



# DESIGN4 HEALTH

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## Designing with People Living with Dementia

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### *Abstract*

*This paper reports on the author's ongoing Arts and Humanities Research Council's (AHRC) Design Research Fellowship that aims to explore how design can contribute to the design and development of a range of enhanced products, services, and systems for people living with dementia. The fellowship, undertaken in collaboration with Alzheimer Scotland, adopts a range of disruptive design interventions for breaking the cycle of well-formed opinions, strategies, mindsets, and ways-of-doing, that tend to remain unchallenged in the health and social care of people living with dementia. Disruptive design is an approach that the author has developed over several years in conjunction with other members of the Design Disruption Group (Rodgers et al, 2013; Rodgers and Tennant, 2012). The key aims of this work are to develop a series of disruptive design interventions (e.g. products, systems, services) that will help change the perception of dementia by showing people with dementia can offer much to UK society after diagnosis. Also, the designed interventions will help reconnect people recently diagnosed with dementia to build their self-esteem, identity and dignity and help keep the person with dementia connected to their community, thus delaying the need for formal support and avoid the need for crisis responses. The paper reports on an initial intervention where the author has worked collaboratively with people diagnosed with dementia across Scotland in the co-design and co-production of a "live project" – a new signature tartan for Alzheimer Scotland.*

**Keywords:** Disruptive Design, Dementia, Alzheimer Scotland.

## The Nature of Dementia

Dementia is the umbrella term for a range of brain diseases that are progressive and chronic in their nature. Symptoms include deterioration in cognitive function, behavioural changes and functional limitations. The illness has a profound impact on society and those directly affected by the illness. Globally there are an estimated 44.4 million people with dementia, which will increase to 135 million by 2050. The estimated worldwide cost of dementia is \$604 billion US dollars, which equates to 1% of GDP (Alzheimer Disease International, 2013). In the UK there are an estimated 800,000 people with dementia with the current cost £23 billion (Alzheimer Society, 2013). Amongst older people, dementia makes the largest contribution to the need for care, much more so than other types of impairment and chronic disease (Prince *et al*, 2013). This demand for health and social care services will continue to increase as a result of demographic changes. Responding to this challenge will require innovative ways of supporting people with dementia to live well from the early stages of the illness. Receiving a diagnosis of dementia creates a “*biographical disruption*”, with the chronically ill “*observing their former self-images crumbling away*” (Bury, 1982). People need support from the point of diagnosis to come to terms with this life altering event, remain connected to their community and enable them to live well with this long term illness. However, people typically do not receive support until the illness is advanced and often at the point of crisis (Alzheimer Scotland, 2008). This pattern is becoming more acute as a result of pressure on health and social care budgets.

### Alzheimer Scotland 8-Pillar Model of Support

Alzheimer Scotland has taken a strategic approach to counteract this failure and create systemic change through the development of the 8-Pillars Model of Post-Diagnostic Community Support (Kinnaird, 2012). This led to a Scottish Government commitment for everyone newly diagnosed being entitled to one-year post-diagnostic support from a named link worker. This Design Fellowship will be focused on this key stage in the dementia journey. Whilst there are an estimated 90,000 people with dementia in Scotland, only 50% of cases have been identified. The insidious and sporadic nature of symptoms makes it difficult to spot the early signs of dementia. People may also delay taking action fearful of having their suspicions confirmed and believing there is nothing that can be done to help in dementia (Keady and Nolan, 2003). Time taken to diagnosis from the onset of symptoms may be around three years (Chrisp *et al*, 2011). At the point of diagnosis people will have lived with many of the difficulties dementia brings and may have become disconnected from their community. Diagnosis then brings the “*sick role*”, challenging their identity and social position (Williams, 2005). The Design Fellowship will be focused on developing and implementing innovative interventions that will promote dignity and independence for people during the post-diagnostic stage. It will focus on reconnecting people to their communities, building these natural supports so that they can continue to be a source of informal support throughout the trajectory of the illness. Alzheimer Scotland works directly with over 60 link workers who provide post-diagnostic support. This will provide the connection for the Design Fellow to work with people recently diagnosed and who are in the early stages of the illness. The Fellowship will bring a

dynamic approach to building the self-confidence and participation of people early in the illness. This will counteract the disconnection and social isolation that leads to earlier use of formal support and crisis intervention measures.

## Disruptive Design

The key aim of this research is to develop disruptive design interventions (*e.g.* products, systems, services) for breaking the cycle of well-formed opinions, strategies, mindsets, and ways-of-doing, that tend to remain unchallenged in the health and social care of people living with dementia in the UK. Past interventions from the Design Disruption Group include things like “WARNING XXXXX can seriously damage your health....” sticker campaigns, “I Trust...” mental health interventions, “DIY entrepreneur” Pop-Up shops with Newcastle YMCA (Figure 1), “Lamppost Data” probes with the MS Society, and many others (see <http://designdisruptiongroup.wordpress.com/>). Disruptive Design is an approach that the author, in conjunction with the other three founding members of the Design Disruption Group, has developed over several years.



Figure 1. A Design Disruption Group Example Project (“Space 2... Buy” Pop Up Shop with Newcastle YMCA)

A disruptive design approach encourages the development of richer, more varied solutions to everyday issues by emphasising fun (Bisson and Luckner, 1996), “safe failure”, and doing things in ways that those working with people with dementia would not normally do. In essence, the disruptive design techniques and approaches developed will provide opportunities for service users to experiment in a relaxed, stress-free environment with expert facilitators. Most of the research in public health seeks to evaluate intervention effectiveness and value for money. In contrast, this proposal proposes to develop and test a series of disruptive design interventions and assess how they might improve the lives of people living with dementia and their carers throughout Scotland.

The design research fellowship adopts a largely interventionist approach, which is based on a number of emerging theories emanating from research in economics, business, and design (Scharmer, 2011; Christensen and Overdorf, 2000; Rodgers and Tennant, 2014). This disruptive design interventionist approach, which celebrates jumping straight in, doing things in order to learn new things, and valuing failure, involves three main stages over the course of the 12 months Fellowship:

1. *Observe, Observe, Observe* - requires one to totally immerse oneself in the places that matter most to the situation one is dealing with.
2. *Retreat and Reflect* - requires one to share and reflect on everything one has learned from the situations one has observed.
3. *Act in an Instant; Design and Develop Product, System and Service Prototypes* - explore the future by doing; develop prototypes that help us explore the future by doing, generating feedback from key stakeholders that allow novel ideas to evolve.

## Recognising Personhood

Philosophical debates on dementia have largely focused around the fundamental nature of being and what constitutes personhood. The failure to recognise personhood and the negative impact of inappropriate care giving can result in “malignant social psychology”, which includes labelling, disempowerment, infantilisation, invalidation and objectification (Kitwood, 1990). One reason behind this malignance is failing to see a person and not showing the respect that properly accords a person (Kitwood, 1990). Even when a person seems to have lost a significant part of what made them a unique individual, core elements of their identity will remain. These “*characteristic gestures and ways of doing things are what keep alive the sense of the individual they once were, even if the more sophisticated levels of that individual have been removed*” (Matthews, 2006). This has important implications for the approach to providing support and what people require in addition to the basics of daily living. A person’s sense of self and self-respect can be fostered through “*reinforcing any remaining elements of conscious self-identity*”; less conscious elements in a person’s identity can be preserved through physical surroundings to retain “*physical links with their past, which help to support a sense of personhood*” (Matthews, 2006). Whilst mood and behaviour may be

profoundly affected, personhood is not; the individual remains the same equally valuable person throughout the course of the illness. Interventions to support the person with dementia should honour their personhood and right to be treated as a unique individual.

## Project Aims

Given the extremely challenging nature of caring for people living with dementia in the UK, and the need to ensure a balanced focus between both the person living with dementia and their main carer(s), the main aims of this Design Research Fellowship are to:

1. Help change the perception of dementia by showing people with dementia can offer much to UK society after diagnosis.
2. Create a series of designed interventions (*i.e.* products, systems, and services) that will reconnect people recently diagnosed with dementia to build self-esteem, identity and dignity.
3. Develop interventions that will provide ongoing benefits in keeping the person with dementia connected to their community, delaying the need for formal support and avoid the need for crisis responses.
4. Explore how prevention and early intervention (*e.g.* through designed products, systems, and services) might enable both carers and people living with dementia to have greater choice and control in their lives.
5. Work with people recently diagnosed and their supporters to participate in the creation of the designed interventions and develop and test these interventions in a number of Alzheimer Scotland's Dementia Resource Centres and Dementia Cafes located throughout Scotland.

## Alzheimer Scotland Tartan Design Project

The first project undertaken as part of this AHRC Design Research Fellowship was intended as an "ice breaker" for the author to get to know better the staff at Alzheimer Scotland, people living with dementia throughout Scotland, their families and care support networks. It was also important that this initial project engaged with all of the stakeholders involved. In particular, it was vital that the planned design intervention supported the person with dementia and that it paid respect to their personhood and their right to be treated as a unique individual (Kinnaird, 2012). Adopting the three-stage disruptive design interventionist approach described earlier, which celebrates jumping straight in, doing things in order to learn new things, and valuing failure, the author launched the Alzheimer Scotland signature tartan design project in November 2014. The brief for this project invited people living with dementia throughout Scotland to design the Alzheimer Scotland signature tartan that will be used in a range of future products including ties, scarves and picnic blankets and sold worldwide to raise money for people living with dementia.





Figure 2. Alzheimer Scotland Tartan Design Workshop Locations with Workshop Participant Numbers

The author has held a number of tartan co-design workshops across Scotland from Kilmarnock in the South to Shetland in the North and Stornoway in the West to Aberdeen in the East (Figure 2). To date, the author has visited 17 Alzheimer Scotland Dementia Resource Centres, held over 20 co-design workshops with over 130 people living with dementia participating. This has involved in excess of 1,900 miles of travel, over 80 hours spent travelling, and using over half a kilometre of coloured ribbon in the creation of the participants' tartan design prototypes. The main aim of the Alzheimer Scotland signature tartan design project is to help change the perception of dementia by showing that people with dementia can offer much to UK society after diagnosis. Specifically, here, that people living with dementia are capable of designing a new product that will be sold across the world. Moreover, this project will help people recently diagnosed with dementia build their self-esteem, identity and dignity and help ensure that every person living with dementia and their families' quality of life and resilience is maximized.

Each tartan design workshop commences with a short presentation of the rules associated with the creation of the signature tartan for Alzheimer Scotland. The rules are that each participant must use no more than 6 colours in their design and one of those colours must be purple (Alzheimer Scotland's primary colour in their new brand identity). The creation of each participant's tartan design begins with an acetate-based version, followed by a physical prototype constructed using ribbon, and finally the creation of a digital version using a publically available Internet-based tartan design tool (Figure 3).



Figure 3. Tartan Design Creative Process (Left to Right: Acetate, Ribbon, and Digital versions)

Working from the physical ribbon prototype, each person with dementia directs the author to create his or her digital design one colour at a time (Figure 4). In the example illustrated in Figure 4, one can see that the participant's main colour in their design is purple (Alzheimer Scotland's primary colour), followed by their choice of orange, green, blue and finally grey.



Figure 4. Creating the Digital Tartan Prototype Step-by-Step

Working from left to right, the person with dementia gradually builds up their tartan design based on the physical prototype they created earlier. This process involves a number of iterations between the designer (person with dementia) and the facilitator (author). Sometimes, the designer will go back and forth between different versions and sometimes they will alter the order of the colours to finally achieve the design that they are satisfied with.

## Outcomes

The results achieved, thus far, include over 130 unique designs for Alzheimer Scotland's signature tartan. Every one of the 130+ tartans created have been designed by a person living with dementia and these tartan designs have been uploaded to the Alzheimer Scotland Tartan project blog - <https://alzheimerscotlandtartan.wordpress.com/>.





Figure 5. Over 130 Designs for the new Alzheimer Scotland Tartan (Judging and Short-listing Table)

This week a panel of tartan experts and representatives of Alzheimer Scotland short-listed seven tartan designs from over the 130 created since November 2014 (Figure 5). The seven short-listed tartans will now be uploaded and exhibited on the Alzheimer Scotland website - <http://www.alzscot.org> - for people to vote for their favourite tartan design. One lucky winner will be announced at a National Final held in April/May 2015, which will then be manufactured in a range of tartan design products and sold all over the world. This project highlights clearly that a person living with dementia has designed the new signature tartan for Alzheimer Scotland and it shows that people with dementia can indeed offer much to society after diagnosis.

## Conclusions and Future Work

This paper has reported on the author's ongoing Arts and Humanities Research Council's (AHRC) Design Research Fellowship that aims to explore how design may contribute to the design and development of a range of enhanced products, services, and systems for people living with dementia. The Alzheimer Scotland tartan design project presented here shows that people living with dementia can continue to make a significant contribution to society after diagnosis. In this respect, this project has helped change the perception of dementia and shown that whilst the

mood and behaviour of the person may be profoundly affected, their personhood is not; the individual remains the same equally valuable person throughout the course of the illness. Moreover, the project has helped reconnect people recently diagnosed with dementia to build their self-esteem, identity and dignity and keep the person with dementia connected to their local community. In many of these co-design workshop sessions it has been abundantly clear that people living with dementia can offer much to society.

As the UK moves to an increasingly older society where more than half of the UK's population will be aged 65 and over, and there will be 101% more people aged 85 and over, we have to face the reality of being woefully underprepared. By the year 2030, over 80% more people aged 65 and over will have some form of dementia (a moderate or severe cognitive impairment) compared to 2010. Design, in general, and design research, in particular, needs to embrace these challenges head on. These huge demographic shifts present demanding challenges to design and major changes are needed in our attitudes to ageing and how we will care for each other. However, rather than viewing these challenges negatively, design has an opportunity to be at the forefront of imagining how we might live together better in the future. To many, there has never been a better time to be a designer (Sudjic, 2009). It is now time, therefore, that design in all its guises (*i.e.* education, practice, research) grasps this opportunity to envision and realize the future that we will all be proud to share.

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