





As a committee member of the Scottish Dementia Working Group (SDWG), I am proud to share with you a project we have developed with occupational therapy interns from Queen Margaret University, Edinburgh and Alzheimer Scotland, to help us challenge stigma and change the image of dementia through the use of our photographs and our stories.

The SDWG is a national campaigning and awareness raising group whose members all have a diagnosis of dementia. We are the independent voice of people living with dementia within Alzheimer Scotland. We are a strong collective voice of diverse people with dementia across Scotland.

We created this e-book, between 2016-2019, in partnership with eight occupational therapy interns and one events management graduate who worked as a volunteer. The partnership work and time spent together provided a unique opportunity for the interns to learn from us, through our photographs and narratives, what it is to live with dementia in our communities.

We have seven members of the SDWG who helped to create this e-book. Each chose their own approach in how they worked with the interns.

Each member wanted to share with you the everyday activities that are important to them, demonstrating that people living with dementia can still do so much.

# Welcome to our first SDWG e-book

**Archie Noone,**  
Committee member of SDWG



I am delighted to support this innovative and creative e-book developed in partnership with the Scottish Dementia Working Group (SDWG) and our occupational therapy interns at Alzheimer Scotland. Our work at Alzheimer Scotland is driven from a rights-based perspective and is informed by the expert members of the SDWG. The e-book strengthens the pivotal role of the SDWG to campaign for people who also live with dementia.

The SDWG have a strong history in Scotland, starting in 2002 and they were the first group to engage the voice of people with dementia directly in the development of social policy, education research and campaigning. Seventeen years later, the group is still a national campaigning and awareness-raising group whose members all have a diagnosis of dementia.

This e-book supports and delivers specifically on the campaign priority of the SDWG to “raise awareness of different types of dementia and challenge stigma, while demonstrating and showcasing some of the ways people with dementia live well”. Through sharing images of the day to day lives of seven of the members, you can see what is important to them as people and the valued roles they all hold in their local communities.

Our occupational therapy internship programme supports our partnership working with the AHP programmes at Queen Margaret University and builds on our commitment to support a future AHP workforce skilled in dementia care.

# Introduction

**Henry Simmons,**

Chief Executive, Alzheimer Scotland



It is my pleasure to add my support to this project undertaken as a partnership between the Scottish Dementia Working Group (SDWG), Queen Margaret University Occupational Therapists and Alzheimer Scotland. The partnership working that is evident in this e-book illustrates the growing number of innovations arising from the collaborative work between these three key stakeholders.

Despite the growing awareness among the general public about dementia and the potential to 'live well with dementia', there continues to be a dominant negative discourse about having dementia. The negative language that is sometimes used discredits the fruitful lives led by many people living with dementia and their continued contribution to families, communities and societies. The SDWG has worked tirelessly to ensure that people living with dementia have an equal voice and their partnership work with Alzheimer Scotland has changed the landscape of inclusion for the Scottish population who are living with dementia. People living with dementia make important contributions to all parts of society and this needs to be recognised, profiled and celebrated.

Occupational Therapists at Queen Margaret University are at the heart of these contributions, enabling persons to retain and regain fulfilment through occupation. This commitment is evident in the teaching and learning programmes provided, in our innovative research and through a variety of internships that trial new and innovative ways of working. Ensuring that our programme of work enables all persons to flourish is a strong personal value that I hold. I am delighted that this is so evident in this project and a range of other work undertaken by the team at Queen Margaret University in partnership with others. This e-book shines a light on people living well with dementia, highlighting the extraordinary in the ordinary and the importance of the 'everydayness' of life to all of us. I hope that this e-book serves as a benchmark for other similar projects and innovations that shape a more positive discourse about living with dementia.

# Introduction

**Professor Brendan McCormack,**

Head of the Divisions of Nursing, Occupational  
Therapy & Arts Therapies

Associate Director Centre for Person-centred  
Practice Research

School of Health Sciences

Queen Margaret University



# Partnership working

## **Dr Fiona Maclean**

Senior Lecturer & Programme Lead of the MSc (Post Reg.) in Occupational Therapy, Division of Occupational Therapy & Arts Therapies, Queen Margaret University, Edinburgh

## **Elaine Hunter**

National Allied Health Professions Consultant, Alzheimer Scotland

Working together in partnership, our focus has been to capture the meaning and importance of occupation in the lives of people living with dementia. Occupation can be broadly defined as the rich tapestry of everyday activities that we do as individuals, families and communities that together bring meaning and purpose to our lives. Occupational therapists are experts in understanding the intrinsic relationship between the person, environment and occupation, to support people living with dementia to continue to engage in the life of their village, town or city; to sustain their identity and sense of purpose through valuing everyday activity.

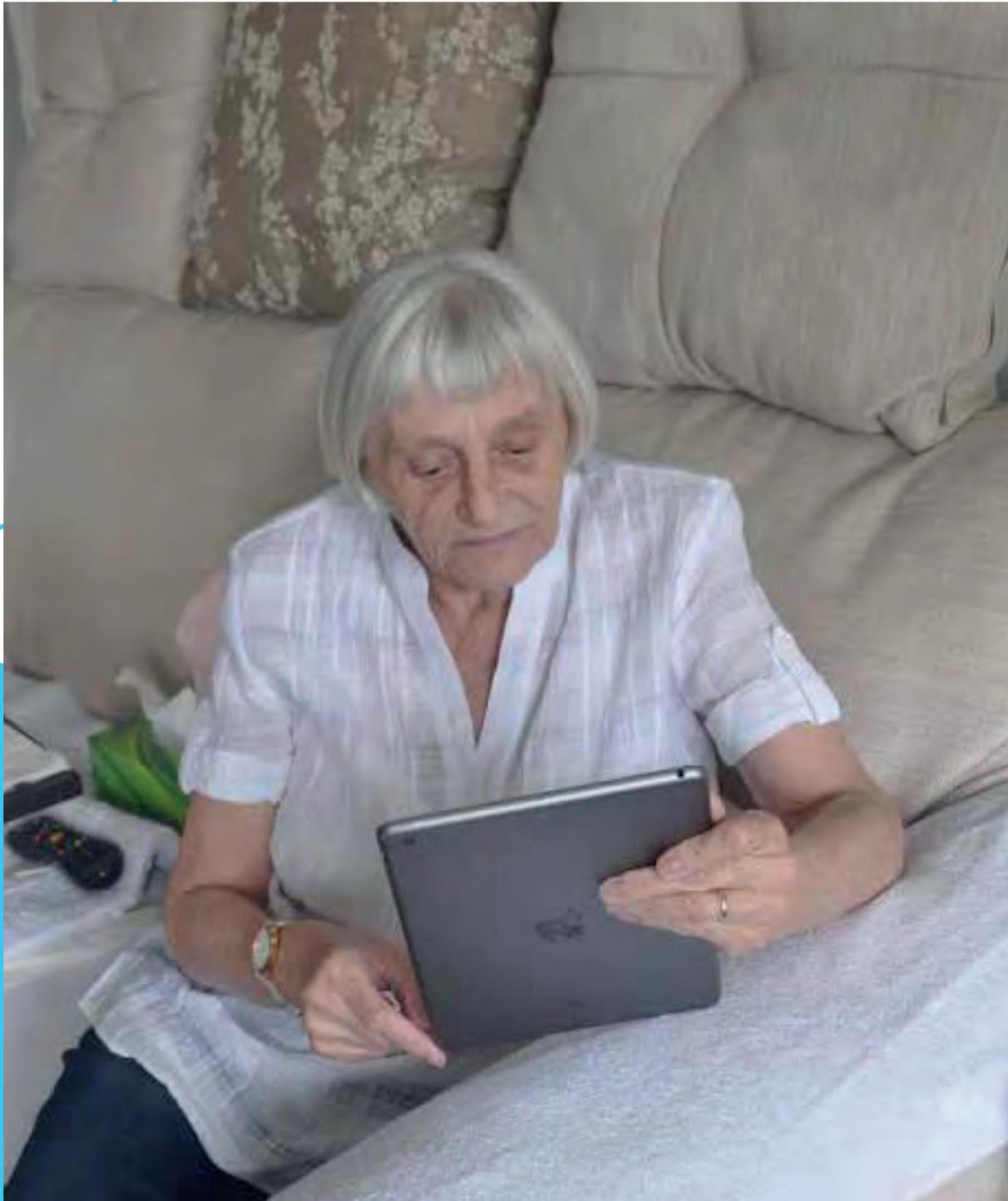
This professional understanding has guided our development of an occupational therapy internship programme, which has become an important part of our working lives each summer since 2013. This has included the opportunity to meet and work with members of the SDWG, whose generosity of time and willingness to share their stories has advanced our understanding and insight of what it means to live with dementia.

Our internship projects are co-designed and informed by the campaign priorities of the SDWG, and this e-book is one example. The photographs included here offer a unique and personal insight into the lives of seven people living with dementia. It aims to capture occupations identified by members of the SDWG that are important to them and which sustain their connection with families, friends and communities. It is not a photography project but an opportunity to share the everyday lives of people living with dementia.

We hope this e-book provides an opportunity for you to develop your understanding of the experience of what it means to live with dementia through the eyes of Josie, Carol, Henry, Archie, Nancy, Tom and Pat. We want to thank the SDWG for sharing their lived experience with us every day.

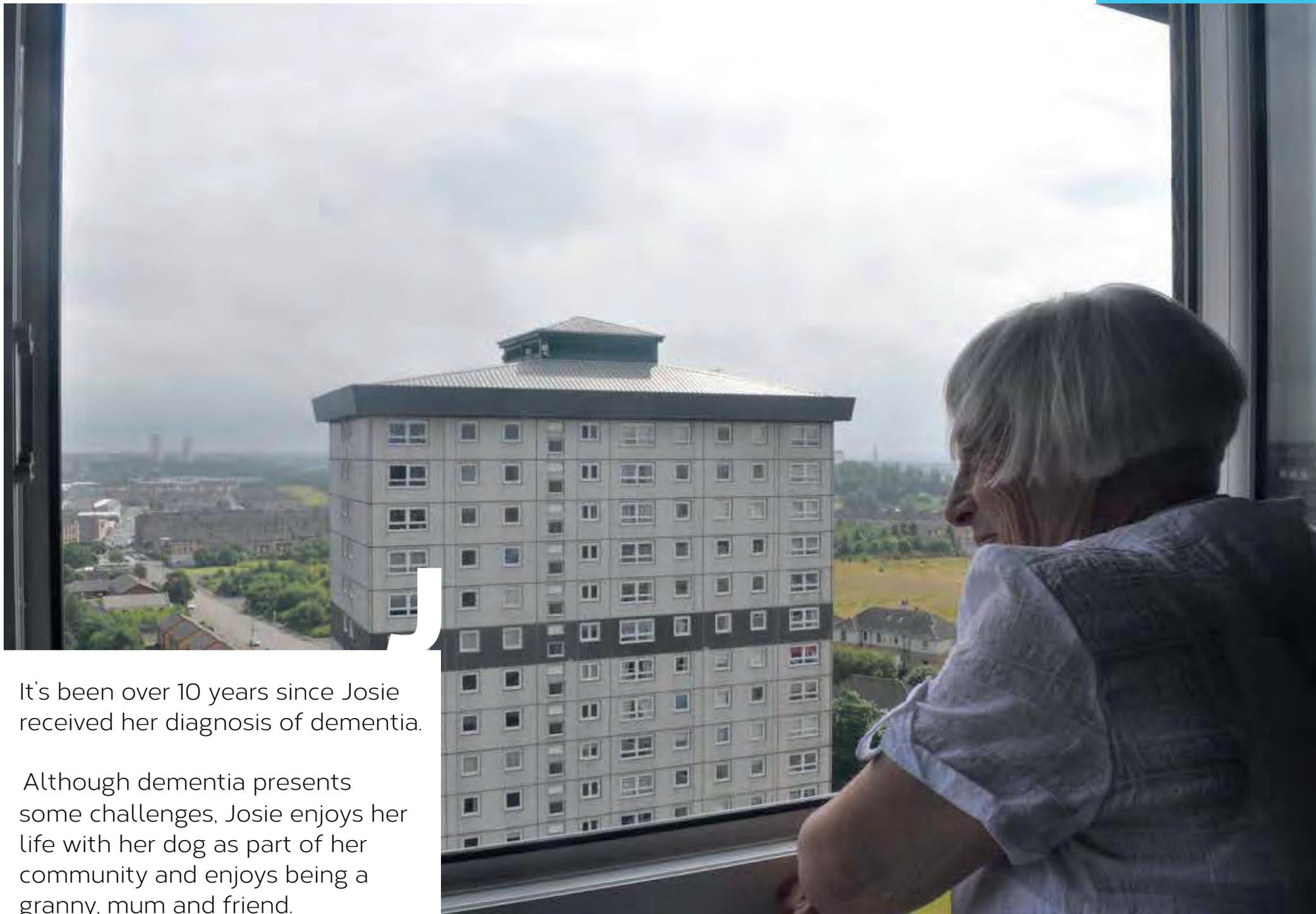
**SDWG**

**Photographs**



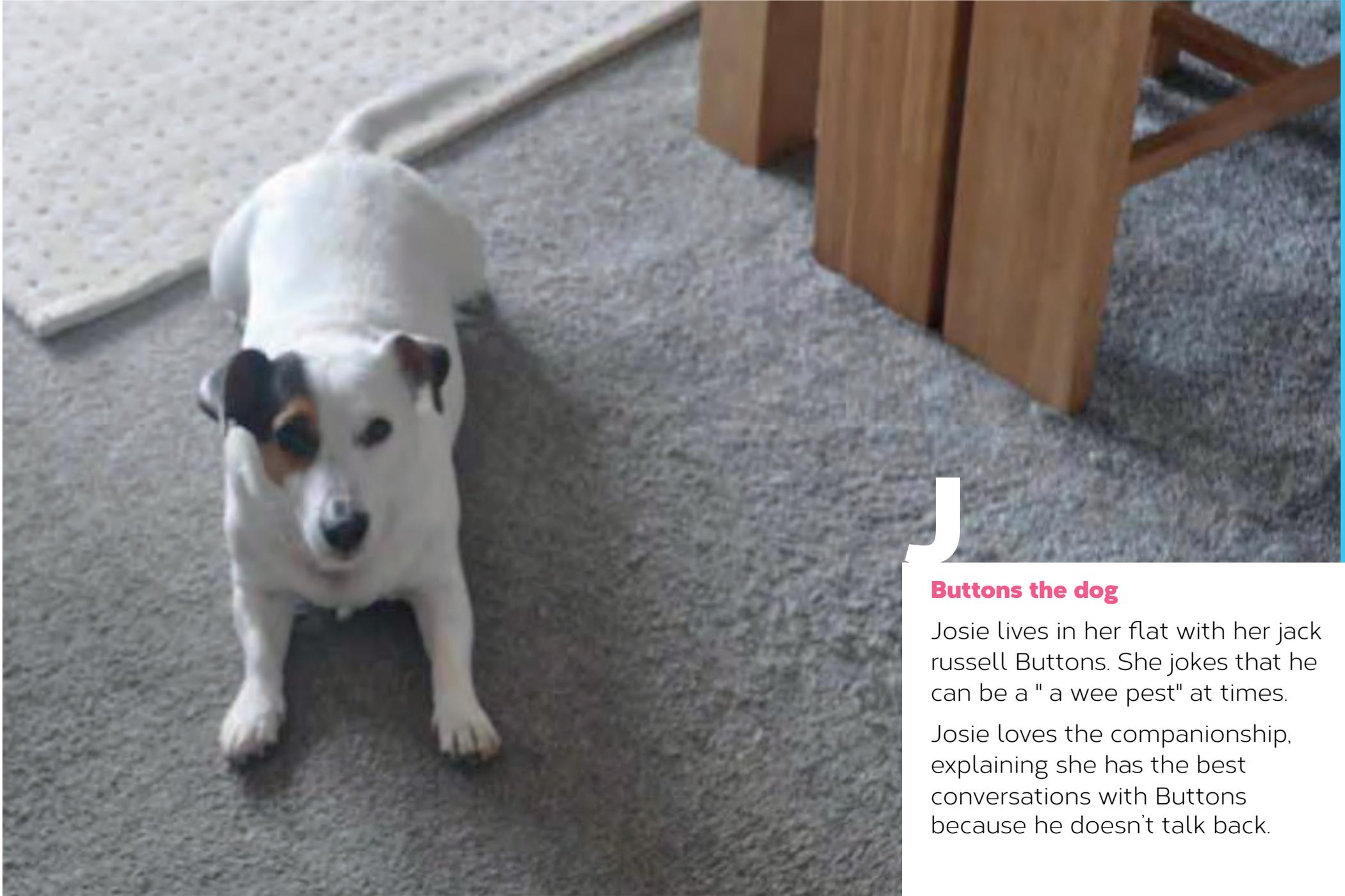
# Josie

Josie would like to show you, through these photographs, occupations that are meaningful to her.



It's been over 10 years since Josie received her diagnosis of dementia.

Although dementia presents some challenges, Josie enjoys her life with her dog as part of her community and enjoys being a granny, mum and friend.



### **Buttons the dog**

Josie lives in her flat with her jack russell Buttons. She jokes that he can be a "a wee pest" at times.

Josie loves the companionship, explaining she has the best conversations with Buttons because he doesn't talk back.



Buttons gets Josie out of the flat for a wee while everyday. Even if it's just to walk around the grass outside their home, this helps to keep Josie active.



### **Community minded**

Josie has various plaques thanking her for all she has done in the local area.

Josie was a volunteer for local crèches and youth clubs for 40 years, and enjoys telling stories of the kid's summer camps and trips to Edinburgh.



### **Getting out and about**

Josie tends to get out and about once a week. She enjoys the shops and popping into her favourite hairdresser.

TO SAVE A PHONE NUMBER

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Josie can't speak highly enough of the SDWG describing it as "everything" and a "lifeline". She has attended meetings within Alzheimer Scotland for over 10 years.

Josie values the experiences that the SDWG has given her, including visits to conferences and universities. "They keep you busy and they have you doing things you never thought you would ever do".



# C

## Carol

Carol would like to show you, through these photographs, occupations that are meaningful to her.



C

### **My beautiful door**

Carol is exceptionally proud of her own home.

It is her "safe haven" and all her family and friends come and go.

Even though Carol has dementia, she explains she is still "normal", she has still "got a life".



C

### **My Wee House**

Carol takes great pride in her home and she worked hard to buy it. It's her house and that is very important to her.

### **Collector**

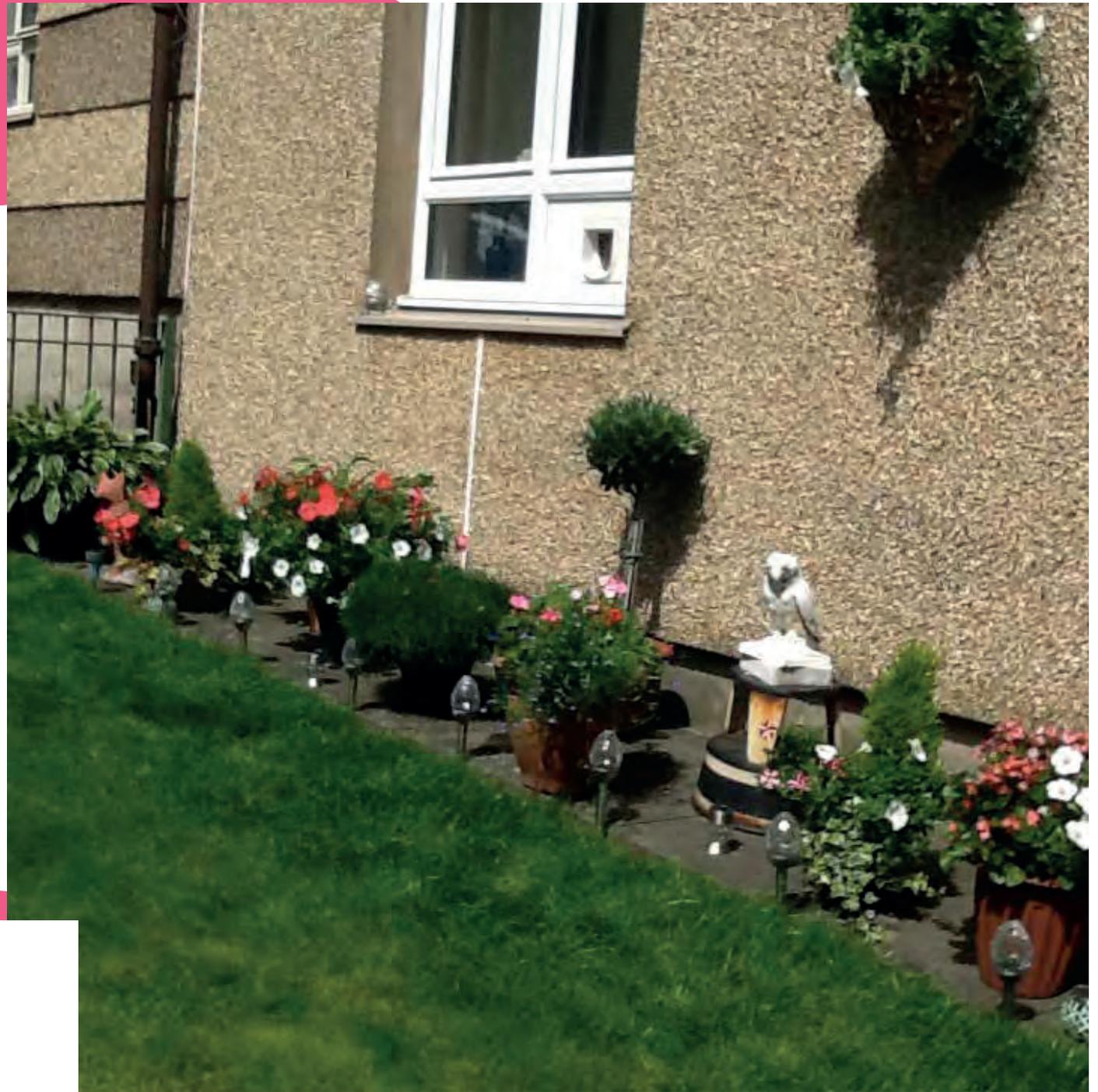
Carol commented on how her house is full of ornaments, and things she has collected and enjoys looking at.

C

**Us**

Carol's wee companion Star. Carol explained Star is always there to welcome her and give her unconditional love. Star is there to hear her laugh, cry and groan!





C

### **Garden**

Carol has always enjoyed the garden as it gives her a sense of enjoyment and peace.



DO MORE OF WHAT  
MAKES YOU  
HAPPY

C

**What else can you do in life?**

Carol explained her Twitter bio says, “love laughter”, and she relates this to the “do more” aspect of this motto.



# Henry

Henry would like to show you, through these photographs, occupations that are meaningful to him.



**H**enry is a really keen bowler and the exercise element of this sport is important for his physical health. As walking up and down the green during a game can quickly amount to quite a distance.

He also enjoys being outdoors for the fresh air, which is also reminiscent of Henry's earlier life as a policeman, walking around his beat, getting to know the community he worked in.



Henry wears his bowling jacket with pride and speaks fondly of his time on the club's committee.

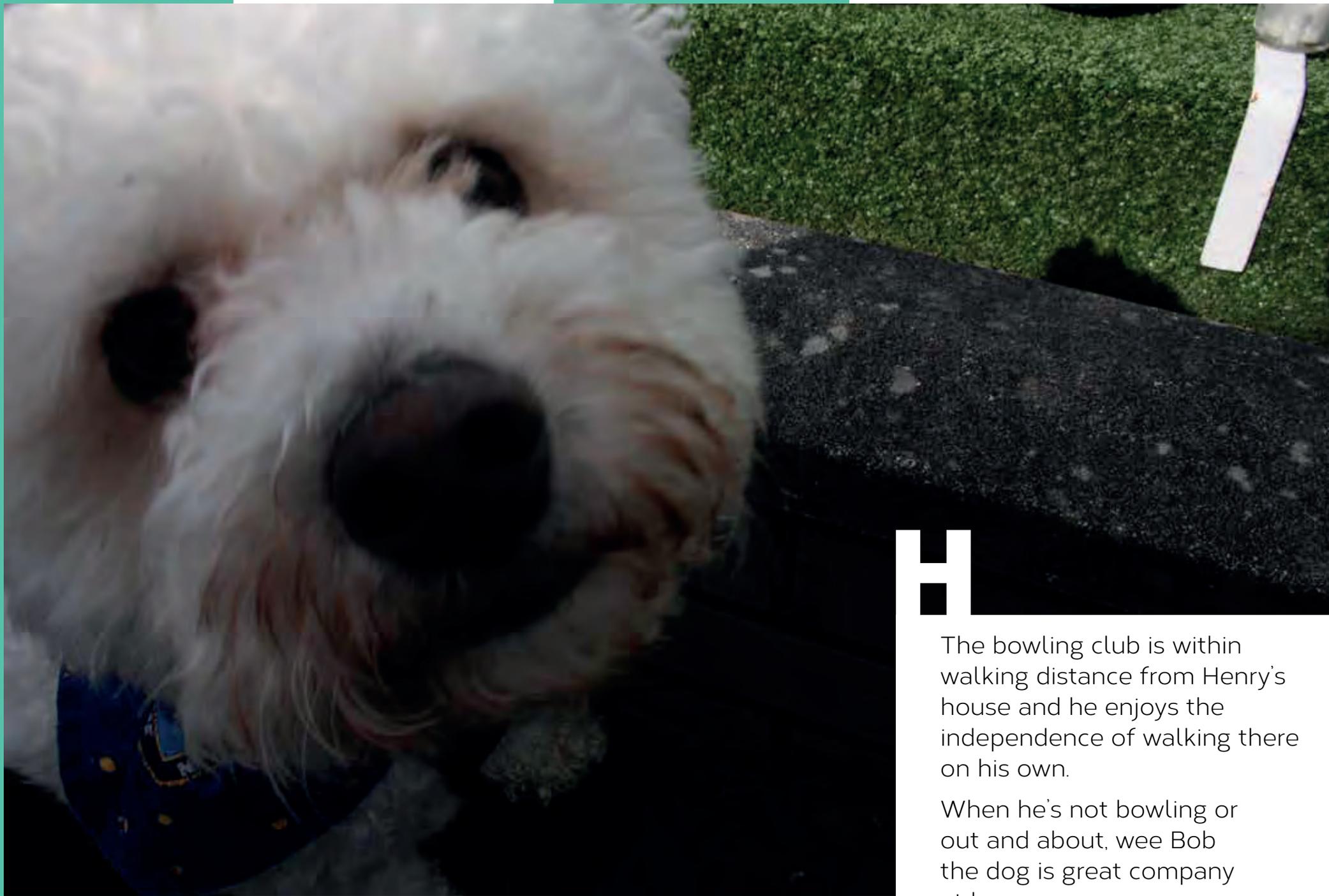
Wearing his bowling jacket is reminiscent of his past working life and Henry refers to it fondly as a way of upholding the standards of the club. Recalling an expression his father used to say, "you know you're clean if your shoes are polished".



Having a shared interest in bowling means Henry and his son can spend time together.

When on the bowling green, Henry uses a set of initialled balls that were a gift from his family.

His wife is not a bowler but through having different interests, it helps him to keep his independence, which he describes as “precious to me”,



H

The bowling club is within walking distance from Henry's house and he enjoys the independence of walking there on his own.

When he's not bowling or out and about, wee Bob the dog is great company at home.



There is a sense of community and friendship Henry enjoys as a member of the bowling club, Henry says, "I've got a lovely community, it doesn't always matter about the game, it's company and that's half the battle".

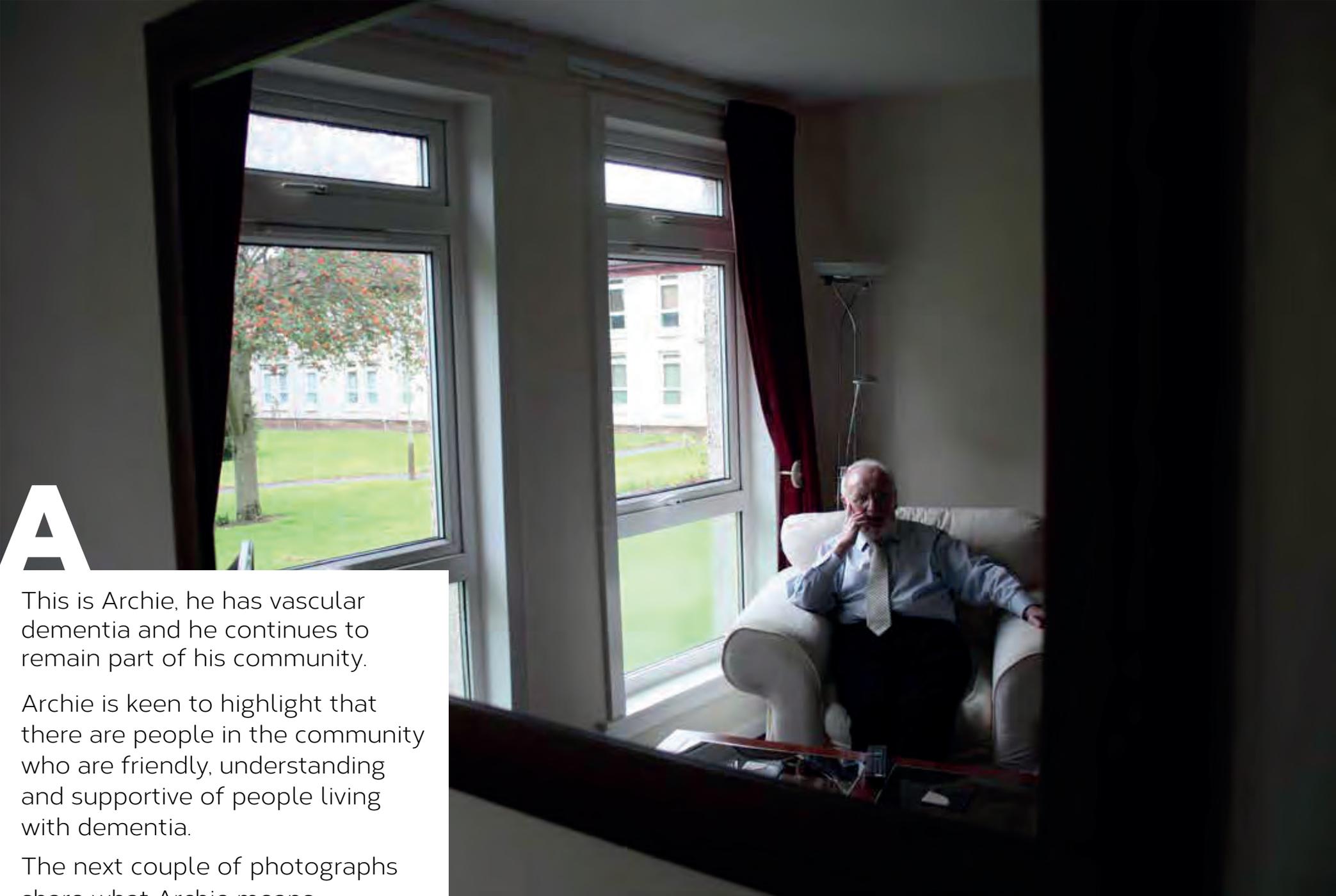
Whether it's playing on the green in the summer or carpet bowls in the clubhouse during winter, "there's something all year round, and it keeps you busy".



A

# Archie

Archie would like to show you, through these photographs, occupations that are meaningful to him.



A

This is Archie, he has vascular dementia and he continues to remain part of his community.

Archie is keen to highlight that there are people in the community who are friendly, understanding and supportive of people living with dementia.

The next couple of photographs share what Archie means.



A

For example, going to the hairdresser may sound like a usual everyday occurrence but for Archie it is a way to stay connected to his community and to sustain friendships.

A close-up photograph of a pair of gold-rimmed glasses resting on a patterned scarf. The scarf is folded and placed on a clear glass shelf. The background is softly blurred, showing what appears to be a window or a doorway. The lighting is warm and natural, highlighting the textures of the scarf and the frames of the glasses.

**A**

Archie describes his visits to the hairdresser as “part of the therapy” as looking smart and maintaining his appearance all help to “keep one’s self esteem”.

A

The contacts Archie has as part of his community all help to maintain his identity.

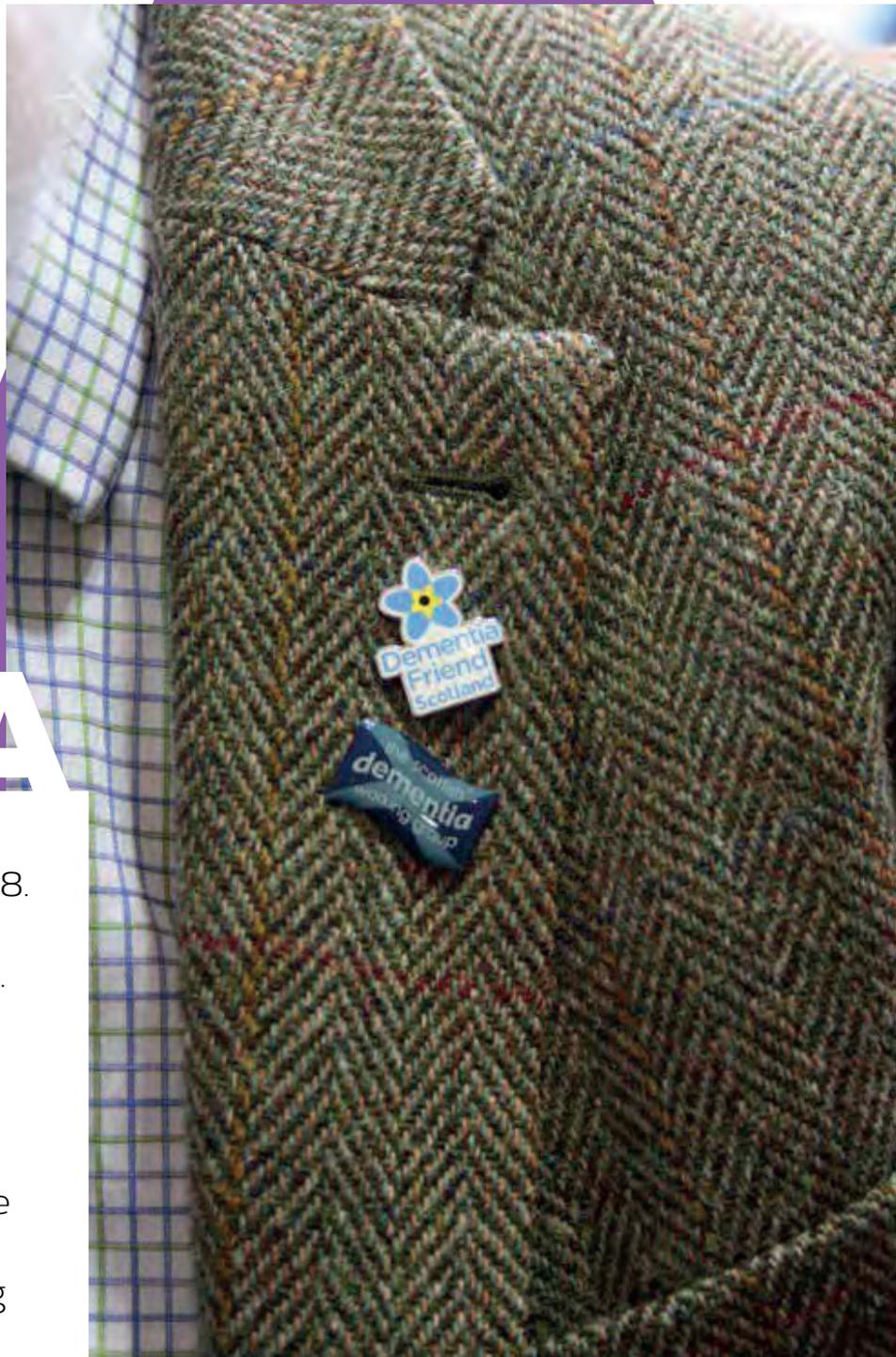
On his visits to the suit shop, Archie describes the staff as “a great bunch of people”.





Being able to stay connected to people is very important to Archie, either by talking to people in his community or using his phone and computer.

Being able to travel by bus is important to Archie and helps him to maintain his independence.



A

Archie is very proud of the work he does with the SDWG and when he was their chair in 2018. He says the SDWG badge is a conversation starter as people don't always know what it is.

"People don't believe me when I say that I have dementia. They think that a person with dementia can't communicate, hold a conversation, use buses or shop. Other people put a label on us that we can't do things and that makes life more difficult for people living with dementia".



# Nancy

Nancy would like to show you, through these photographs, occupations that are meaningful to her.



Nancy feels that Tai Chi gives her the time to check in with her body and allows her to just breathe. She is always amazed how much Tai Chi can help to refresh her.



After finishing off some lunch with a hot chocolate (a “treat for me”) as part of her Tuesday routine, Nancy joins her walking group at the leisure centre.



N

Looking back over the piers, or across the Firth, perhaps catching sight of some wildlife at the lighthouse, Nancy finds that keeping active and being surrounded by nature on her walks are the things that keep her well.



Nancy has a long list of books she would like to read and also welcomes new suggestions.

Nancy is well-known to the library staff and is thankful for their resourcefulness, “they are always able to look up anything you’d like, or get you any book you’d like to read”.

Reading is something that keeps Nancy busy in the winter months.



N

As someone who grew up in cities, Nancy decided to move to rural surroundings to enjoy a peaceful life. She finds meaning amongst nature with minimal disturbance. With a big beautiful garden, campfire pit, an old barn, and spare lofts in the house, this is also a place where Nancy loves to entertain.



N

Nancy harvests various small crops on her farm and was keen to “lift some tatties to see if they are ready this season”.

Living in a rural part of the country, it is important to Nancy to keep herself fulfilled and happy and being outdoors is one of the things that brings her the most pleasure.

“If at all possible, I like to take advantage of being outdoors”.



As an active SDWG committee member, Nancy thinks her role as an activist is important work.

Nancy feels that by adapting to all of the things she has already faced in life that she is “ready for anything that life will throw”.



# Tom

Tom would like to show you, through these photographs, occupations that are meaningful to him.



T

Since Tom stopped driving, he now walks to the local gym.

He has also been using the local bus to get around and although he misses driving, he likes getting the gossip from the other locals on the bus.



T

Tom regularly attends a fitness class at the local community campus. This is important to Tom as he enjoys both the exercise and the music.



T

As well as keeping fit and active, Tom gets to enjoy a blether with friends in his local community over a biscuit and a cup of tea.

When Tom isn't exercising, he enjoys attending the football and supports his local team.

Tom and his daughter attend the football regularly and have even made a brief appearance on BBC Alba.



**T** Tom lives with his wife and is a father of 3 daughters, 3 grandchildren and he is now a great grandad. Spending time with his grandsons is important to Tom.



# Pat

Pat would like to show you, through these photographs, occupations that are meaningful to her.



P

Pat's house is a hub of activity. It is a private garden for her grandson to play in, to invite friends over for a coffee in the sunshine or simply to admire the flowers whilst enjoying a cup of tea. Pat loves to spend time in her garden and is proud of how it has developed over the years. Retirement to Pat is about being active and her garden provides a space to host people and continue to be sociable.



After retiring from her career as a nurse, Pat gave much of her time as a volunteer with citizens advice, never losing her pulse on what was happening in her community.

Pat loves getting a bus ticket, a map and a travel book to explore her local community. Her dementia has not discouraged her from traveling and she enjoys taking an "away day" to surrounding towns in Scotland to discover more of her own country. Pat has started to refrain from international travel on her own but will continue to travel abroad with family.





With such a busy social life, Pat is grateful she has so many regular visitors that will pick her up for an outing. Pat waits on her front bench to be collected by friends or on other days, she takes the bus into town. Getting a lift or using the bus means Pat is able to attend meetings for the SDWG, continue to enjoy her hobbies and stay connected with friends and family.



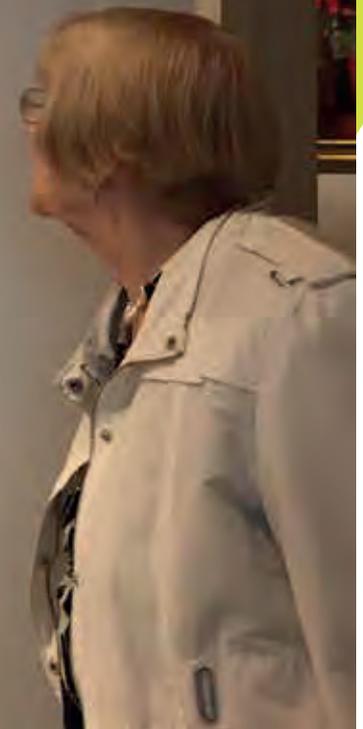
**P**at is more than able to manage her own finances as she has done for many years.



P

Pat has always loved art, and is particularly fond of this piece depicting the Tay rail bridge, painted by a local artist.

Pat enjoys visiting the art gallery which highlights some of the cities well-known treasures, as her heritage is important to her.





While around town, Pat also likes to stop in at a local charity shop where her friend volunteers, to see what bargains are on display.

Her favourite items are handbags and “nick nacks” and will often “rescue” a piece of china that has been disregarded.

At the end of the day, Pat wants people to know that dementia is not the end of the world but rather something you learn to live with.

**Teamwork**

# Our occupational therapy internship pathway

**Claire Kennedy**  
Connecting policy to occupational therapy education

**Catriona Chapman**  
Developing governance processes for AHP role emerging places with Alzheimer Scotland

**Marianne Wallace & Rachel Brew**  
Developing a photo-voice project, Occupation Matters to Me  
Instagram account: a day in the life of an intern

**Sarah McFarlane & Ciara Felle**  
The Roots to Occupation  
A day in the life of a SDWG campaigner  
Developing an occupational therapy social media strategy

2013

2014

\*2015

\*2016

\*2017

\*2018

\*2019

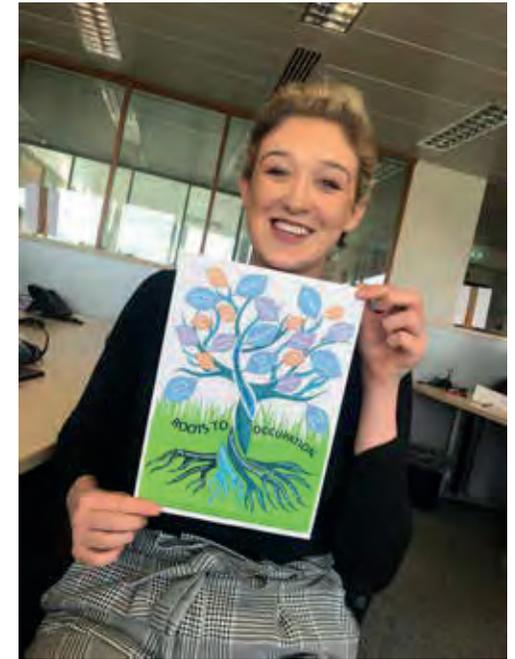
**Lyndsey Robertson-Flannigan & Chris Cousins**  
Top Tips booklet to Living Well with Dementia: A peer to peer resource  
Sharing what it means to live with dementia using social media and creating films

**Elizabeth Crockett, Lyndsey Robertson-Flannigan & Nicola Kane**  
Extending the photo-voice project, Occupation Matters to Me  
Post Diagnostic Support: A peer to peer resource  
Developing a creative therapies resource for Alzheimer Scotland

**Danielle Timmons**  
Creating a Roots to Occupation intervention manual  
Completing Occupation Matters to Me photo-voice project  
Building a social media profile on Instagram  
Sharing day in the life of a SDWG campaigner

Acknowledgement: Elspeth Talbot, Graphic Designer

\*These projects were completed in partnership with the Scottish Dementia Working group (SDWG)



# Thank You

## We could not have done it without you

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Queen Margaret University

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Queen Margaret University

Emily Jane, BA (Hons) Events Management Graduate, Queen Margaret University

Mike Pretious, Senior Lecturer in Management, Queen Margaret University

Elsbeth Talbot, Graphic Artist (retired), Queen Margaret University

Andy Palfreyman, Design & Print Manager, Alzheimer Scotland

Hannah Johnston, Graphic Designer, Alzheimer Scotland

All members of the Scottish Dementia Working Group who have worked on this project and allowed their thoughts and images to be shared.



A special thank you to Uno, Henry's fantastic dementia dog.



run by people with dementia



[www.sdwg.org.uk](http://www.sdwg.org.uk)



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[www.alzscot.org](http://www.alzscot.org)



@alzscot



Blog: [www.letstalkaboutdementia.wordpress.com](http://www.letstalkaboutdementia.wordpress.com)



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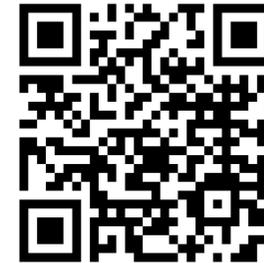


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ALZHEIMER SCOTLAND, 2019. Occupation Matters to Me [online]. Edinburgh: Alzheimer Scotland. Available from:



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