

# Designed with Me: Empowering People Living with Dementia

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**Abstract:** This paper presents on-going research that adopts an open and truly collaborative approach to working with people living with dementia by recognising and utilising the inherent personal creative abilities that every individual possesses - no matter their cognitive ability. The research project entitled “Designed with Me”, via a series of carefully developed innovative co-design workshops, supports people living with dementia to express themselves fully in “live” design collaborations. Every individual’s input in this research is highly valued and is held in the same esteem as any other collaborator. In this project, participants become collaborative designers helping to propose possibilities, evaluate and select solutions, give their knowledge and skills freely, and generally make things happen. “Designed with Me” highlights clearly that people living with dementia can continue to make a significant contribution to society long after a diagnosis of dementia.

**Keywords:** Designed with Me, Designing, Making, Dementia, Empowerment

## 1. Introduction

Life expectancy in the UK, over the last few decades, has risen steadily and it is projected to continue increasing; with life expectancy at birth for females projected to be nearly 90 years by 2036. Males are also projected to live longer, increasing to nearly 85 years by 2036. The consequences of these population changes in the UK, however, means the shape of the UK population is transforming significantly with those of a working age shrinking whilst those of a pensionable age increasing dramatically. While a larger population can increase the size and productive capacity of the workforce, it also increases significant pressures and questions the sustainability to provide social services such as education, health and social care, and housing. The rise in life expectancy in the UK is a key factor in the forecasted rise of people living with dementia in the UK. The number of people with dementia in the UK is forecast to increase to over 1 million by 2025.

In the UK, dementia and how we respond to it has reached a crisis point. It is a problem that improved public awareness or a better diagnosis alone will not solve. The management of long-term conditions associated with dementia is the key challenge facing the health and social care system in the UK. The UK Government believes we need to see profound changes to the way we view the person living with dementia as well as the overall system of health and social care (All Party Parliamentary Group on Dementia, 2016). With this in mind, the “Designed with Me” co-design

projects presented in this paper help to show that people living with dementia can continue to make a significant contribution to society after diagnosis. The approach taken here actively involves a range of stakeholders in the co-designing and making processes such as care workers, people living with dementia, and their family and friends to help ensure the collaborative projects meet individual and collective needs and is truly valuable and useful. The co-designing work presented in this paper has been carefully developed to be appropriate to people living with dementia and meet their emotional and practical needs by responding to their shared cultural activities. Moreover, the co-designing and making work presented here aims to help reconnect people recently diagnosed with dementia to help them build their self-esteem, identity and dignity and keep the person with dementia connected to their community.

## 2. Research Aims

This paper describes an ongoing AHRC-funded research project that aims to empower people living with dementia to take ownership and build self-efficacy, to offer personal opinion and to propose product and service design interventions that engage wider communities through a number of disruptive co-designing and making workshops. The ongoing research is developing a number of disruptive design interventions that break the cycle of well-formed opinions, mind-sets, and ways-of-doing, that tend to remain unchallenged in the health and social care of people living with dementia. Many misconceptions surround people living with dementia, which can result in the perpetuation of stigma, isolation, and generally negative reactions. The idea that nothing can be done to help people with dementia often leads to feelings of hopelessness and frustration (Batsch and Mittelman, 2012). Many people living with dementia have a sense of inadequacy and low self-esteem. They perceive their status within society has been reduced as a result of their diagnosis (Katsuno, 2005). Generally speaking, people living with dementia are not considered capable of contributing to UK society. Rather, they are often seen as a social and economic burden. Very few would consider people living with dementia to be able to contribute to the UK's international reputation for designing and developing innovative new products and services. This ongoing work, however, sets out to directly challenge this assumption. The co-designed and developed interventions and outcomes presented here have all been devised and undertaken from a "designing with" perspective where the person living with dementia is not viewed as a "subject" but rather as an active "participant" in the project (Sanders and Stappers, 2014). Our approach, presented here, 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. The co-design work presented here adopts a largely interventionist approach, which is based on a number of recent theories emanating from research in economics, business and design (Christensen and Overdorf, 2000; Scharmer, 2011; Rodgers and Tennant, 2014; Rodgers, 2017) that celebrate jumping straight in, doing things in order to learn new things, and valuing failure. Recognising the value of an anecdotal evidence in support of actions (Kenning, Treadaway, Fennell and Prytherch, 2018) this work sets its values and notions of satisfaction, personal identity, engagement, enjoyment and esteem through the observed and recorded actions and feedback of participants that naturally occurred during the co-design sessions presented here.

### 3. Methodology

Thus far, “Designed with Me” has comprised a series of co-designing and making workshops, activities and events over the last 24 months. The Designed with Me co-designing and making sessions make use of the latent creative abilities of an individual’s personal knowledge and skills (Kelley and Kelley 2015) and adopt a truly collaborative approach where people living with dementia are highly valued and their inputs and collaborations are held in the same esteem as any other collaborator. The Designed with Me sessions have involved working with groups of people living with dementia, their carers, family members, and dementia support workers. The sessions have occurred in a number of different environments including dementia support service centres, art galleries and museums, and other external locations with organisations that include Alzheimer Scotland, Edinburgh and Lothians Dementia Network Group, the Eric Liddell Centre Edinburgh, the Scottish Dementia Working Group, Open-Door Edinburgh, and the Bridgeton Resource Centre in Glasgow. Recently, a group of people living with dementia have produced a series of textile designs based on the life and work of the famous Glaswegian comedian Billy Connolly. The participant co-designers (people living with dementia) created a number of textile design patterns with a view to selecting a range of patterns to manufacture as a set of limited-edition printed textiles. During the textile design process, the group of people living with dementia agreed on the production scales for each pattern that have been produced in heavyweight cotton using a digital textile printer. In subsequent workshops, the group were explored where and how the fabrics might be used. The ideas of which originated from group discussion about where the fabrics might be used within their dementia resource centre. Within the creation of the Bridgeton 75BC textile designs, individual and collective working, design facilitation and experimental practices have produced and proposed a series of textiles and products that are the result of a highly collaborative process. In what is now a continuing approach another group also based within an Alzheimer Scotland Resource Centre are undertaking the development of a new *Stained-glass Window for Glasgow* that responds to the excursions and explorations that they too have undertaken as a collective. In a third co-design project *Re-design Sundays* a group of people were invited to undertake a different kind of co-design project, where their approach and participation deviated from the projects above. Though all the projects were instigated in the same ways the directions in which they have gone have been driven by the participant co-designers. In this third project their initial discussions were much more focussed on problems that they wanted to engage with. As the group took control of the project the participants decided to integrate their carers and partners or loved ones to be integral to follow up work which resulted in the proposal to *Re-design Sundays* in particular to make them special again.

### 4. Designed with Me Projects

In the first two projects the cultural underpinning has been in the form of visits to a number of recognized Glasgow institutions and environments where participation in programmed activities occurred but where the groups have also been asked to undertake their own primary research. Here they have been encouraged to talk in their groups about what was important for each of them during these visits. The key aspect of these collective programmed visits has been the discussions and insights that have been generated by those involved and the origination of primary research. During these sessions, many of the participants shared their own knowledge and skills, insights and interests. These have informed and directed the group actions and have evolved the projects that have been undertaken. Working as co-designers, the groups have followed recognisable design pathways resulting in prototypes and propositions that are beyond art-pieces or acts of art therapy. These design pathways have incorporated the construction of a brief formulated by the group

themselves, primary investigations incorporating research, drawing or mark making, photography and discussion, creation of content, refinement in use of content, propositions regarding that content, prototypes and applications of those prototypes resulting in tangible outcomes and future possibilities. To instigate such a design process the collaborative facilitation actions responded to the groups involved supporting an organic non-prescribed approach. For example, in 75BC *Co-designer 5* informed the use of photography as a primary research tool. He had previously asserted that he was exceptionally proud of his niece who was a professional photographer and that he shared her love of photography but that now “nobody would give me a camera”. In celebration of jumping in (Rodgers and Tennant, 2014) and in direct response to the participant, cameras were given to the co-designers here in order to document an art exhibition at the Tramway Gallery and The People’s Palace both in Glasgow. Breaking down barriers and allowing the group to document what they found important resulted in 90 photographs being produced which became the focus for the 75BC textiles project.

Important to all of the projects has been primarily discussion, supported by mark making, writing and collaging in order to generate insights and to form collective opinions. This highly sociable and inclusive approach allowed for opinions to be aired, the creative responses often feeding off of other people’s ideas and sometimes reacting against the structures that appeared to be forming. The acceptance of deviation and unexpected behaviours or outcomes enhanced and altered the already rich creative environments that were occurring and has been accepted within the co-design process as being important in the creation of unexpected outcomes.

#### 4.1 Group 1 Projects - Bridgeton Textiles, Travel Postcards and Printing Toolkits

The 75BC project developed from an excursion that occurred prior to the formal co-design sessions. The group had been on a walk to see the new 75BC Billy Connolly murals that have been painted on three buildings in Glasgow. The group were not keen on the representations of one of Glasgow’s best-known sons and thought that they didn’t depict the character they knew in a way that was relatable. During the discussion of the work an invitation to join the group at the Tramway gallery the following week was received. From there a co-design process was started. The visit to see the work of Tschabalala Self aligned with the 75BC murals led to a plan to create Billy Connolly representations that were informed by the Tramway trip but that presented Connolly in a fashion that was more recognisable to the participants. Through a collaging kit of printed scraps that contained patterns of local textiles the group worked in the style of Tschabalala Self to produce figure forms. The kits allowed for various selections of component parts to be chosen from and the intention was to produce Connolly in the form of iconic poses. 4 pose kits were generated and two were chosen by the group to be worked with. The two poses were Connolly at *Dressed to Kilt* in New York and the *Big Banana Boots* (Feet). The group deemed these two representations to be more appropriate. The group produced figure forms, apart from one co-designer (CD4) who decided to arrange the components in a far more abstract method. Unexpectedly to the researchers the participants arranged their creations in multiples on a single sheet of paper. No direction had been given one way or other but the arrangements they created became the basis for pattern making which informed the next stage of the project.

Originally the intention had been to produce posters that would both support local engagement with the 75BC Murals and to be provocative about the 3 selected artworks. The murals were selected from a range of Billy Connolly paintings and drawings that had been on display at the People’s Palace Glasgow. The group also visited and photographed this exhibition. However, during the making of the collage pieces discussion developed around the potential of these images to become patterns in their own right. The arrangements of the scraps of textiles that formed the collages had previously

been chosen as they related to the heritage of the Bridgeton area where textile production had historically been a key industry.



Figure 1. 75BC Textiles and Products

In the following phase of the project the new designs were taken and arranged by the researchers to generate a number of patterns from which the group would decide on the scales of reproduction. The group firstly chose at which scale they liked the patterns, there were five variations for each design. From there the group were asked to select three designs that would be produced as prototype digital textile prints on cotton. They selected four. The group discussed what worked for each of them and chose designs that were based on a collective appreciation rather than on personal affiliation to their own designs. Following this the prototypes were sent off for production allowing space and time for another project to occur.

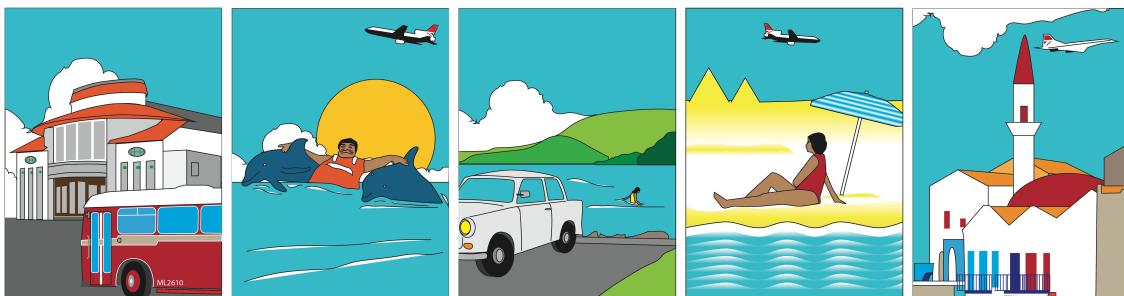


Figure 2. Co-designed Travel Postcards

Throughout the co-design approaches taken and alongside the research group's main project, other smaller projects have been undertaken, in order to provide a rich variety of activities. Working in a designerly manner where multiple projects are usually happening at once. This was experimental, in as much as it asked the co-designers to engage with different projects and themes over a period of time and in a somewhat inconsistent pattern. During the 75BC textile project a visit to the Riverside Transport Museum in Glasgow occurred. In support of this visit the group had discussions around favourite trips and travel experiences. In support of this discussion design toolkits were generated that invited people to write a ticket to their favoured destination. The destination or trip was then discussed and through collaging prototype postcards were created. These postcards were then interpreted by the facilitator worked up in computer software in order to create a quick group collection. The desire for this project is to get the set of postcards into the Riverside Museum gift shop.

On receipt of their new prototype 75BC/Bridgeton textiles, the group reflected upon where and how they might be used. Interior design and fashion formed the key considerations of these discussions. It was decided by the group that the former should be explored as ways to propose applications for their designs. The kinds of objects where textiles play a role listed and a selection of rudimentary objects and forms were chosen. These were then worked into kits which would allow the group members to select surface to apply their chosen textiles to. The result was a selection of rugs, cushions, light-shades, a sofa, a lounge chair, bed linen and wallpaper. Prototypes of some of these objects were created including a set of cushions which have become a key part of the Alzheimer Scotland resource centre in Glasgow. Other prototypes of the fabrics have since been produced in different cotton weights and silks with the intention of exploring avenues for getting these textiles to market.



Figure 3. Production of Cushions

Following this work the group developed textiles printing kits to explore themes of local cultural interest. The group initially co-developed these kits based upon the works of Rabbin Burns but subsequently through testing and development supported the production of a kit for public participation. The work that had evolved within this group of projects was displayed and engaged with in a public event in Lancaster. Here over 200 members of the public were invited to view an exhibition of the 75BC Bridgeton Textiles, the prototype lights, furniture and wallpaper and to get involved with using the printing kits the group had developed. This positively received event led to feedback that suggested valued engagement through comments such as “It was wonderful to learn about the project and get involved!” and that core project experiences were “Different local people making things together”.



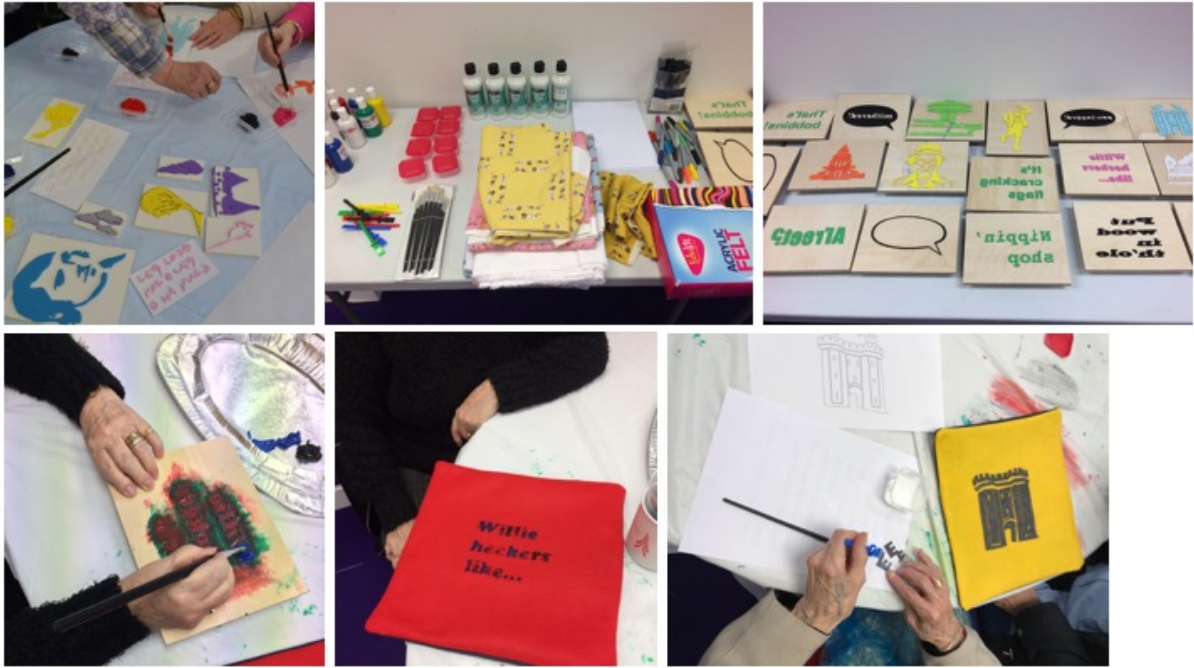


Figure 4. Exhibition kits in development and in use

## 4.2 Group 2 Project – Stained-glass Window for Glasgow

The work occurring with Group 2 is in its early stages in regards to this on-going research project. The investigations that they have been developing have centred around excursions to the Scotland Street Museum, Glasgow – paying particular attention to the methods, ideas and processes of Charles Rennie Macintosh, St Mungo’s Museum of Religious Life and work where attention was paid to the stained-glass window displays and discussion of Macintosh’s influence on contemporary stained-glass window designer-makers, and the Kelvingrove Art Gallery and Museum where archives of Glasgow and images of Glaswegian life were explored. The group undertook programmed tasks of making and drawing within these venues to explore various themes that had been discussed and these along with the discussions of what had been seen and done informed group activities to develop in stand-alone workshops. Situated within the group’s regular meeting space these activities were designed around the group set brief to design of a new Stained-glass Window for Glasgow.



Figure 5. Stained-glass Window development works

The first project invited the participants to get involved in making a lantern that explored some of Macintosh’s lighting designs. The project made connections between their visit to Scotland Street Museum, a Charles Rennie Macintosh building, and the recent news of the second fire at the Glasgow School of Art his most famous building. The approach was an introduction to the process of making stuff together and in a collaborative fashion. In this task which facilitated the production of a

prototype the group were encouraged to undertake tasks that would require everyone to participate and to provide content. Though largely directed the approach allowed for considerable free forming to occur and started to suggest individual qualities in how they might engage with design tasks and to what extent those responses would become quite personal and individualistic representations. Many comments have been made by the participants about their enjoyment in the processes. Through their demonstration of making these items the individuals showed great independence in thinking, styling and personal preferences. These attributes were further demonstrated in their second developmental works which required them to produce designs for representations of the coat of arms of Glasgow in the form of stained-glass. These designs had followed group discussion of the lampposts outside St Mungo's Museum in Glasgow where the coat of arms was depicted. This work developed their own individual styles and utilised a set of pre-designed elements which were cut out and arranged by the participant co-designers. These transparent elements were arranged by the co-designers on a transparent sheet and coloured using stained-glass pens. Following discussions surrounding the main project theme the group identified the elements required for the Stained-glass Window for Glasgow which comprised components of their cultural visits and other important buildings or representative elements. The group arranged similar transparent components as those they had previously used to then create a prototype scheme. This prototype is the foundation for the outcome they are continuing to develop.

### 4.3 Group 3 Project – Re-designing Sundays

In the third project a dozen people living with dementia were encouraged to discuss things in society that they would change, fix, bring back or design based upon personal and collective experience. The participants responded to prompts on a set of postcards to engage with discussions. Unlike the previously discussed projects this group were not engaged with cultural visits and explorations. Instead they were coming together as a group of people living with dementia to discuss issues of living with the condition. The group engaged in an hour of discussions that resulted in the drafting elements that were to be part of a brief for a follow up session. At the follow up session the group invited their carers to take part in a café style environment for open discussion and collaging where they literally scribbled and produced representative images upon tablecloths. The Brief that had been formed was to ***“Redesign Sundays to make them special again, where fun can occur that supports respect and communication.”*** The visual propositions, mark making, notes and diagrams produced along with the deep discussions that occurred resulted in three concrete propositions for services that could make this a reality. These three proposals continue to be explored in order to make one of the propositions a reality. The propositions are:

- **“Our Big Picnic”** - allows people of all ages and backgrounds to congregate in an organised event and make the entertainment.
- **“Open Street”** - will become a local hub for play, talk and local understanding to make the street more like streets from yesteryear.
- **“D:Caf”** - where people living with dementia deliver a hospitable place for fun, conversation, innovation, play and companionship.



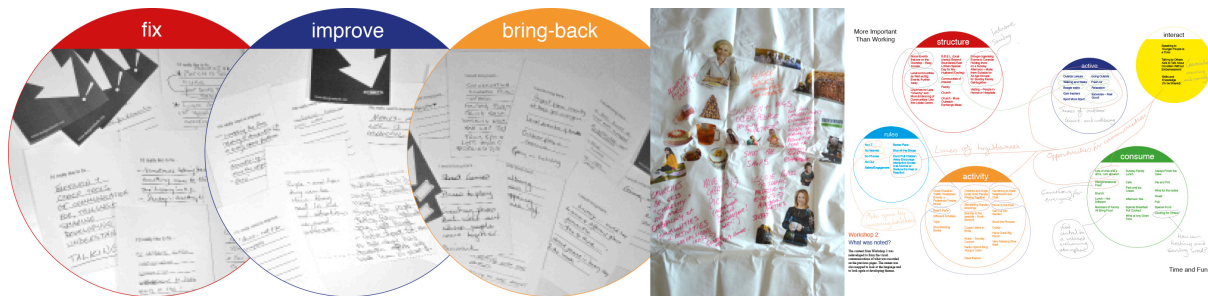


Figure 6. Re-design Sundays Ideas Generation

Personal assertions, affirmation and esteem and identity have been particularly evident in the discussions that have naturally occurred during these group design activities. This has manifested itself in personal insights and revelations that have reinforced the individual's worth within the group dynamic but have also been demonstrated by the decision making, personal choices and collective negotiation that has occurred as the works have evolved. This approach builds upon Fredrickson's (2013) view that emotional responses are key to the mood of people living with dementia and that as emotional responses are one of the last areas to be affected by dementia (James, 2009) that dementia care should start with things that support good feelings and moods. These are best demonstrated by the way in which people personally respond to engage with and make associations through the projects discussed here. Throughout the process the people involved showed enthusiasm to be involved and to share personal insights or narratives that aligned to that which was being explored.

During the Re-design Sunday sessions, a powerful piece of commentary received by a person living with dementia was "You made us think more than we are usually asked to do and it is good for us to have to think." Proposing that a changed perspective for all involved is both beneficial and welcomed.

In the 75BC Textiles project one example of how personal esteem, identity and narrative was revealed was through collaging activities. Here one co-designer reiterated how important this process had been throughout her life. The craft approach was rooted in her personal history, leading to tails of the deeply personal cards and images that she had created for friends and family throughout her life. With such empowered knowledge, this co-designer regularly demonstrated approaches that were non-conformist and that displayed personal choice which directed very individual creative outcomes. Her approach demonstrated a desire to bend the rules of the systems that she was engaging with supported by a very distinct desire to make things on her own terms. The arrangements that she designed resulted in one of the fabrics that was produced.

In relation to the Travel Postcards project for the Riverside Museum another one of the group members again revealed something of importance to them. During the conversations and creation of the postcard prototypes one of the quietest members of the group discussed his love of travelling up the West Coast of Scotland by bus and suggested that his destination would be Campbeltown. The conversation revealed that in the late 60's for a couple of years had worked on such busses. On completion of the postcard prototype the co-designer offered the following "ML2610" when asked "was that the number plate of the bus" he responded that it was actually the identification number of the bus he worked on. The importance of the process allowed him to find a way to discuss a part of his life and experience that no other members of the group or the support staff had been previously aware of.

Another co-designer who joined the group mid-way through the 75BC project demonstrated the importance of his involvement in the group and their designed outcomes through his designs for a set of lampshades. For this participant, dementia affects his ability to verbally communicate and as such can hamper his involvement in discussions. Within the collective process of choosing the patterns to be produced as textiles this individual made great efforts to inform the group's decision making. Here his ability to play an equal role became evident through being an active participant in the process. This co-designer really came into his own, however, when sketching through craft allowed him to apply the final textile designs to templates for objects. The templates were as previously discussed were a cross between collage and jigsaw structures that allowed for the textiles to be arranged within outlines that had been preselected by the group. Though he struggled to find the words to describe what he was doing or what he desired to make the outputs he generated were evidently thoughtful and resulted in two important designs for the group's collection. The engagement that he demonstrated was most evident when he joined the Stained-glass design group. Although the researchers had not engaged with the 75BC group for five months the co-designer made a determined approach to say hello and to welcome us to the new group. In the introduction to this work, a presentation of what the previous group had done and achieved was made. During this presentation, this co-designer made great effort to show his pride in being part of the project and to state "I did that". His excitement and pride were evident as he let the group know that he had been heavily involved in designing for the collection and making the 75BC cushions that have become part of the fabric of the centre in which the group meets.

## 5. Insights

Reflecting on this ongoing co-designing and making project, it is abundantly clear that people living with dementia can offer much to interest groups and society after diagnosis. Working closely with stakeholders including carers, family members, and collaborating organisations such as Alzheimer Scotland, the authors have received regular highly positive feedback. Participants have stated that the co-designing and making experiences have been very positive; they have been interested, engaged, and enjoyed co-designing and making; there has been concentration, focus and discussion during the co-designing and making sessions. Participants and their family, friends and carers have expressed that this work has been very beneficial. Several of the stakeholders involved considered there to be significant impact for participants in the way the co-design sessions gave people confidence to try new things and that the sessions generated excitement and anticipation of what would be achieved. The project presented here shows how co-designing and making methods and tools can enable people living with dementia to make a significant contribution to their groups and wider society after diagnosis. Specifically, this work has shown how design can empower people living with dementia to change public perceptions of dementia. Through public exhibition of new designs and by inviting the public to engage in design focused activities people living with dementia have invited and directed the public to engage and discuss pertinent issues. Moreover, this co-design 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 communities. While the symptoms associated with dementia affect the way a person living with dementia interacts with others, and some activities may be inappropriate as a result, there are still many activities such as co-designing and making in which they can participate and which they can demonstrate skills and great pride in achievements. Moreover, people living with dementia should be encouraged to make decisions or partake in decisions that affect them and the ways in which they pro-actively live for as long as possible, to maintain their dignity and self-esteem. This has been at the heart of this project.

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