pilot project involved the general public in the making of bespoke sensory objects to promote ‘in the moment pleasure’ for people with later stage dementia, while facilitating an exchange of information about dementia both formally and informally with participants engaged in the making process.

The study found that while participants’ individual knowledge and understanding of dementia varied significantly, each participant was able to contribute, share their knowledge and become empowered through activity.

Keywords: dementia; ageing; media; communication; textiles; creativity; play; design.

(6400 words)

Introduction

Scientific and medical advances and improved social and economic conditions have resulted in more people than ever before living into advanced old age. This has implications both for society and for individuals. Limited economic resources and social change with regard to how care is undertaken, is pushing towards a deinstitutionalisation of general care as aged and dementia care facilities primarily focus on palliative care, chronic illness, and the specialised care of those in advanced old age and the later stages of dementia (Commonwealth of Australia 2010). Personal choice and limited access to and availability of residential care facilities means that people are staying at home longer and many people living with dementia, some undiagnosed, will remain living

in the community for most of their lives. Furthermore, family members and informal carers, in all likelihood, will take on the responsibility of caring for more than one older members of their family (AIHW 2013, Commonwealth of Australia 2010, World Health Organisation 2012).

What type of care is needed and how care is undertaken and supported in the community is influenced by the public perception of the disease (Kitwood 1997). These perceptions continue to be shaped, through bio-medical and economic discourses (Adams and Manthorpe 2003 p 5, Mitchell, Dupuis, and Kontos 2013). Such viewpoints foreground the need for a cure and the primacy of scientific and medical research and pharmacological solutions, and highlight the economic implications of not finding a cure in light of the globally ageing population (Mitchell, Dupuis, and Kontos 2013). Dissemination of information about dementia has often taken the form of awareness campaigns that position a cure as *the* solution to the problem of dementia; focus on ‘fighting’ the disease; provide tool-kits for getting personal and economic affairs in order following diagnosis; and prepare individuals and family members for the debilitating impact of dementia (BRACE 2015, Swaffer 2016). But, this approach can promote fear as members of the general public feel overwhelmed by the enormity of the issue; powerless to act; ill-equipped to ‘fight’; and feel they do not have the required ‘expertise’ to make a valuable contribution. To empower individuals and communities to act, it is necessary to remove the stigma around dementia and bring issues relating to ageing and dementia into popular discourse. This enables members of the general public to be part of the conversation about care, who does it, and what form it takes. The challenge is how to introduce the potentialities of non-clinical approaches into existing discourse, and communicate possibilities to the general public.

There has been a noticeable growth in psychosocial approaches that acknowledge the emotional reality of living with dementia (Adams and Manthorpe 2003 p 60) and a growing understanding of the importance of social and cultural aspects of health and wellbeing (Kelaher et al. 2005, Kenning 2015b). Innovative, creative and arts-based approaches are empowering communities

by showing them they have an important role in supporting healthy ageing and in finding ways to improve the quality of life for those living with dementia (Cutler 2009). This paper argues that people living with dementia, family members and primary carers, health care professional (all stakeholders in dementia care), and members of the general public, are central in the setting up of innovative, creative, effective non-clinical approaches and in how they can be disseminated deep into communities (Treadaway and Kenning 2015, Treadaway, Kenning, and Coleman 2015). It discusses a pilot project that uses craft textiles as media (Mitchell 2012) in a making workshop or ‘funshop’—referencing John Killick’s suggestion that workshops should be about fun not work (Killick 2013)—to address issues relating to dementia and to breakdown the associated stigma. The study was conducted with the aim of making objects and activities that provide sensory stimulation for people with dementia, while gaining insights into the current level of understanding of dementia and raising awareness of the disease in the community.

Background

Ageing and dementia

An extended lifespan together with a reduction in fertility rates is causing an on-going global shift in the median age of the population (World Health Organisation 2013, 2014). The number of people over 60 is set to more than double by 2050 and the number over 80 will increase to almost four times that of 2001 (ABS 2011, Commonwealth of Australia 2010, World Health Organisation 2012, 2014). As people live longer the prevalence of age-related conditions, such as dementia will increase significantly. With the growth in number of older people, limited social and economic resources, and the expressed preference for staying at home longer, there is an on-going shift away from an institutionalised model of aged care to in-home and care in the community. As a result, people living with dementia will become more visible in everyday life as care is undertaken in and by the community, (ABS 2011, Commonwealth of Australia 2010, World Health Organisation 2012, 2014).

Ageing discourse

The public perception of ageing and dementia is most often shaped by the pathologising of ageing and the embrace of the ‘medical gaze’ (Biggs and Powell 2001, Kenning 2015a, Mitchell, Dupuis, and Kontos 2013). The dominant bio-medical view positions old age in terms of deficit, lack, and loss, and something to be overcome rather than enjoyed or embraced and from this viewpoint dementia is overwhelmingly addressed in terms of loss of abilities, memory, and lack of independence (Kenning 2015a)(Kenning 2015). This view promotes the concept of an essentialist self that is being lost or worn away as a result of the ageing process, which results in the older person being perceived as a lesser version of themselves or an inferior version of a societal healthy norm. Increasingly this view is being challenged as sense of self and identity are no longer considered fixed, and quality of life and wellbeing are no longer seen to be inextricably tied to good health (Foucault 1982, Dervin and Foreman-Wernet 2013, Jacobson 2016). As people age individuals wants and needs change, as does what brings pleasure and satisfaction (Goebel and Brown 1981) and so despite, or because of change, old age can be a time of potential and possibility.

Disability, discourse

The stigma and discrimination that arises in relation to ageing and dementia is comparable to that of disability. The shift away from the institutionalisation of disabled people and their increased presence in the community, contributed to a growing awareness of social responsibilities and the need for the provision of basic human rights (Meekosha and Shuttleworth 2009). This prompted the rise of social models of disability that differentiated between ‘impairment’—functional limitations—and ‘disability’—social discrimination and ‘othering’ (Meekosha and Shuttleworth 2009 pp 48-50). Our understanding of disability is increasingly being impacted by such social models, as they become less binary and take into account the medical, social, economic, political, psychological, cultural, discursive and carnal (Meekosha and Shuttleworth 2009 p 50). This broader view of disability recognises the impact of the crisis of representation; rise of new social movements; identity

politics; globalisation; fragmentation and compartmentalisation of everyday life; interrogates belief in a theoretical context free science and medicine, and views of society of culture that can be captured by quantitative approaches; and links theory with praxis. (Meekosha and Shuttleworth 2009 p 51). Under this framework impairment and disability are perceived as dialogic, and there is a recognition that people living with disabilities are, not a consensus but, individuals with personal values and a range of ‘functionalities’ of ‘doings’ and ‘beings’ (Jacobson 2016 p 793)

Dementia discourse

Discourse in relation to dementia has been shaped by ageing and disability discourse. Following diagnosis, people living with dementia often undergo an ‘othering’, as they are seen to ‘not be themselves’, to experience a loss of self, to be lacking, and are ‘at the mercy’ of the disease (Kitwood 1997, Mitchell, Dupuis, and Kontos 2013). In this context dementia is a condition to ‘fight’ and for which we must find a cure (BRACE 2015).

However, Kitwood contested this sense of ‘othering’ and sought to restore dignity and personhood in the care of people living with dementia, recognizing the on-going, and changing, presence of the person living with dementia (Kitwood 1997). Subsequently, Person-Centred Care has built on the work of Kitwood to show the importance of acknowledging personhood, respecting the dignity of the individual, and recognising potentiality and possibilities (Chenoweth et al. 2009, Mitchell, Dupuis, and Kontos 2013). But, Person-Centred Care also needs to take into account relational needs and to recognise context; the relationships that people living with dementia have with other people, their own past, present and future; and simply how people live. (Mitchell, Dupuis, and Kontos 2013). Viewed through the embodied, experiential lens of care, dementia is not a linear transition into loss and decline as might be suggested by the pathology, but, a transition that involves, “continuing relationships and love, persisting patterns of one’s values and activities, and moments of humour, joy, and peace...new learning and emergent possibilities” (Mitchell, Dupuis,

and Kontos 2013) p10.

Information, dissemination and communication

Careful consideration of the choice of language has been at the core of disability discourse and more recently in research and developments in healthcare (Kitwood 1997, Chenoweth, et al. 2009).

Kitwood, writing in 1997, called for issues of dementia care to move beyond health professionals, gerontologists and out into the broader community (1997). However, the language used in relation to dementia models and frames understanding of the disease and impacts individuals' perceptions of whether they feel they can contribute (Mitchell, et al. 2013). The focus of the organisations, such as Alzheimer's is often on "fighting" "battling" "winning" and "defeating" dementia (Alzheimer's Australia 2015, 2016, Alzheimer's Society 2016, 2015). It is an approach that has the greatest impact in fundraising and grant applications. But, faced with the views expressed by scientific and medical experts, the enormity and scale of the problem, and the potentially debilitating impact of dementia being the primary messages communicated, the general public can feel overwhelmed and disempowered to act (Gonzalez 2014, BRACE 2015). How then do we communicate that there is a role for the 'everyday' person in the treatment and care of people living with dementia?

To empower individuals and show communities how they can engage and contribute in the care and support of people with dementia, it is necessary to challenge the stigma associated with dementia and the reticence to engage in open discussion and build empathy, understanding and opportunities for the sharing of experiences. It is not only necessary to look at what language is used, but also the broader context in which communication takes place. The social practices of communication "constitute reality (or alternatively deny, transform, or merely celebrate it)" (Carey 2009 p 65). They shape and form issues and impact on perception and understanding. Changing how they are modelled opens up the possibility for change (Carey 2009: p 64).

'Distributed experts'

The embodied practice of care provides insights into the lived experience of dementia and challenge understandings of who the 'experts' are in relation to dementia (Kontos and Martin 2013). Medical, clinical and health professionals offer an expertise, but so too do stakeholders in dementia treatment and care—family members, formal and informal caregivers, members of the community and the many services and organisations that intersect in the everyday—and those with first-hand experience of living with the condition. These 'experts' distributed throughout the systems of care, have a great deal to offer understandings of the embodied everyday experience of dementia (Reckwitz 2002).

Social Practices and social making

Gaining access to the tacit knowledge and everyday experience of 'experts' distributed throughout the system of care can be difficult. The structures and frameworks that allow access to medical expertise, scientific knowledge, and systems of care are in existence and prominent (Alzheimer's Australia 2016, Alzheimer's Society 2016, BRACE 2015) whereas such frameworks do not exist to gain access to 'distributed experts'. The key to gaining access is to focus on the embodied and experiential social practices of the everyday and the acts of being and doing that inform them (Reckwitz 2002 p 249).

Increasingly social practices such as hands-on workshops and 'making' environments are being used to support and facilitate communication at both individual and organisational levels (Lotts 2015). Social making activities, such as, craft textiles, have established social practices that encourage relationships, and participants are often familiar with the social practices of the making space and comfortable with the overall environment. These spaces therefore can facilitate communication and shape outcomes (Rogerson, et al. 2013, Bateson 2000, Nachmanovitch 2009). The on-going interest in craft, DIY (Do It Yourself) the DIWO (Do It With Others) culture, and participatory media are also increasingly being linked to good health and wellbeing outcomes for participants as they bring about personal joy and satisfaction and facilitate connections with other

people (Gauntlett 2011, Ignite NYC 2010, Jenkins 2006, Jenkins, et al. 2013, Kenning 2015).

Making not only fulfills the need for creativity as a symbolic action but, can become an act of communication and empowerment and they are, as Sennett suggests, “social acts of civilisation” (Gandolfo and Grace 2009, Johnson and Wilson 2005, Sennett 2008, Turney 2004,).

Communication, collaboration and practice

In an attempt to engage with issues relating to ageing and dementia beyond clinical, medical and health care professionals and out into the community, as suggested by Kitwood, the pilot research project used social making practices to engage with participants across a large spectrum of the public. They included those who are potentially ‘distributed experts’ with a great deal of everyday experience of dementia, to those with no experience at all. The study was experimental and emergent. It was conducted through a making activity, which focused participant attention on making for other people in the form of sensory objects that could be used to stimulate, occupy and provide ‘in the moment pleasure’ for people living with late stage dementia. People living with dementia currently experience fewer opportunities to socialize or engage in activities with other people and there is a lack of objects and activities specially designed for them (Treadaway, et al. 2014). Sensory objects, things to stimulate, calm, or simply amuse can relieve boredom and the depression that often accompanies dementia.

Maker Faires

Increasingly social approaches to designing and making for the community are being explored that draw on communities of makers and their expertise, and explore sustainable approaches by building capacity in communities through sharing knowledge, information and know-how (Wildevuur, et al. 2013). Therefore, the pilot project was held as part of a Mini Maker Faire. The *Maker Movement* and the subsequent emergence of Maker Faires was born out of shared interests in making, production, knowledge and information sharing and brings together makers; technology enthusiasts; crafters;

educators; tinkerers; hobbyists; engineers; science clubs; authors; artists; students; and entrepreneurs to share information, skills and projects (Maker Media Inc 2015).

The pilot project focused on craft-based textile activities because of the familiarity of these types of textile activities, which have not only been used for utilitarian purposes, but is also how practitioners make meaning and understand the world around them (Adamson 2010, Gandolfo and Grace 2009, Johnson and Wilson 2005, Kenning 2015, Rowley 1999). In this context craft textiles become media and present ways to model new practices and forms of communication, means of expression, and a vehicle through which people feel they are contributing and making a difference.

The Study

The qualitative pilot study took place at the Sydney Maker Faire, at the Powerhouse Museum which was part of Sydney Design Festival 2014. The study sought to:

- Engage with the general public through fun and creative making sessions to empower them to make a positive contribution to people living with dementia.
- Use craft activities and processes as media to engage the public with the important issues and provide opportunities for knowledge sharing.
- Disseminate information about dementia and give pointers to help and support services.

Methodology

The study built on findings that dementia impacts not only the person living with dementia, but also carers, family, friends and health professionals (Treadaway and Kenning 2015, Treadaway, et al. 2014). Researchers set up a stall at the Mini Maker Faire where they ran a *Hand i Pockets* ‘funshop’ which engaged directly with the general public in making objects, artefacts and activities for people with dementia and so directly responded to Kitwood’s call for issues of dementia care to move

beyond health professionals, gerontologists and out into the broader community (Kitwood 1997).

The Maker Faire was a series of stalls open to the general public with demonstrations, opportunities to interact and attend workshops, or invitations to join clubs. The majority of stalls at the event were technology related; showcasing electronics, computers and robotics. There were few arts, crafts and textile stalls. Only five of the 35 stalls were issue-based, they focussed on the environment, material recycling, education, and general health and wellbeing. *Hand i Pockets* was the only stall with specific outcomes relating to an issue. Alzheimer's New South Wales provided banners, posters, brochures and leaflets, which included the message 'fight dementia', and gave details of support organisations. An Alzheimer's counsellor, with experience of working with people with dementia and their families and carers pre and post diagnosis, was also on hand. The organisers of the faire were particularly supportive of the approach and gave the stall a prominent position at the faire and highlighted the 'funshop' in all publicity media.

The *Hand i Pockets* 'funshop' included a maker table for 10-12 people with craft materials such as textiles, papers, bells, and scented oils; basic craft tools such as knitting, needles, sewing equipment and scissors; and basic electronic components and objects that could be 'hacked', including children's toys, LED lights and buzzers. The visually stimulating assortment of brightly coloured materials on the stall was an invitation for passers by to get involved. Participants were invited to write comments on a paper tablecloth, which provided opportunities to capture comments and questions about dementia that came to mind during the creative session. Post-It notes were also provided for participants to leave comments or dedications inside their pocket creation.

Participants

Members of the general public attending the maker faire or visiting the museum self-selected to take part. They included young adults, families with small children, couples and some older people—although they were noticeably in the minority. The age range was from two years old to eighty.

Participants were from a variety of educational backgrounds and included academics; teachers; lawyers; engineers; tradespeople; stay at home parents; primary, secondary and tertiary students; and health care professionals. There were in excess of 5500 visitors to the museum during the two-day Mini Maker Faire. Over seventy people attended The *Hand i Pockets* stall and completed consent forms. Researchers carried out informal unstructured interviews as they worked alongside participants engaged in individual or collaborative making activities. Participants were encouraged to interact, collaborate and share experiences with each other. But, this was not a requirement of being at the maker table. Researchers made journal notes of their experiences at key points throughout the workshops and at the end of each session, which were also audio and video recorded and photographed.

Making

Participants were individually given an overview of the pilot study and background information as they approached the maker table. They were asked to make a sensory ‘pocket’ for a person living with dementia. The pocket form was chosen because it is practical and enables people to store their few possessions safely; is representative of privacy and safekeeping; because it prompted joy on the discovery of unknown or forgotten objects being found; and it was fun putting things in and taking them out of pockets. Participants were invited to play, make, be creative and simply have fun, and to select materials that suggested fun, enjoyment and pleasure. They were asked to keep in mind someone they knew living with dementia, who had lived with dementia, or think about their possible future self and to explore what would make this person laugh, bring them joy, or give them ‘in the moment pleasure’.

Participants were provided with pieces of pre-cut fabric sewn together on three sides to form a pocket and invited to make, decorate and put things inside the pockets. Makers could knit, sew, weave, glue, use craft materials, were encouraged to introduce noises or smells to the pockets to

stimulate a range of senses, and invited to introduce electronic elements such as sounds, buzzers, vibrations and lights. On completing their pocket, participants were encouraged to add it to a banner of pockets hanging on the wall of museum.

Findings

Conversations on the edge and engagement with the issue

The energy at the table where people made the pockets was light-hearted, playful, and creative. Some participants were drawn to the stall by the bright craft materials, while others were interested to find out more about dementia or the role of the sensory pockets. Conversations at the table focussed on personal experiences and emotional issues and there were many instances of people engaging with issues of health, ageing, dementia, and the impact on their families. The level of knowledge about Alzheimer's and dementia varied.

On several occasions conversations took place some distance from the maker table. The conversations at the edge of the *Hand i Pockets* stall were often lengthy, sometimes an hour or more, engaged, and reflected a range of experiences. They were often mutually informative about ageing and dementia as people with or without interest in craft activities talked about their personal or professional connection with dementia, or were keen to find out more. They included health care professionals, teachers, an architect, a physiotherapist, artists and academics. A young man, working on a nearby electronics stall disclosed that the incidence of dementia in his family was high, and he wanted to know about causes, prevention, types of dementia and how and when it impacted. An Architect contributed information with regard to how the built environment impacted people with dementia and how design could take into account peoples' needs and wants. A physiotherapist who had been working with people rehabilitating from strokes by teaching them how to do Origami began to think about how he might adapt some of his professional practice to suit people with dementia. Academics in design, textiles and cultural studies began to talk about how ageing and issues relating

to dementia was increasingly becoming part of their research.

The cohort

The brightly coloured craft materials were an invitation to people to join in the activities. Younger women in the 20-35 age range were well represented at the table. They were comfortable with the materials and making process. Children were particularly attracted to the table and brought along siblings, parents and/or grandparents to take part. Mothers and daughters were the most frequent visitors to the making table, fathers worked with sons and daughters, grandparents worked with grandchildren and at one stage there were three generations from one family working together. Large numbers of children were a deterrent to those without children from taking part (including female teachers who at other times were well represented at the table), and appeared to inhibit deep engagement with issues relating to dementia. However, on occasions when adults engaged directly with children in discussion about dementia, it proved to be productive for children and adults alike. There were no instances of men working alone on projects, but one man taught his son to sew, and teenage boys engaged in making, two of whom worked together for more than an hour sewing and decorating pockets.

Working together and working alone

Participants frequently worked in twos or threes. Grandmothers, mothers and fathers were often keen to show their children that they could knit, crochet or sew and tried to teach others their skills. Two women tried to remember how to knit but ended up playing 'Cat's Cradle' encouraged by others around the table. Some participants worked alone and did not talk as they worked in a comfortable silence, but they entered into conversation after they had completed their pocket. These conversations were often emotional and non-trivial. As people sat without talking they frequently reached out to pass materials to others or made suggestions about materials that someone might use. Some tools had to be shared, which created an air of camaraderie and teamwork as people 'helped

each other out’.

Veronica’s story

Participants at the maker table often had concerns about a diagnosed, or as yet undiagnosed, family member; or had a history of dementia in their family and wanted to find out more. Some engaged in sophisticated conversations with others at the table, while others worked quietly. ‘Veronica’ came to the table with her daughter of about 10 years of age to make a pocket and seemed intent on getting into the creative making activity. She remained at the table for two hours and conversations about Alzheimer’s, dementia and ageing cropped up frequently around the table, but she did not engage in any conversation even when invited to respond. The pocket was a collaborative work between mother and daughter and it flourished and grew. When finished it was placed on the wall alongside a range of other completed pockets. ‘Veronica’ started to leave the table then sat back down and began to explain that her mother had been diagnosed with dementia some time ago and she and her siblings were taking it in turn to look after their mother in their homes. ‘Veronica’ had come to the conclusion that their mother should now be in a residential care facility, but this had caused a divide in the family and no decision had been made in over two years. She talked with the Alzheimer’s counsellor present. Her demeanour changed, particularly when, just before she left, ‘Veronica’ began to chat with another person at the table who had been a Director of Nursing (DoN) and an assessor of care facilities. She was able to provide ‘Veronica’ with insights into the type of residential care facility that might suit her mother and the rest of the family.

The DoN’s story

A woman came to the table with her 11-year old daughter explaining that her daughter was keen to make. The daughter’s body language suggested otherwise. The mother created a finely made pocket with a high level of craftsmanship. The daughter took little notice of it. The mother and daughter did not speak to the rest of the people at the table, but when they had completed the pocket

they began to talk to the researchers. The mother explained that she had been a Director of Nursing at a residential care facility and understood first hand both the need for objects and activities, such as the ones that she had been making. She expressed concern about the need to normalise discussion of dementia, its impacts and what can be done, and added "...its not all doom and gloom". She explained that she had recently been an assessor of residential care facilities and was aware of both good and bad practices in the industry. Before leaving with her daughter she spoke with 'Veronica' and was able to advise her how to start looking for a suitable residential facility for her mother.

The lady with the green hair

Many participants knew of someone who had died, been diagnosed or was living with dementia and were happy to make pockets for them, or in their memory. A lady with bright green hair and a silver dress joined the table and began to make. She had read the information sheet and signed the consent form, but then did not engage in any further conversation. She worked alone for an hour and half. As she completed her pocket she explained that her grandmother, for whom she had been the primary informal carer, died a year previously. She recalled "She was my favourite person in the whole entire world... she would have loved this! (laughs)" She explained that when her grandmother was mobile she attached plastic bags to her walker so that she could carry things around and give them to people. She recounted how she would hoard things and hide them. However, later as the condition progressed she recalled that she had seen her grandmother sit inactive in a chair; not having anything to do and she was pleased to be "making something for her".

Bill's story

After a busy two days at the Powerhouse Museum the stall was being de-assembled as a man, who appeared to be in his early seventies, stood reading Alzheimer's NSW leaflets. Bill began to talk, seemingly thinking out loud. After looking at the craft materials on the table he began pondering out loud as to whether his wife, who used to do craft activities, would be interested in them again. Bill

seemed exasperated and was tearful. He explained he was living alone and caring for his wife, they had not seen any doctors about her condition and that he had assumed it was just that she was 'getting on'. He explained that her behaviour had changed and she hid things from him. The Alzheimer's counsellor was able to talk to Bill and give him details of a telephone helpline to contact; the first step in seeking help for his wife.

Student and children's responses

Some children were very proud to have made something that would be given to somebody who needed it, while others were reluctant to leave objects they had made preferring to take them home. Conversations about ageing, memory and the impact of dementia, with children and younger adults, were often stimulated in the process of deciding who they should make the pocket for. Some children were able to display a sophisticated degree of knowledge and experience. For example, Lucy and Jenny were focusing hard on the pockets they were making as they talked about how dementia had impacted on 'Granny'. 'Lucy' and 'Jenny' were friends who had arrived together with 'Lucy's' mother. 'Jenny' was several years younger than 'Lucy', who was nine:

'Jenny' asked: "Who are we making these for, again?"

'Lucy' replied "For people with dementia" she continued "it is when you have good long-term memory and bad short-term memory" and added "It means you can remember things from long ago but you can't remember yesterday." She stated: "My granny has dementia, she can remember where she lived as a little girl, but can't remember that we went on holiday a few weeks ago". She was not perturbed and very matter of fact about this as they continued to both make for her grandmother.

'Lucy' suggested that perhaps the blue fabric she was using would remind 'Granny' of the sea.

In memoria

Children frequently left messages in pockets they made: “Remember, remember”, “Please get well”, “Down with dementia”, “Love you”. However, it was not only children that left notes in memoria. A young woman, the first to the table on the first day of the ‘funshop’, immediately sat down and began to make in silence. She made a well-crafted pocket and placed it on the wall. She explained it was for her father who had died a couple of years ago after living with dementia. Inside the pocket she had placed a paper blower with a feather attached and a note saying, “this would have made dad laugh!”

Discussion

The *Hand i Pockets* ‘funshop’ at the Mini Maker Faire provided an alternative model for communication to the hierarchical dissemination of information that remains the primary means of communication in relation to ageing and dementia. Noticeably, the form of engagement and the environment shaped the content of the communication. For example, while public discourse relating to ageing and dementia all too frequently focuses on deficit and loss, the focus on ‘fun’, and making sensory objects to promote fun meant throughout the research project conversations were primarily focussed on possibility and potential and what could be done. There was little reference made to medical or clinical understandings of dementia or discussion associated with the medical views or the ‘medical gaze’, and only minimal use was made of the information brochures and flyers supplied by Alzheimer’s. But, this is not to suggest that discussion was shallow inaccurate or misleading; the Counsellor from Alzheimer’s was busy throughout the day answering questions and talking about the impact of dementia. For the most part discussion was experiential and involved personal embodied accounts that communicated important information about what it is like to live with or alongside dementia, and what help is available.

Dementia was rarely referenced in abstract or theoretical terms. It was embodied and related to a particular person, context, remembering, funny story, or personal concern about the self or a

loved one. In this context the Alzheimer's taglines that encouraged 'fighting', 'battling' and 'winning' were apparent anomalies, highlighting differences in approaches needed for fund-raising and compared to the type of engagement effective in relation to those involved in everyday care.

Conversations about dementia cropped up at the making table, in close vicinity of the *Hand i Pockets* stall, and were also overhead in the coffee shop, seminar rooms and Museum entrance. Throughout the two-day project, in this environment, discussion of ageing and dementia was normalised and the stigma associated with dementia was removed. Conversation and communications were non-hierarchical; participants shared information, stories, and advice with each other. Individuals were able to engage and share their own experiences or enquire in general terms about age-related conditions and their impact, or seek help on specific issues. This networked format of information dissemination and exchange is familiar in social media networking and online environments (Macnamara and Kenning 2011). Similarly, in the context of the Maker Faire, which focussed on 'grass roots' engagement, every individual was perceived as having something to contribute and were empowered to speak.

The 'Funshop' modelled a form of communication that was open-ended and exploratory. It encouraged participants to recognise that they had a level of expertise and could make a valuable contribution on their own terms. It became apparent that there were many 'distributed experts' who had important contributions to make by sharing their experiences. Many, including architects, physiotherapists, designer, and carers, daughters had an intimate and individualised knowledge and understanding. The making environment gave a platform for those, who would not consider themselves 'experts' to share their experiences and to make a difference. Engaging through social practices is an important aspect of how these 'experts' can be reached.

People living with dementia were not knowingly represented among the participants in the study. However it is possible that, given that the number of people living with dementia in society is high, undiagnosed people were present. As the participants self-selected for the study it was not

appropriate to specifically invite people living with dementia to attend, nor to enquire of any participants about whether they had a diagnosis. While people living with dementia were not represented in this study they have been engaged in subsequent research aimed at ensuring they have a voice in research.

Participants felt they contributed both physically in making a sensory object to be given to someone and symbolically in the making an object that would have entertained someone no longer alive, as in the case of the lady with the green hair. Communication was observed in memoria, as when messages were placed in pockets for a particular person, or sometimes non-specifically for “people with dementia”. These were not directly articulated forms of communication, but fulfilled the need for an affective communicability that, for the person initiating it, may not be possible in any other form (Nouvet 2007).

Conclusions

The scale of the ageing population and incidences of dementia have the propensity to be overwhelming for the wider community and those who are not in care-related work or clinical or medical professions. There is the potential for the public to feel disempowered, or overwhelmed and to feel there is nothing they can do or simply not know what to do. Facilitating communication through socially engaged creative making approaches provides, a forum for people to share issues and concerns, recognise and share their own expertise, provides points of contact for on-going help, and can bring issues related to ageing and dementia into the public domain. Textiles, craft, creativity and making became the media through which this was facilitated. The focus on familiar creative making activities provided opportunities for people of all ages to openly talk about their own experiences, share stories, and access information, in a supportive environment that sought to overcome the stigma associated with dementia. This presented opportunities for a range of ‘distributed experts’ to contribute to the discourse on ageing and dementia. It is through engaging

with alternative models of communication and ways of thinking that we can begin to change our understanding of dementia and how care is undertaken in the community.

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