



Making sure nobody faces dementia alone.



# Dementia Advisors Our 10 year impact

2009-2019

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# Foreward

## Henry Simmons, Chief Executive Alzheimer Scotland



It is quite incredible to see how the role of Dementia Advisor has evolved in 10 years. Much of this is down to the hard

work, passion and commitment of the people in post. When I joined Alzheimer Scotland in 2008 we had, and still have, an impressive level of local support services. Much of this focused on our day services and home support teams. We also had a vast array of innovative community projects, some focused on supporting individuals, some on carers and some on the community. These projects and initiatives formed the basis of the Dementia Advisor role and I was delighted, after some considerable consultation, to introduce this new role on World Alzheimer's Day 2009.

The 3 pronged approach of working with people with dementia, their carers and families, and the community has been something that has remained consistent throughout the 10 years and I have always advocated for the Dementia

Advisor in each locality to establish their own position in the community; to understand what the needs are. I'm really proud that, whilst the overall role will be the same, what they do on a day-to-day basis will differ from one Dementia Advisor to the next to fit in with the specific requirements of the area that they work in.

Alzheimer Scotland aims to make sure nobody faces dementia alone and our Dementia Advisors are an integral part of providing support at every stage of a dementia diagnosis. Their care, compassion and commitment has been central to enhancing the lives of thousands of people who have come to Alzheimer Scotland, often in crisis. I am extremely grateful to every one of our Dementia Advisors, past and present, for helping to achieve the best possible outcomes for people with dementia, their carers & families and the wider community. I look forward to another very successful 10 years.

**Henry Simmons**

# Foreward

## Tony Worthington, Scottish Dementia Working Group

As someone who has had a positive experience with a Dementia Advisor, I am delighted to see the impact they have had across Scotland in 10 years. I was previously an MP and councillor which helped to give me a broad understanding of what local communities need and, since my diagnosis, I have further observed what would benefit a community when it comes to dementia-specific support.

Dementia Advisors have a wealth of knowledge in so many different areas and it's a great advantage to a person with dementia, and their families to have someone who is a 'one-stop-shop' when it comes to getting access to a wide range of Alzheimer Scotland support and other external services.

From my experience, I really believe that Dementia Advisors are extremely valuable in bolstering those who have dementia, however they provide a great deal of support to carers too.

It's really important that carers are supported outwith what's offered in the medical environment and my wife especially found great comfort from having that additional support.

Furthermore, Dementia Advisors play a key role in tackling social isolation, creating access to, and signposting me to, activities which continue to keep me engaged and part of my local community.

I would like to applaud the emphasis that Dementia Advisors place on improving the lives of people living with dementia and their carers. Being linked in with my local Dementia Advisor has given me a great sense of optimism where there was once depression and I would wholeheartedly encourage other people living with dementia to access their local Dementia Advisors.

**Tony Worthington**

## Marion Ritchie, National Dementia Carers Action Network

For me as an unpaid carer for my husband, my Dementia Advisor has been my 'go to' person for everything dementia related for the past 9 years. She was my library of knowledge for local resources and support groups and was also my comforter and confidante. She was the only person in those stressful years who I knew would understand what I was going through and would do her best to help, without making me feel useless or inadequate.

From the early stages of my husband's vascular dementia journey, my Dementia Advisor was there with information, activity suggestions, coffee and a hug, or whatever I needed. She organised dementia cafés, singing memories, cinema afternoons and carer groups, providing vital peer support for me and my fellow carers, and stimulation for our loved ones living with dementia.

As the illness progressed, she was still there, in person or by phone. She also signposted me to help elsewhere, like a much needed counsellor, when caring became very difficult. My Dementia Advisor has been my 'dementia angel', through the later stages, then care home admission and to the end of my husband's life a few months ago and she was the inspiration for me to join the National Dementia Carers Action Network.

The Dementia Advisor post attracts like-minded individuals who are compassionate, caring and dedicated to the job they do.

Congratulations to the Dementia Advisors for celebrating their 10 year anniversary and thank you for your incredible work.

**Marion Ritchie**

# Our impact in numbers



\* All statistics in this report are based on an average.



# Where it all began

Alzheimer Scotland has always been passionate about making sure we provide the very best in support for people with dementia, their families and carers. Prior to the introduction of the Dementia Advisor role in 2009 we had 8 regions, with 8 Regional Managers, and were funding a huge variety of roles, as well as our everyday offerings such as the 24 hour Freephone Dementia Helpline. All of this work was excellent and we were keen to ensure we continued to provide high-quality support, which was person-centred. We took time to plan for the future and identified a clear core message, which sits at the very heart of everything we do.

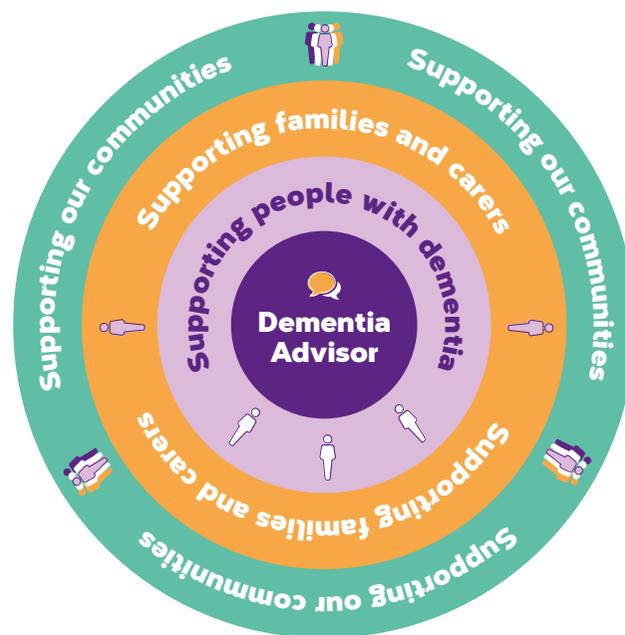
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## Core message:

**“Support for people with dementia, their families and their communities.”**

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The idea was to convert all of the existing roles into Dementia Advisor roles, and the first 20 Dementia Advisors were created to celebrate World Alzheimer’s Day in September 2009. The benefits of having one role meant that we were more easily identifiable to the people who we wanted to support and were then in a better position to build a strong network of Dementia Advisors across Scotland.



This was only the very start of the journey. In 2009, people were more reluctant to talk about dementia; there was still a huge stigma attached to the condition and there was very little support for people in their communities.

This is why we wanted the Dementia Advisor role to work with people with dementia and their families, but also with the wider community. Our Helpline was taking calls from people in crisis and asking for help, and this gave us a chance to really have that face-to-face personal contact; having someone who would be there for them, at any point, without a referral process and without becoming part of a 'service.'

We wanted people to feel that, from the first point of contact with Alzheimer Scotland, someone was there for them. The Dementia Advisor role has become an integral part of that support; they are very often a lifesaver for people and an extension of their own family.

The role has grown substantially over the years, however one thing has always remained the same: to make sure people know that there's someone there that they can turn to, that they will never feel on their own and that, once they reach us; they're with us.

# Our monthly impact

On an average month, our Dementia Advisors:



Support approximately **900** carers and families



Facilitate nearly **100** peer support groups



Have an ongoing relationship with approximately **20** schools and intergenerational projects



Connect with approximately **100** local businesses, providing opportunities such as Dementia Friends

# What people with dementia say

“

You're the first person who has come and **really talked through my problems with me** – thank you.

“

You have **no idea the difference** you have made to my life.

“

It's really important to have someone to talk to who understands – **someone to speak to and run things by, especially so close to receiving news of the diagnosis. You helped me feel like I was still worth something.**

“Since we met you have introduced me to a Dementia Friendly Working Group and supported me to become part of the Scottish Dementia Working Group, both of which have been really important in helping me feel more positive about my experience of dementia.”

“

Your empathy and understanding have been **a great help to my family and I in what is a very trying set of circumstances.**

“I've recently been diagnosed and am really scared right now because I don't know what is going to happen to me. Everyone keeps telling me it will all be fine but they don't know that. I don't have to pretend not to be scared when speaking to you.”

“I have had lots of people come to see me but none of them have been like you – it's been good just talking to you, and I feel much better about things.”

“

I love talking with you. **You make me feel nicer about myself and give me a sense of normality.**

# What carers and families say

“I can’t express how much help it was to have you there; someone to ask questions regarding the illness. The role was also emotionally supporting me during the time I was caring for my mum and since she has passed away. It’s such an isolating illness and without you I would’ve struggled to cope, then and now.”

“It all seems much clearer now, it’s nice to speak to someone who uses everyday language.”

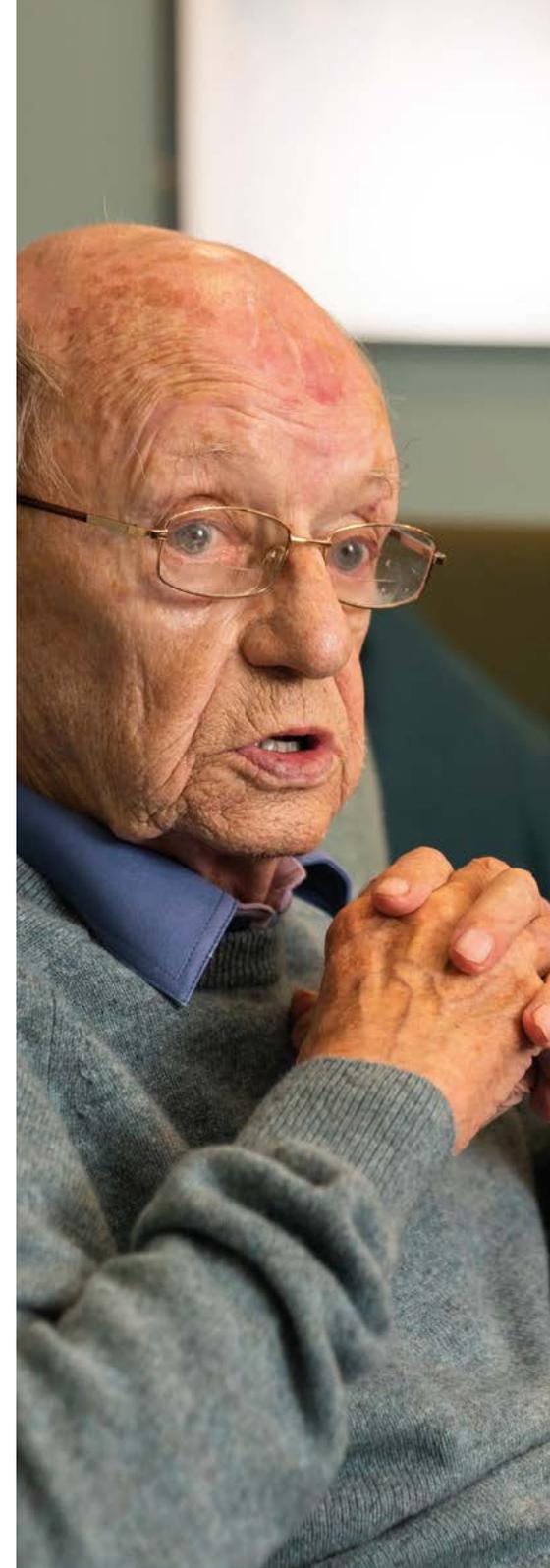
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**You’ve really made a massive difference – we know that we aren’t on our own anymore. We feel far more connected to everything that is going on for people with dementia and there is actually quite a lot out there when you know about it.**

“

**I couldn’t have gotten through this without your support. Knowing you were at the end of the phone made all the difference.**

“Over the years you have become a valuable mentor. The contrast between our isolation before we met you, and the belonging and support that we now have has made things so much more bearable. As dementia advances you have made sure we are not alone and keep me up-to-date on the wider work of Alzheimer Scotland – your role has been invaluable.”





## What communities say

“Dementia Friends has been so helpful. I’m the manager of a cleaning company and work with people in their own homes. Sometimes you’re unsure what to do and I will take all I’ve learnt to put into practice.”

“On behalf of the firemen here I would like to extend our thanks to you for what was one of the most informative and well delivered presentations that we have received at the station. It was clear from your delivery that you are both passionate, and well-informed in this field.”

“**A very informative Dementia Friends session. I didn’t realise that the environment could affect people with dementia so much.**

“

**Your support is so helpful for the customers who come into the bank. Staff see the changes in customers as they get older and your information helps us understand this.**

“The input for our group has been so helpful – you are always available with advice and help, not only for our club but especially for our members. The support, care and knowledge provided to both people with dementia and their carers is invaluable – it is often difficult to know where to get help and support. You understand the challenges families face and are able to provide practical support as well as emotional support.”



Alzheimer Scotland  
Helen Hollywood  
Dementia Advisor



# Supporting people with dementia

**The support that Alzheimer Scotland's 36 Dementia Advisors offer to people with dementia is person-centred and designed to meet the specific needs of each individual. The first interaction can often come before diagnosis, when people are worried about their memory and are looking for some advice, and, on many occasions, the relationship will continue the full way through a dementia diagnosis.**

Because the Dementia Advisors provide support that is person-centred, the extent of what they can offer to a person with dementia is varied. It ranges from simply listening and providing information to helping maintain connections with the community and provide support, to working with people with dementia to make sure their voices are heard. They will help people navigate the often complex system of health and social care services and

be a supportive figure at what can often be an extremely distressing time. A Dementia Advisor can provide guidance on what your entitlements are as a person living with dementia and give information on the other external agencies that may be of assistance. They will also explore the types of groups and activities that may be of benefit to people with dementia.

The support will often change as the condition progresses and the role of the Dementia Advisor is to adapt to the person's needs and make sure they feel supported at every point in their journey.

# Supporting people with dementia:

## Personal experience: Margaret Northedge

**Margaret Northedge was introduced to her local Dementia Advisor after she was diagnosed with dementia aged 57. Margaret describes the impact this has had on her life:**

I was diagnosed with Alzheimer's disease 3 years ago, aged 57, which was quite early in my life. It came as a shock to me and I initially went into a depression as I just couldn't cope with the information that was being presented to me. I ended up in hospital and, from there, all of the support started to kick in. I was initially allocated an Alzheimer Scotland Dementia Link Worker and it feels like everything has been on the up since then.

Through Flora, my Link Worker, I was introduced to my local Dementia Advisor, Gillian, who is one of the kindest people; I always feel uplifted when I know I'm coming to see her. I know I can always phone her if anything is needed; she isn't someone who says things blithely – she is so genuine, and it has made a huge difference to my life.

Gillian has involved me in so much which goes beyond the more standard support offered at

the local Dementia Resource Centre. I gave up work after my diagnosis which I found really difficult and, through Gillian, I was given the opportunity to put my skills to use by being

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introduced to the Highland Dementia Working Group. It was something I could go to which wasn't just a support group or where I could go for a cup of coffee. I could actually go and do some proper 'work' which is what I was missing. The support I get now ticks all the boxes. Being involved with the Highland Dementia Working

Group has given me a focus, and a sense of purpose which has been really important. In the early stages, I didn't think I had any purpose but I've gone from a point where I felt like life wasn't really worth living, to living a life where I want to help.

I was also given the opportunity to be part of the interview panel who recruited for a new Dementia Advisor role in the North Highland area. When I was working, part of my role involved training staff. I used to deliver courses on management which included interview skills and trying to get people jobs. Being able to have the opportunity to take part in something similar to work again was heart-warming for me because I really do miss it. I enjoyed the sense of responsibility that came with being in the interview panel and being part of making a substantial decision for Alzheimer Scotland.

I find it a pleasure to be working alongside Gillian. She is very motivational; you can't feel down when she's around. She seems to be able to tap into people's feelings at any one time; she has great skills of empathy which is really important. I've been to so many things with Gillian; she has involved me in so much. I was at the Alzheimer Scotland Staff, Members' and Volunteers' Conference last year and spoke on stage, with others, about the work being done

in our area. There was a few of us involved and we all had our own part to say. It was amazing to see everyone in our group supporting each other, both beforehand and on the day. We've had a lot of contact between us and Gillian makes me feel like I'm part of the 'dementia family.'

If I could look back to the person I was at the start; I would tell her to get involved sooner, not to be hanging back saying I didn't need support. I've found that the support that you get is at the level that you want. It isn't spoon-fed; it's what you need when you need it. The Dementia Advisor role is a really key part of my wellbeing, and the wellbeing of everyone who has dementia. Without them, I think we would have an awful lot more crises and wouldn't perhaps have so many people living well with dementia. The fact that you can get involved with things makes you feel socially useful, which is something that you lose if you're isolated. I did hide myself away at the start; I was in denial. However, opening up and welcoming all of the support that people have offered me has made a huge difference to my life. Gillian has been my rock; through her and the support Alzheimer Scotland offers I can honestly say my life has been changed for the better.



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# Supporting carers and families

**Supporting carers and families is a vital part of the Dementia Advisor role. Dementia doesn't just affect the person with the illness – it affects the people most involved in their day-to-day care and support. Dementia Advisors are here to make sure that the carers are cared for and that they feel just as supported as the person living with dementia.**

The journey of caring for a person living with dementia can be lengthy, challenging and variable and Dementia Advisors are there to provide information, guidance, advice and support at every stage. Supporting a carer can include holding regular carer groups, training or information sessions to talk about what you may expect during the various stages of dementia.

As the person with dementia progresses through the illness, their needs may become more complex. A Dementia Advisor can help carers and families explore what other support may be available and be a trusted person to help access those other supports.

Many carers remain close with their Dementia Advisor even after their loved one has passed away and are encouraged to still seek that support for as long as they require.

# Supporting people with dementia: Personal experience: Una Smith and Frances Watt

**Una Smith and Frances Watt benefited from the support of their local Dementia Advisor, Fiona, when their respective husbands were diagnosed with dementia. As well as the support of a Dementia Advisor, they gained a strong friendship too as they explain:**

We first met our local Dementia Advisor, Fiona, after our husbands had been diagnosed with dementia. Ian had just been diagnosed and Jim had been living with dementia for a year and a half. As soon as Fiona walked into our lives; it was a lightbulb moment.

Initially, the men started coming to the Dementia Resource Centre and took to it very quickly. We initially met through coffee mornings and both Ian and Jim loved going here for the social element. They got on with each other very well which meant both of our friendships grew as a result. Fiona was quite new to the role when we both met her and one of the first things she did in her role was set up a carers group. It was a wonderful feeling, sitting with other people in similar circumstances and

knowing you weren't on your own. Fiona also brought in speakers which helped us to realise what other support was available for us; that there were places to go and people we could speak to. We had no idea of what was available, and Fiona brought these people to us. Even though the speakers addressed to the full group, the support was then personalised depending on the needs of the individual.

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**One of the biggest things that came from Fiona's role was the friendship that we both have.**

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One of the life-changing moments for us was the allotment. We had heard about Alzheimer Scotland's allotment and knew we wanted to make it more dementia friendly. Our husbands were both interested in this type of thing and we knew what we wanted to do but didn't know how to do it. We didn't have funding, expertise or contacts but we spoke to Fiona and she helped us move it forward. Fiona identified funding we could apply for through the Life

Changes Trust and helped us apply. We were awarded with £56,000 over 3 years to cover 3 remits and, from there, we formed a committee, chaired by Fiona. It made such a huge impact on all of our lives and it wouldn't have been possible without her.

Through Fiona, we've been able to raise awareness of dementia. 10 years ago, dementia wasn't widely spoken about in our area. There was very much a stigma; people would cross you in the road to avoid speaking about it. Through things like the allotment and the work Fiona has undertaken educating the community; there has been a huge difference in the awareness raised and she has been the driving force for this. Ian used to go to the schools and colleges with Fiona and talk to the students and she also helped to educate the local policemen, which they then won awards for. There was also great education for us, as carers. We learnt so much about the stages of dementia, what to expect and how to cope with it.

However, one of the biggest things that came from Fiona's role was the friendship that we now both have with each other. There is no way our paths would have crossed if dementia, and our Dementia Advisor, hadn't connected us. Unfortunately Ian is now in a care home and Jim is no longer with us but our friendship

has survived and gotten stronger as the years have progressed. Having friends who have been in similar situations has been so important because they understand. We have great family support, but to have people who understand what it's like to be a full time carer for someone with dementia was of great benefit, especially when it got to the stage where Ian and Jim were going into a care home..

We now volunteer for the Daycare service at Clydebank. There are many of the groups now that aren't relevant to us and it can be really upsetting to go to the groups that we helped to create and went to with our husbands, but volunteering means we're still part of Alzheimer Scotland.

Fiona's combination of knowledge and excellent people skills meant that the support she gave us was invaluable. Ian would've been in a care home much earlier if it wasn't for the support she gave us. Fiona had the ability to turn talk into action – we would speak about an idea and by the next meeting it would have progressed so the care that we received, as carers, then progressed.

For people looking to access a Dementia Advisor; we would say to pick up the phone and they will do the rest.



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**Fiona's combination of knowledge and excellent people skills meant that the support she gave us was invaluable. Ian would've been in a care home much earlier if it wasn't for the support she gave us.**





# Supporting the community

**One of the biggest tasks for a Dementia Advisor is to get to know their community. Understanding what's already available, what the areas for opportunity are and what the community wants are some of the first things a Dementia Advisor will do in their role. From there, they will identify opportunities to raise awareness of dementia through partnership working and relationship building.**

The Dementia Advisors will support local communities to become more inclusive of people living with dementia. This can be helping people think of ways to make existing areas more dementia friendly or making small adaptations to the physical environment to make things easier for people living with dementia to engage with.

Part of the community engagement work will include Dementia Friends sessions and dementia awareness sessions to local shops, businesses, groups and clubs. They will also support learning at schools by holding age appropriate Dementia Friends sessions and encouraging intergenerational work, such as schools coming to a local group and meeting people with dementia.

More than anything, a Dementia Advisor's role in the community is to grow support for people with dementia and their families, raise awareness of the condition and educate people in the small things they can do to make the local area a more accessible, dementia friendly place to live.

# Community connections



## Making shopping easier

In Forres, staff at the local Tesco were supported by the local Dementia Advisor to help raise awareness of dementia and the steps they could take to help make a difference to the lives of people with the condition in the Forres area. During the discussions with staff, they looked at ways to create a dementia friendly environment on the shop floor and came up with the idea to open a relaxed checkout. This benefited the local store, and people with dementia, by helping them to feel confident in continuing to shop independently in their local community for longer. The relaxed checkout is also available for other customers who may feel they need extra time without the stress or worry that they are potentially holding up other shoppers.

The relaxed checkout, which was the brainchild of the store's community champion and the first of its kind in Scotland, shows that companies can make a huge difference by spending very little or no money – all it took was a good idea and some awareness training.



## Bridging the gap

Winner of a 2018 Scotland's Dementia Award, 'Bridging the gap between acute and community care' is a combined partnership between NHS Ayrshire and Arran, Alzheimer Scotland and the University of the West of Scotland. The aim was to provide people with dementia and mild cognitive impairment and their families access to tailored information and emotional support from an Alzheimer Scotland Dementia Advisor, both during admission to the acute hospital setting and after being discharged from hospital.

A three-month test project commenced in March 2018 and, during the test period, all offers of referral to the Dementia Advisor were accepted. Evaluation feedback collated from nursing staff, people with dementia and families also highlighted a positive impact on key outcome areas such as discharge planning, staff confidence and knowledge and the care experience of people with dementia and their families. The feedback included the below from the hospital's Charge Nurse: **"The Dementia Advisor shared her knowledge and expertise with me which then allowed me not only to educate my staff but also to give correct information to families and patients."**



## Intergenerational working

The 'Green Hands Together' project, established in 2017, is funded via Tesco Groundworks and is a partnership between St Aidan's Primary School in Wishaw, St Aidan's Parent Council and Alzheimer Scotland staff in our Lanarkshire locality. Pupils and people with dementia have co-designed a sensory garden and are working together to learn about (and grow) organic produce, from soil to plate, within a large polytunnel.

Sensory gardens are a very useful way of helping people with dementia stimulate memories and reflect on past events and experiences, and this type of experience can be used to help people reconnect to their sense of self.

As a spin-off of Green Hands Together, both the school and Alzheimer Scotland decided to hold a community event known as a teddy and trowel picnic. This was to encourage the community to come together for a picnic which encouraged further intergenerational work where participants – who were aged between 3 weeks old and 93 years of age – all planted flowers and plants and played games together. As well as being a fun day, this partnership continues to help raise awareness of Alzheimer Scotland, dementia and the importance of a community coming together to make something successful.



## Building safer communities

In West Dunbartonshire, a partnership with two local police officers led to not only a safer, better informed community, but also recognition through the form of two awards at the Scottish Policing Excellence Awards.

PCs MacMillan and Marsland had noticed a rise in the number of incidents officers were attending in the community that involved people with dementia. They worked together with the local Dementia Advisor to develop a social media campaign as well as organising awareness inputs for more than 100 officers across West Dunbartonshire. A group of police volunteers also attended a Dementia Friends session.

A series of videos were developed for the social media campaign which gave both police officers and members of the public a better understanding of how to interact with a person who has dementia.

The project was completed with no funding and received the Equality Award at the Scottish Policing Excellence Awards in 2017. Both police officers were also personally selected to collect the Chief Constable's Award for this work.

# Community connections



## Animal assisted learning

The pioneering Animal Assisted Learning (AAL) project in Dumfries is a partnership between Alzheimer Scotland and Mossburn Community Farm, an animal sanctuary near Lockerbie in South West Scotland, NHS Dumfries & Galloway and the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland. The project was facilitated by the local Dementia Advisor and provides activity sessions for people living with dementia and their families through the interaction with the farm animals.

The approach is for participants to come to work with the horses and other animals, grooming, preparing feed and making up pig pens, rather than a petting activity. It started as a pilot but, with the help of local fundraised income, this is now offered as a longer lasting Animal Assisted Learning programme consisting of two-hourly sessions at Mossburn over blocks of six weeks.



## The great outdoors

The Tipi Project is a Lens winning idea which is the brainchild of a Dementia Advisor and Dementia Link Worker. It was recognised that spending time outdoors is very important to many of the people with dementia that they support and they worked on the idea of an outdoor project for people with dementia, their families and carers. Initially a parachute was used to provide shelter from the elements before applying for funding through The Lens, which is an intrapreneurship programme, for a Tipi and other kit, such as a woodburning stove, to ensure this project was sustainable throughout Scotland's weather conditions. The Tipi Project combines the knowledge and resources of organisations including the Royal Society for the Protection of Birds, Cairngorm National Parks Authority, Forestry and Land Scotland and the Highland Council ranger service, with Alzheimer Scotland's expertise in supporting people living with dementia. On top of the fantastic support from the staff and volunteers from these organisations, the project is also supported by John, a dedicated Alzheimer Scotland volunteer. The evolutionary and relaxing response people get from socialising around a log fire is intangible. Each month the group try different activities, learn new skills and take walks in the surrounding woodlands. Food is heated over the fire, adding to the genuine camping-like experience and there is the ability to have exposure to, and feel, the benefits of the outdoors with the comfort and safety of shelter.



## In partnership with Shotts prison

The partnership with Shotts prison, a maximum-security prison in Scotland began after they got in touch and asked the local Dementia Advisor to talk to the staff and prisoners about dementia. The innovative partnership began as a pilot project, and was the first of its kind in Scotland. 13 prisoners were initially engaged through a dementia awareness session, and 16 staff completed a Dementia Friends session. This approach identified a real need for dementia awareness in the prison and that engagement with both prisoners and their families was essential.

To date over 300 prisoners, 60 staff and 100 family members have engaged with Alzheimer Scotland through one-to-one discussions, group work and attending visits with Memory Buses. Most recently, the prison introduced a quieter visiting time for family members who have dementia, and also held a fundraising event which is a rare occurrence in the prison. One staff member said, **“I know you are here primarily for prisoners, but the staff are ageing too, I’m worried about myself.”** In 2017, this project won a Scotland’s Dementia Award for Most Innovative Partnership.



## A volunteer voice

**By Alan Johnstone, volunteer**

“The Dementia Advisor in my local area works very closely with her volunteers, encouraging and supporting them in the running of activities in order to develop and take forward programmes, and striking an appropriate balance between the management of volunteers and delegating the responsibility for day-to-day actions. This team approach may be illustrated by my own involvement in the implementation of a football memories and local reminiscence initiative at Aberdeen Royal Infirmary.

This is one of the first football memory projects which Alzheimer Scotland has taken into a hospital setting and having reviewed the first session held in July this year I was of the opinion that we should combine football with local reminiscence. By doing so we could offer a programme which both people in hospital and visitors could attend, whether or not they have an interest in football. The Dementia Advisor gave her approval for me to take this forward by recruiting another person from our volunteer pool and taking account of suggestions from the activities nurse.

Over several months, the excellent working relationship between myself and the local Dementia Advisor has allowed for the smooth and successful implementation of this reminiscence programme and is a good example of how teamwork between staff and volunteers can produce outstanding results.”



# An insight from our Dementia Advisors

Alzheimer Scotland has been recruiting passionate, committed and enthusiastic people into the role of Dementia Advisor since 2009. Angi Inch is one of the longest serving Dementia Advisors, having come into the role when it was first introduced and Anne Marie King is one of the newest Dementia Advisors to come into post, starting at the beginning of 2019. They talk about the role and what it means to them.

## Angi Inch

### Dementia Advisor, East Dunbartonshire Dementia Resource Centre

I was one of the first Dementia Advisors to come into post in 2009. The role is really varied. We work with people with dementia, their carers and families, and the wider community to raise awareness of dementia and reduce the stigma that can still be associated with the condition. Our relationship with people can often start prior to any diagnosis; many people will come to us if they're worried about their, or a loved one's, memory.

The initial idea of the role was to work locally to identify what each area needed and how we could meet those needs whilst

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**All the roles link up and create a real pathway of support for people, the full way through a dementia diagnosis.**

recognising the support that was already there. There's local support in every community which may make a difference to people with dementia and their families and it's good to know what we can signpost to that isn't solely Alzheimer Scotland support.

Whilst the role of the Dementia Advisor is established within Alzheimer Scotland and our work is centred around people with dementia, their carers and families, and the local community, each Dementia Advisor has shaped their own role and very much work based on what their area needs. A typical day or week for a Dementia Advisor could involve meeting people who drop into the Dementia Resource Centre looking for information or advice; either for themselves or for their loved ones, arranging to go and see people in their own homes, running a group or carrying out Dementia Friends sessions.

I've been lucky to support people from before diagnosis through to end of life and that really is quite a privilege. I don't think I've ever 'advised' in my life because it's up to the people we're interacting with how they want to move forward. We never claim to understand their situation but we empathise. If they leave a meeting with me looking like I've taken a weight off their shoulders then I've done my job.

## Anne Marie King

### Dementia Advisor, Helensburgh Dementia Resource Centre

I began my role as Dementia Advisor in January 2019, after 10 years in other roles with Alzheimer Scotland. I was very lucky to follow in the footsteps of the previous Dementia Advisor and I'm building on a really strong foundation. I initially heard about the Dementia Advisor role when it was first introduced. I had seen an advert in a newspaper for the role and, at this point, my dad had dementia. As a family we were approaching the end of his journey with the illness and I remember thinking that the role would have made such a difference to our family - just having someone to go to for information, to point us in the right direction or to lift the phone and have a chat to. Fast forward 10 years and here I am.

Over the years since I've worked with Alzheimer Scotland, it has been great to see how the support has grown. In my area, we initially had a room, a couple of staff members and a very small group of dedicated volunteers. This has all grown and it's down to how the charity works as a team. All the roles link up and

create a real pathway of support for people, the full way through a dementia diagnosis.

The role very much depends on the needs of the community and it's so important to continue to engage with people so that they're living the lives they want to, with their diagnosis, and are having their voice heard. We get a lot of people who will initially come in looking for information. Sometimes they'll come into our café or one of our groups for a few weeks before they feel comfortable enough to speak to someone. Seeing people grow their confidence and build connections and friendships is really rewarding.

When you see someone who comes to you and they feel anxious or worried, but then leave feeling much lighter and have spent some time socialising and getting to know people; that makes it worthwhile. You can see the difference you have made; the impact you've had on someone's life. You can be involved with families for such a long time, from before the diagnosis right the way through and that is a real privilege to be able to do that. You get to know people really well and that's part of the job I really love.

# Developing the role

**As this report showcases, Alzheimer Scotland's Dementia Advisors are encouraged to forge their own role in their localities. For Ann Williamson, Shetland's Dementia Advisor, she started with a blank sheet and has shared a timeline of her 10 years to showcase just how far the Dementia Advisor role has come.**

Pre-2012, there was little Alzheimer Scotland presence in Shetland. The Assessment Service had been set up two years previously by the NHS and, during 2011, under the leadership of the Alzheimer Scotland Nurse Consultant, some interagency work to identify gaps in the islands had been commissioned.

Alzheimer Scotland had secured funding to develop three new Dementia Advisor posts and Shetland was one possibility. The then Regional Manager visited Shetland to meet with different agencies, as well as carers and people living with a diagnosis, to gauge interest.

Since starting in January 2012 the post has evolved massively, as you will see with the timeline on the adjacent page.

I was given an office in a Specialist Dementia Centre, courtesy of the Local Authority, by way of getting started.

Publicity was important as Shetland needed to know they had a new Dementia Advisor, so I courted the press. This strong relationship with the local media – newspaper, independent magazine and BBC Radio has persisted and we are always assured of good exposure.

Working alongside the Nurse Consultant as well as the Dementia Services Operational Group, I began to get a feel for the needs of individuals and families living with dementia.

I spoke with many organisations both statutory and voluntary to explore how we might work together, I set up time-limited working groups and attended various roadshows to raise awareness of our work in the local area.

I wanted to use existing venues, so working alongside Shetland Arts and Shetland Museum & Archives, a knitting group and reminiscence group were set up, as well as a daughter's support group.

I approached one of the hotels and secured spaces which would allow a carers group and a football memories group to be held simultaneously. A newly constructed modern church gave us the use of their community areas and a fortnightly memory café was launched.

By the end of the year, it felt right to think about establishing a local branch and in November 2012, the Regional Manager made another trip north to attend a public event to gauge interest again. A good turnout resulted in a committee of 10 being formed. At the start of 2013, I had reached capacity. I was conscious however, that there was more to be done and, more importantly, that activities need to be located in rural areas of Shetland – not just in the main town of Lerwick.

Funding was secured for a Community Activities Organiser and this was advertised and recruited in August 2013.

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**We were becoming more and more visible in the community by visiting schools, local groups and events which then attracted spontaneous fundraising.**

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With a second team member, we were able to look at increased activities such as tea dances, musical memories and establishing memory lane cafés in the North, South and West mainlands.

We were becoming more and more visible in the community by visiting schools, local groups and events which then attracted spontaneous fundraising.

The next step was to have a physical presence in the shape of our own premises – a Dementia Resource Centre for Shetland.

Alzheimer Scotland Dementia Resource Centre in Shetland opened in 2015 which became our base, as well as a point of access for members of the public, who could drop in for advice, information or just a chat.

In 2017, as the centre became more established, it was apparent that regular opening hours would be of benefit to allow greater accessibility. We recruited a receptionist and administrator which allowed for this regularity.

The team of three is now well established and working in collaboration with other agencies and Alzheimer Scotland well and truly has a presence in Shetland.

## Timeline

### Alzheimer Scotland in Shetland



#### Pre-2012

Funded Alzheimer Scotland Nurse Consultant.

#### 2012

Dementia Advisor established in Shetland.

#### 2013

Community Activities Organiser recruited for Shetland.

#### 2015

Dementia Resource Centre opened in Shetland.

#### 2017

Regular opening hours established with recruitment of receptionist and administrator.

#### 2019

Team well established and working in collaboration with other agencies to deliver specialist care and services to the local dementia community.



## A look to the future

When you reflect on the last 10 years, it's clear we have come a very long way. There's no doubt that, previously, there were significant issues in terms of stigma, discrimination, a lack of rights and perhaps indeed a lack of true voice of the person with dementia, their families and carers. We now live in a world where the person is at the centre of everything we do and where choice, power, control, inclusion and citizenship make up the core of what we believe in.

Our movement and every single policy that has been developed in Scotland in the past 10 years has been informed from this approach. We've developed many of our people and our organisations, and implemented some really good policies, all with the immense commitment and effort of people living with dementia through the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN), with the Charter of Rights at the centre of this.

Our Dementia Advisors have been an integral part of making sure the person is at the centre of everything we do. They can often be the first contact that people living with dementia and their carers and families will have with Alzheimer Scotland, which is displayed in our Locality Pathway. This pathway is how we aim to be there with the people we support and our Dementia Advisors will often be there with them as they make their journey along that path –

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**The future for Alzheimer Scotland is clear. We will remain a support structure for people with dementia, their carers and families and the wider community.**

and quite often afterwards for ongoing carer support.

Our priority is to ensure that, when someone needs or wants to access support, they never feel on their own and, no matter where they are, they always feel that there's someone there to help.

We're looking to build on our current locality model and we'll commit our fundraised income, support and resources so that people with dementia and their families, as they go through the more statutory route of the system, always feel that we as a charity are delivering in their locality to support them, as their condition progresses. Getting this right will transform the way that people are living with dementia in their communities and the way that they feel supported. We want to make as big a difference in localities as possible and our Dementia Advisors will remain a key part of this.



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