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First published 2016

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ISBN 978-1-86135-466-2

Designing with people living with dementia

Paul A Rodgers

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Foreword

People living with dementia throughout Scotland have the right to a range of therapeutic activities that will support their ability to live as full citizens and have full participation and inclusion in all aspects of life.

Therapeutic activity comes in many ways and Alzheimer Scotland leads the way with many ground-breaking projects such as football reminiscence, singing groups, craft cafes and art groups.

The Disrupting Dementia project tartan workshops fitted the themes we know can work for people living with dementia, around inclusion, participation, creativity and an increased sense of self identity through an activity that is carefully thought through and facilitated in a dementia friendly setting.

For people experiencing more advanced illness this requires additional support and for creative approaches to be found. This participation was made possible with creative co-operation between Paul Rodgers and the Alzheimer Scotland staff throughout Scotland who supported the design workshops.

What you see in this book is the results of those creative design

sessions hosted in Alzheimer Scotland Resource Centres across the country from Kilmarnock to Shetland.

I was fortunate to be present at the Kilmarnock workshop where the creative juices certainly got flowing and this engendered a lot of enjoyment. It was a catalyst for conversations and reminiscence on past working lives, hobbies once loved, and maybe the opportunities to share those hobbies again.

Alzheimer Scotland is the leading dementia organisation in Scotland. Through working with others, such as Professor Paul Rodgers who brings his depth of design expertise, we can add great value to our work and most importantly provide great benefits for people who are living with dementia.

We hope that this book and the associated interest will provide a tangible legacy of the 20 design workshops that produced beautiful work and created such an enjoyable activity for the many people with dementia that took part.

Joyce Gray
Deputy Director Development
Alzheimer Scotland
January 2016





Introduction

This project was undertaken as part of the author's larger Arts and Humanities Research Council (AHRC) funded Design Research Fellowship that aimed 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, adopted 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.

The main aims of this project are to develop a series of disruptive design interventions that will help change the perception of dementia by showing that people living with dementia can offer much to UK society after diagnosis. It is hoped the designed interventions will help reconnect people recently diagnosed with dementia to build their self-esteem, identity and dignity and help keep the person living with dementia connected to their community, thus delaying the need for formal support and avoid the need for crisis responses.

During the creation of the Disrupting Dementia project tartan, the author worked collaboratively with 130 people diagnosed with dementia across Scotland in the co-design and co-production of this new tartan.



Designing the tartan

The Disrupting Dementia project tartan sessions involved a number of co-design workshops held across Scotland from Kilmarnock in the South to Shetland in the North and Stornoway in the West to Aberdeen in the East. In total, 17 Alzheimer Scotland **Dementia Resource Centres** were visited and over 20 co-design workshops were held 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 over half a kilometre of coloured ribbon used in the creation of the participants'

tartan design prototypes. The main aim of this 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 could have a commercial value. 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 started with a short presentation of the rules associated with the creation of the Disrupting Dementia project tartan. 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 design of each participant's Disrupting Dementia project tartan included a series of creative stages. For many participants they begun by sketching out their ideas using paper, coloured pencils and crayons.





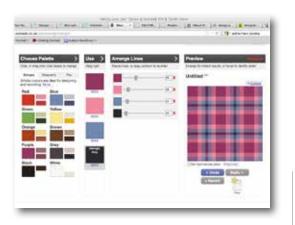


The next stage involved the participants using coloured acetate to create an acetate-based version of their tartan.

The coloured acetate stage was followed with each participant creating a physical mock-up of their tartan using ribbon in a variety of different colours and thicknesses. to create a prototype of their tartan design.

The next stage of the Disrupting Dementia project tartan design process involved each participant creating a digital version of their tartan using a publicly available Internet-based tartan design tool.

Working from the physical ribbon prototype, each participant co-created his or her digital design one colour at a time using the Internet-based tool (Figure right).









In the example illustrated in the figure above, one can see that the participant's main colour in their tartan design is purple, followed by their choices of pink, light blue and finally midnight grey.

Working from left to right, each participant gradually created their Disrupting Dementia project tartan based on the physical ribbon prototype they created earlier. Often this process involved a number of iterations between the designer (person living with dementia) and the facilitator (author). Sometimes, the designer would go back

and forth between different versions that they created and alter the order of the colours to finally achieve the design that they were satisfied with. Ultimately, each participant would complete the process by printing their Disrupting Dementia project tartan on paper.





Perth

In Perth, Eddie, Helen, Mae, Maureen and Reay all designed wonderful tartans during the workshop held there on 11th February 2015. Perth has been known as The Fair City since the publication of Sir Walter Scott's "Fair Maid of Perth" in 1828. The name Perth comes from a Pictish word for wood or copse. Perth is the home of both the Aberdeen Angus and Highland Cattle Societies.





Eddie



Helen



Maureen



Reay



Kilmarnock

In Kilmarnock on 30th October 2014, Denis, Grace, John, Margaret and Michael all created fabulous tartan designs. Kilmarnock, the 15th most populated place in Scotland, is famous for its dairy produce, and every October holds the largest cheese-show in Scotland. Kilmarnock rose into importance in the 17th century by its production of striped woollen "Kilmarnock cowls" and broad blue bonnets, and afterwards acquired a name for its tweeds, blankets, shawls and lace curtains.

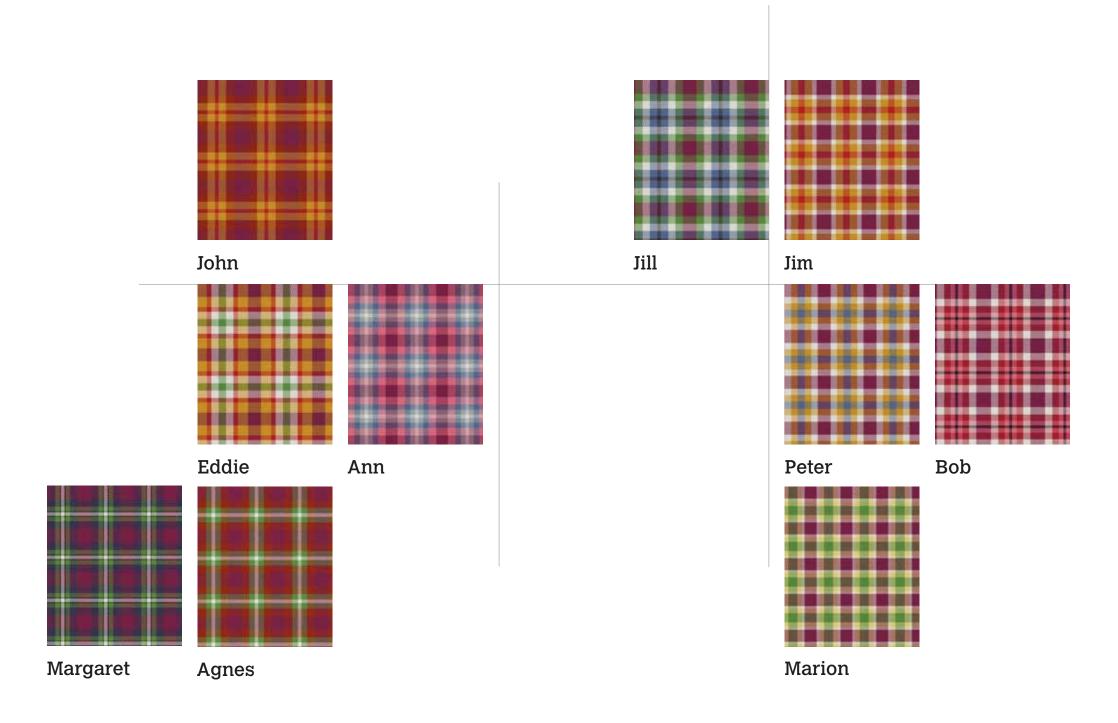


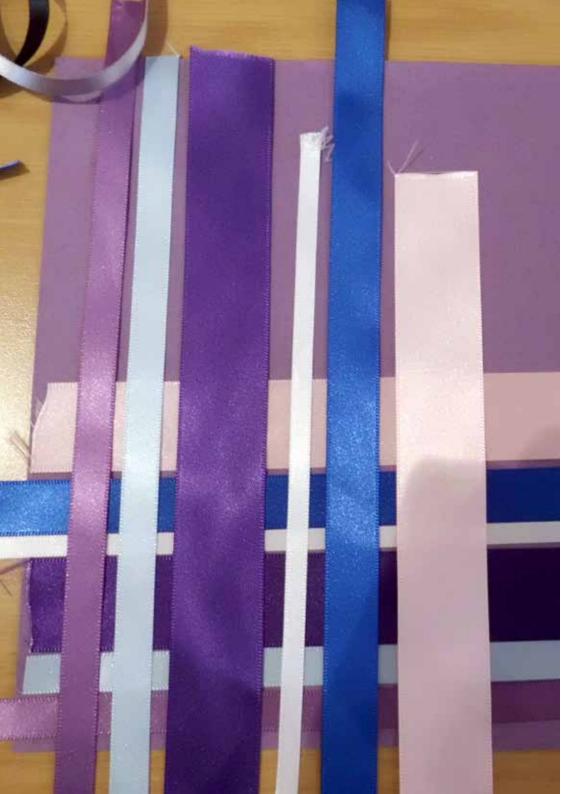




Falkirk

Falkirk was voted Scotland's most beautiful town in 2011 and was the scene of the famous battle fought half a mile north of it on the 22nd July 1298 between English forces commanded by Edward I and the Scottish patriots led by William Wallace. Over the course of two days in December 2014, John, Eddie, Ann, Margaret, Agnes, Jill, Jim, Peter, Bob and Marion created amazing tartan designs during the two workshops held there.





Bonnyrigg

Bonnyrigg is a small former mining town in Midlothian and was home of the writer Thomas De Quincey "Confessions of an English Opium-Eater" from 1840 until his death in 1859. Bonnyrigg also saw the highest number of tartans designed by a single centre with 16 wonderful tartans created. The designers were Dave, Jack, Mary B., Hughie, Marion, Richard, David, Nessie, Jean, Mary K., Robert, Jimmy, Olive, Alan, Arthur and Gordon.



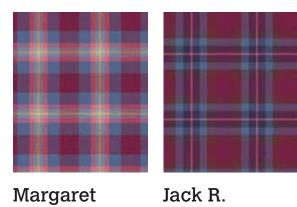


Inverness

Inverness is one of Europe's fastest growing cities and is ranked 5th out of 189
British cities for its quality of life, the highest of any Scottish city. In 2014, a survey found Inverness to be the happiest place in Scotland. In January 2015, Jack M., Margaret, Jack R., Mick and Nan, the eventual winner of the Disrupting Dementia project tartan, designed five truly outstanding tartans in Inverness.



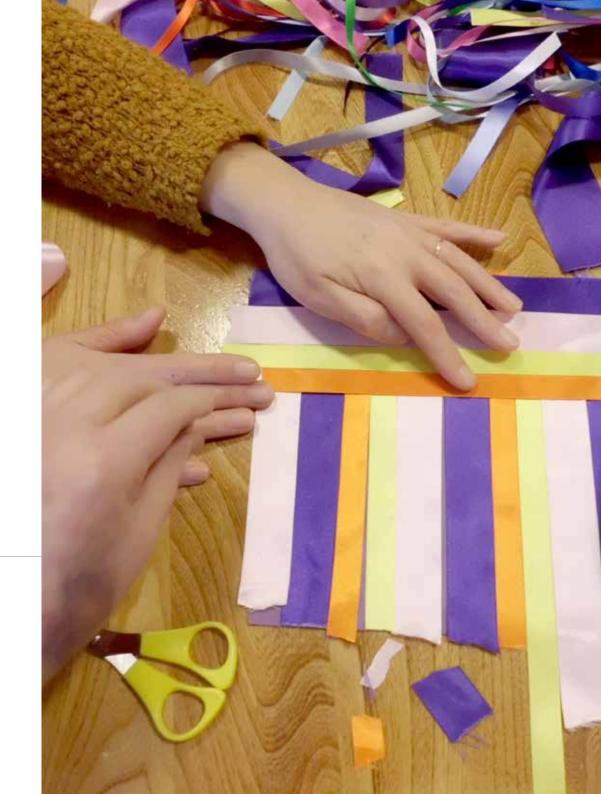
Jack M.

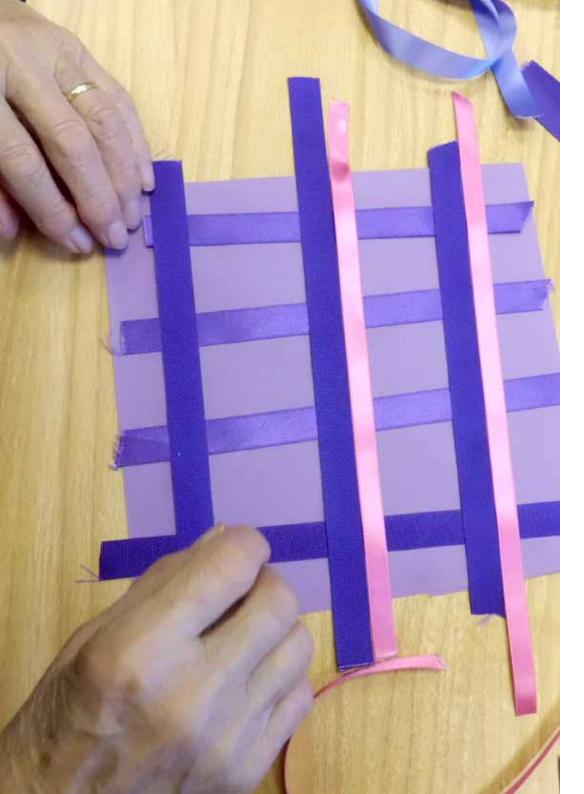


Margaret

Mick

Nan





Stornoway

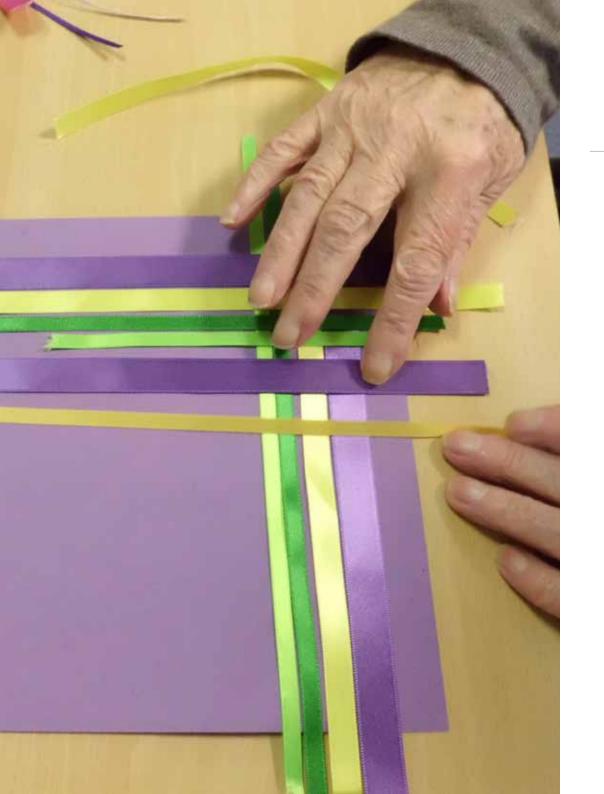
In Stornoway just before Christmas 2014, Sandy, Alice, Chrissie M., Joan, Chrissie Mac., Ian, Donald Angus, Phyllis and Bella all created truly stunning tartans – perhaps due to the town's long association with Harris Tweed and the weaving industry. Stornoway has a population of around 6,000, making it the largest town in the Outer Hebrides, and almost half of the population are Gaelic speakers.





Thurso

Thurso is the northernmost town on the British mainland, situated on the northern coastline overlooking the Orkney Islands. Historically, Thurso (called Thjorsá then Thorsá in Norse, based on the deity of Thor meaning "the place on Thor's River") was known for its production of linen cloth and had a thriving tanning business. In January 2015, however, Betty, Charlie, Dora, Etta, Jean and Joan all designed amazingly beautiful tartan designs.







Wick

Wick's history stretches back, at least, to the era of Norwegian rule in Caithness, which ended, conclusively, in 1266's Treaty of Perth. The name Wick appears to be from a Norse word, vík, meaning bay. Later on the same day as the Thurso tartan design workshop, Esther, Jock, John, Joyce, Lillian, Maisie and Mary all created truly stunning tartan designs. Wick is also famous for having the world's shortest street, Ebenezer Place, measuring just over 2 metres.





Shetland

Shetland, also called the Shetland Islands, is a subarctic archipelago that lies northeast of the island of Great Britain. The islands lie about 80 km to the northeast of Orkney and around 280 km southeast of the Faroe Islands. Shetland is home to the diminutive Shetland pony, a well-known and important part of Shetland farming tradition, famous for its size and its strength. In February 2015, Frances, Ina, Jemima, Jessie, Mary, Meg, Nan and Olive all created stunning tartans designs.







Clydebank

Clydebank is a town situated on the north bank of the River Clyde. In the early 20th century the town was synonymous with many of the Scottish socialist movements led by the shipyard workers along the river Clyde, giving rise to the title of "Red Clydeside". Clydebank hosted two tartan design workshops and 14 amazing tartan designs were created over the course of two days by Alex, Iain, Margaret, Isa, Hugh, David, Helen K., Stewart, Ann, Betty, Bessie, Maggie, Helen C. and Ian.





Dundee

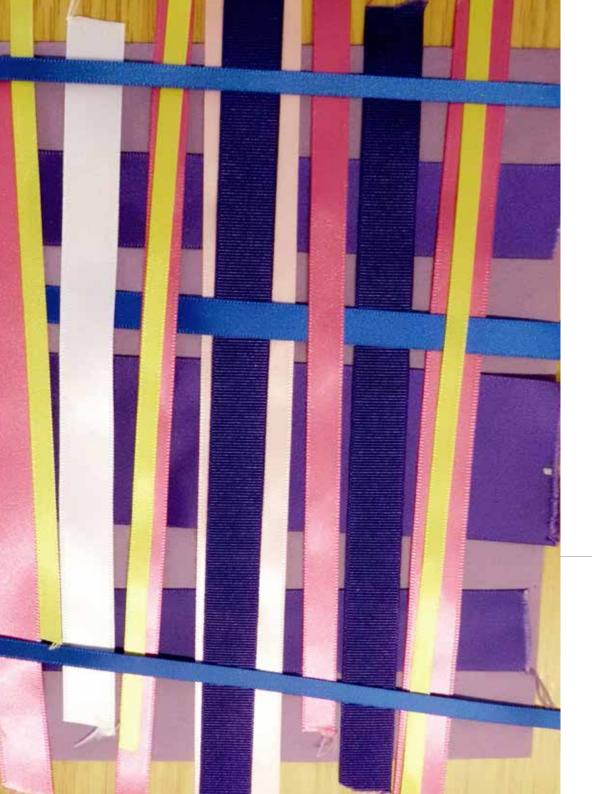
Dundee is Scotland's fourth largest city with a population of around 150,000. The city expanded rapidly in the 19th century largely due to the jute industry. This, along with its other major industries gave Dundee its epithet as city of "jute, jam and journalism". The Dundee workshop participants, Alex, Andy, David, Irene P., Irene T., Johnson, June, Kenneth, Michael, Nessie and Walter, created a total of 11 amazing tartan designs.





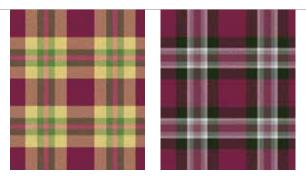
Stirling

Stirling produced 3 wonderful tartan designs. Jeanette, Stan and Toby worked really well and created truly glorious tartans. Stirling is clustered around a large fortress and medieval old town and is known as the "Gateway to the Highlands". It has been described as the brooch, which clasps the Highlands and the Lowlands together. Famous residents of Stirling have included the Barnwell brothers, Frank and Harold, who in 1909 designed and flew the first powered aircraft in Scotland.





Jeanette



Stan

Toby





The legendary song "The Dairy Maids Of Hundred-Acre Hill", from Old Glasgow Street Songs etc. (1850) is a tribute to the fine features and qualities of the dairymaids who live on Hundred Acre Hill, an area in modern King's Park, which is described by Hugh MacDonald in his book "Rambles Round Glasgow" (1854). On the 27th February 2015, nine wonderful tartan designs were created by Alice, Bill, Eunice, Hannah, Irene, Mairi, Nancy, Rachel and William.

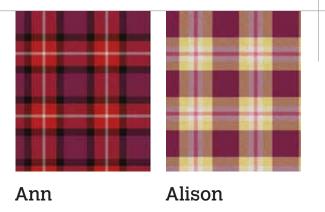


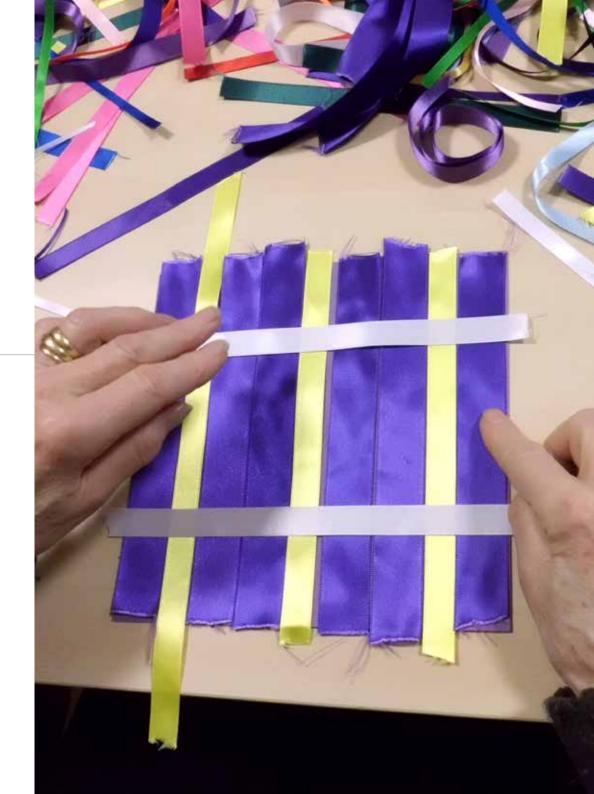




Orkney

In Orkney on the 25th February 2015, Ann and Alison produced amazing tartan designs. Orkney is an archipelago situated off the north coast of Great Britain and comprises approximately 70 islands, of which 20 are inhabited. Apparently the shortest scheduled air service in the world, between two of the islands, Westray and Papa Westray, is scheduled as a two minutes long flight. But locals claim it can take less than one minute if the wind is blowing in the right direction.







East Renfrewshire

Betty, Joyce, Margaret, Mary and Pearl spent a lovely afternoon on the 6th March 2015 designing their tartans in East Renfrewshire. They all produced wonderfully creative tartan designs. Interestingly, in a 2007 Reader's Digest poll, East Renfrewshire was voted the second best place in Britain to raise a family. Even more interesting is Rudolf Hess, one of Adolf Hitler's top deputies within the Nazi Party, parachuted into a field near Eaglesham on a secret mission for peace negotiations in 1941. The botched landing led to his capture and arrest.







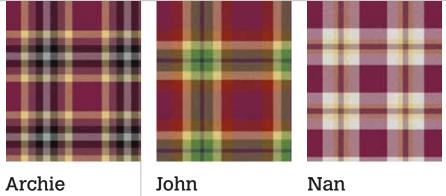
Aberdeen

Nicknamed the Granite City, Aberdeen is a port city in northeast Scotland where the Dee and Don rivers meet the North Sea. Aberdeen is famous for some of its food, including the Aberdeen buttery. The buttery, also known as "rowie", looks like a cross between a pancake and a croissant and has a buttery, salty taste and is usually eaten cold, served plain or with jam or butter. Aileen, Archie, John, Nan and Norma attended the tartan design workshop in the city and all created magnificent tartan designs.





Aileen



Archie

Norma



Glasgow

Glasgow grew from a small rural settlement on the River Clyde to become the largest seaport in Britain and the largest city in Scotland. Inhabitants of the city are referred to as Glaswegians. Daniel Defoe visited the city in the early 18th century and famously opined in his book "A tour thro' the Whole Island of Great Britain", that Glasgow was "the cleanest and beautifullest, and best built city in Britain, London excepted." On the 16th March 2015, Betty, Bill, Jessie, Lena, Martha and Winnie created truly beautiful tartan designs.







Judging

Of the 130 tartan designs created by people living with dementia, a Judging Panel comprising Alzheimer Scotland staff members combined with experts in tartan manufacture narrowed it down to a shortlist of 7 for people all over Scotland to vote for their favourite. The winning tartan was chosen after several thousand votes had been cast.

Seven finalists

After visiting 17 different Alzheimer Scotland Dementia Resource Centre locations all over Scotland, totalling over 81 hours travelling, and racking up almost 2000 miles, 130 unique tartan designs for the new Disrupting Dementia project tartan were created by people living with dementia.

From 130 tartan designs, we shortlisted a final 7 amazing tartans. Here they are below and opposite.







Mary, Shetland

Margaret, Clydebank

Reay, Perth







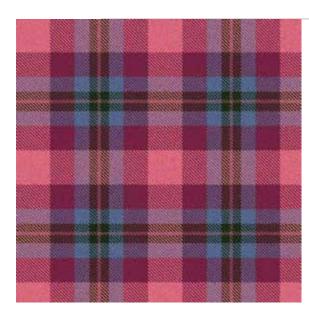
Irene, King's Park



Mary, Wick

The chosen Disrupting
Dementia Project Tartan
was designed by Nan from
Inverness as part of an Arts
and Humanities Research
Council project led by
Professor Paul Rodgers
of Northumbria University
Design School. 130 tartan
designs were created by
people living with dementia
all over Scotland with Nan's
design being chosen as

the project tartan. All things Scottish, particularly tartan, have played a huge part in Nan's life. Nan really enjoyed creating her tartan as she is very proud of her highland heritage. Nan's tartan features the primary colours (purple and pink) of Alzheimer Scotland in its design. Nan has gifted the copyright of her design to Alzheimer Scotland.



Nan, Inverness

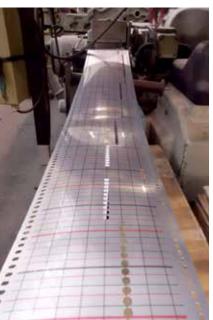


Making the tartan

Making the Disrupting Dementia project tartan involved several stages. Taking Nan's digital design as a starting point, coloured yarn in purple, pink, petrol blue and midnight grey was then chosen to match her design. Next, a thread count pattern was created and weaving instructions defined before a handwoven sample was created to check the overall appearance of the tartan. The final stages involved in manufacturing the tartan included the manufacture of punched card instructions for the loom before the cloth was finally produced.



















Epilogue

This book highlights the author's Arts and Humanities Research Council's (AHRC) Design Research Fellowship, which 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 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 goes a little way to help change the perception of dementia and shows 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 hopes to help reconnect people recently diagnosed with dementia to build their self-esteem, identity and dignity and keep the person with dementia connected to their 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.

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.

Acknowledgements

This project would not have been possible without the amazing support of Alzheimer Scotland, the financial backing of the Arts and Humanities Research Council (AHRC), and my colleagues at Northumbria University School of Design.

Most important, however, were the 130 people living with dementia from all over Scotland – from Kilmarnock in the south to Shetland in the north and from Bonnyrigg in the east to Stornoway in the west who took part in this collaborative project. Without these 130 incredible individuals the project would never have achieved anything. So my greatest gratitude is reserved for these people.

Special thanks must also go to the fantastic Alzheimer Scotland dementia care support workers at the 17 centres I visited during the course of the project.

I would also like to express my sincere thanks to the following individuals at Alzheimer Scotland – Henry Simmons (Chief Executive), Joyce Gray (Deputy Director of Development), and Lindsay Kinnaird (Research Manager) who have all provided me with their expert knowledge and support over the course of my year long Design Research Fellowship with them.

It has been a real privilege to work with so many amazing people on this tartan project and other design projects over the course of the last year.

The final word of gratitude must go to Alison, Charlie and Max for their constant help and their unquestioning support especially when I was away from home for days on end during my Fellowship year.

