

Loud and Clear!

Exploring two decades of involvement, voice and activism by people with dementia in Scotland

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An accessible summary

Introduction

This book tells the stories of twenty years or so of involvement, voice and activism by people with dementia in Scotland.

It's important to tell these stories about what activists have achieved. This will make sure we don't forget what they have done.

And it will help people who are living with dementia now, and in future, to learn from those who came before.

Early days

The Scottish Dementia Working Group (SDWG) was formed when activists, advocates, researchers and policy-makers all came together.

The group was determined to bring the voices of people with dementia to the attention of Scotland.

They wanted to make changes that would improve the experience of living with dementia.

Its members also found new hope and meaning in their lives, instead of despair.

But the group faced many challenges.

Moving up a gear

SDWG grew in confidence and made important connections.

They started to influence national policy and Scotland's rights-based approach.

Some experienced members outgrew the group, deciding to follow their own priorities and to set up the Scottish Dementia Alumni.

The Life Changes Trust brought many more opportunities for the voices of people with dementia to be heard.

DEEP in Scotland

DEEP – the UK Network of Dementia Voices – led to a large number of groups connecting with each other across Scotland.

The groups are all very different, but they share a sense of belonging and connection.

The groups get involved in a wide range of projects (often funded through small DEEP grants).

The DEEP Gatherings enable groups to meet together physically as often as possible.

As time goes on, many more voices are being heard, and in many different ways.

Involvement in research

Twenty years ago, people with dementia were often ignored, left out, or represented by others in research.

Then researchers started to ask them for their own views.

People with dementia began to help them understand how to do research better.

Some were involved in advisory groups, employed as co-researchers, or even became fellows of research bodies.

Now people with dementia are designing and leading their own research projects on their own chosen topics.

However, people with dementia are still regularly left out of research about wider issues.

Creativity and voice

Activists, researchers and artists have worked together to enable the voices of people with dementia to be heard loud and clear.

Examples include poetry, fine art, film and video, photography, quilt-making, bird sculptures, plays and banners.

These creative approaches have enabled many more voices of people with dementia to be heard in Scotland.

Scotland and the wider world

Activists have created strong connections abroad. They have tried to bring back learning and new ideas to Scotland. But policy-makers have not always been very interested. However, Scottish activism has had an important impact on developments all around the world.

The motivations, costs and rewards of activism

Activism is not easy. People have to cope with tiredness, financial costs, ill-health, lack of appreciation – and sometimes criticism. But there are also many benefits. These include a strong sense of achievement and belonging. Activism also brings new relationships, confidence, skills, and meaning to life.

What has been achieved?

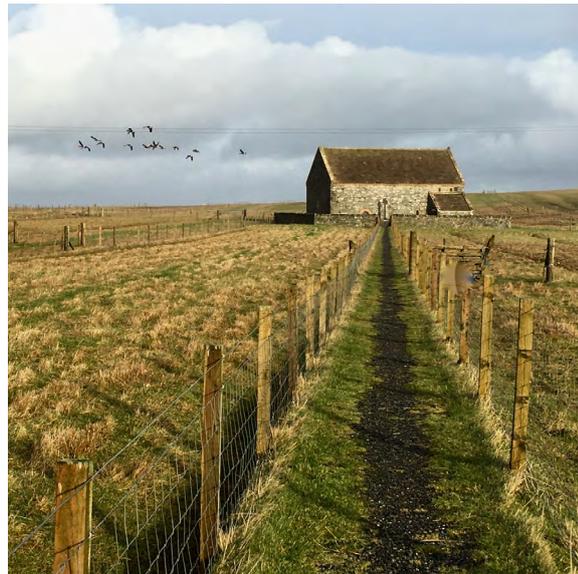
The courage and energy of the activists has inspired many individuals. Activism has helped to change both policy and practice. There is much more work to do: stories of poor diagnosis and post-diagnosis experiences are still common. Some people feel activists lost the freedom to follow their own ideas and express their views. But there are now more ways for people with dementia to have their voices heard.

In the Appendices at the end you can find a glossary of acronyms and some practical tips for newer dementia activists, their advocates and allies. There is also a paragraph about the author.

Foreword

A story of progress...

The 13th Century Church of St Moluag, on the northernmost tip of the Isle of Lewis in the Western Isles, is traditionally associated with healing, especially for those afflicted with mental problems. But the healing is quite radical: the treatment of the ‘insane’ involves being given water from the nearby well, being led seven times sun-wise around the building and then, bound hand and foot, being laid all night before the altar, head resting on the



Church of St Moluag

stone pillow of the saint. The expression ‘I’ll take you to the temple’ is used well into the twentieth century as a threat to anyone behaving foolishly.

But let’s fast forward to today... and just up the road lives Ron, who has Mild Cognitive Impairment and is still waiting for an official diagnosis of dementia. He is working to futureproof his house by equipping it with all sorts of gadgets and gizmos. He uses a digital platform, ZOOM, for meetings with people all over the world, and he has written a play about Artificial Intelligence!

Ron lives less than a mile from the church and its tradition... but his aspirations and expectations are surely a million miles away. He is not spending his time thinking about a magical cure for dementia – he’s using all his skills and energy to live as well as he possibly can with the condition he has. To have his voice heard and to stay in control of his destiny. To create a story of hope.... and, working together with others, to make change happen.

1. Introduction

Why tell the stories?

For many centuries, people with dementia have been largely undiagnosed, unseen, unvalued, ignored and disrespected... and their voices have been unheard. It is only from around the turn of this century that people with dementia start to connect with each other and make their needs and views known directly, without the medium of (however well-intentioned) proxies. This impetus initially comes from a handful of remarkable individuals raising their own concerns about their rights, their place in their community and the quality of services being provided (or not provided) for them. Further progress comes as those with the lived experience begin to meet and work with each other – making new connections which strengthen their shared conviction that there is still hope for a kind of recovery. *“After decades of silencing and discrimination, people with dementia are beginning to join forces, take action and campaign for social change.”*¹

In the early days of the Scottish Dementia Working Group (SDWG), from 2002, Scotland leads the way in involvement, voice and activism – not only in the UK, but around the world. The impact of this involvement in Scotland has been huge – the first Charter of Rights for people with dementia and carers; contributions to the formation of the first national dementia strategy in the world; people with dementia as research co-investigators; standards for researchers who want to work with people with dementia; leading a University design school; creating resources from the perspective of people with dementia; and raising awareness every day in small and large ways. Further afield, countries such as Japan and Australia attribute much of their awareness of the importance of involvement to Scotland’s movement. Building on the work of Alzheimer Scotland in raising the profile and reach of the SDWG, the growing DEEP network in Scotland and numerous other innovative projects are now adding to the richness of this tapestry, with more and more people with dementia inter-connecting and telling their stories.

¹ The emergent modes of dementia activism. Bartlett R. Ageing Soc. 2014a;34(4):623–44.

Most people who are diagnosed these days are unaware of the history of involvement that precedes them. But stories are still told and remembered about some of the forerunners to, and key players in, the current dementia movement in Scotland. This includes people with dementia, unpaid carers/ care partners, academics, artists, staff and volunteers from charities, politicians and practitioners.

It is essential that we record the stories of those involved and their achievements, so that the overall impact and legacy of user involvement in dementia is not lost. We hope that awareness of some of the pioneering work of their predecessors and peers can benefit those who are more recently diagnosed, as well as their groups, advocates and networks.

As a member of Ceartas, a DEEP group in East Dunbartonshire, puts it:

“I think it’s important to tell my story and to hear other stories. It helps others in the same situation as me, to realise they are not alone and that life goes on after dementia.”

And Ron Coleman from the Isle of Lewis reflects:

“[Earlier activists] let me know there’s so much more I can do in my life. It gives my life hope.”

James McKillop (who has now been living with dementia for two decades) also points out that those who know the stories can build on them, rather than risk reinventing the wheel.

With the total number of people living with dementia in Scotland soon to reach 100,000, it is surely time to tell – and honour – the stories of the first twenty years of involvement, voice and activism.

Shaping the project

At an event in Perth in February 2019, people from Evanton Woods DEEP group and from the SDWG come together with two Innovations in Dementia directors – myself (Philly Hare) and my colleague Damian Murphy. We spend the day shaping the project and drawing up a list of potential contributors. Participants also discuss why the stories need to be told. They agree it is in order to:

- pass on this experience and these approaches
- learn lessons and help improve things going forward
- offer a strong example for other countries
- provide *hope* – through successful and inspiring examples of breaking barriers



Perth event

In the next phase, 24 people (see below) are interviewed, mostly individually (either face-to-face or on ZOOM), but with some emailing their responses. The interviews are semi-structured, using a flexible topic guide.

This book is the initial outcome of that work. It contains a narrative of key events and developments, with some analytical discussion about facilitators and barriers, impact, challenges and learning. It relies strongly on the memories and reflections both of those directly involved in the movement, and of those looking on from a little further away.

There is also a collection of photos and some video/audio footage, and a number of Dementia Diaries (audio reports) recording reflections about the stories of user involvement, activism and impact in Scotland.

The importance of the process

It is important to recognise that this project has been a significant and often emotional process and marker for many of those involved. For example, Nancy McAdam, while being interviewed, suddenly reflects: *“The memories come flooding back! It’s good!”*. And fellow campaigner Agnes Houston describes the whole process of helping with this book as *‘very healing’*. In a Dementia Diary² recorded just before she is interviewed, she says:

“What are we going to be discussing today? We’re looking at my reflections about the story of activism in Scotland, and I think this has been quite good for me. I’ve... known about this since Christmas. My living room’s been covered in paperwork, trying to convey the appropriate stuff that Philly would require. And I should take a photograph of that, now that I’ve got it all fixed out in years and subjects etc.

2 Dementia Diaries website <http://bit.ly/33uygcX>

“You know, I was wondering why I was a wee bit apprehensive about this this morning?... I realised that I was apprehensive because activism in Scotland is so close to my heart, and I’m very passionate about it, and with my memory I’ve forgotten so much. So, James was interviewed yesterday, and James and I spoke on the phone last night about how much work was put into this. And so I just hope we do a good job for Philly and for... the real story of activism in Scotland, which is about ordinary people getting a diagnosis of dementia and the lack of services and other emotions that we’ve felt...”

And after the interview, Agnes records another Diary, reflecting...

“I’ve enjoyed myself... I’m feeling slightly tired but not too tired, and it’s a good tired. And as I said, this is me tying the big bow and ribbon on my memories of my campaigning over the last thirteen years. It’s a celebration and we celebrated with some vegetable soup, hot rolls and Anne Pascoe’s jam. How about that!”³

3 Dementia Diaries website <http://bit.ly/2yVcAbS>

With further hindsight, Agnes finds the process of contributing to this book very emotional:

“Looking through all my information, it felt like a celebration and a pause to reflect... I’m no longer compelled to being part of a specific group. I want to be free and speak from my heart. Doing this story has made us realise, even in spite of the challenges, it has brought us joy in our lives. The places we’ve been... and the people we’ve met.”

Agnes’ daughter, Donna, agrees:

“We would not be where we are without the campaigning. I have huge respect for all the campaigning we have done. We’re both immensely proud of it, we’ve really moved things forward.”

So this story is not just a historical record but a celebration, an honouring of what has been done... and an anticipation of what more can be, should be, will be done.

Acknowledgments

We are very grateful to those who gave their time to this project, most in interviews, but also some in group discussions. Many have also sought out and lent key documents from their personal collections. The individuals are (alphabetically):

Professor June Andrews OBE	Dr. James McKillop MBE
Professor Ruth Bartlett	Rachael McMurchy
Davy Bell	Kumiko Magome
Joanna Bell	Professor Mary Marshall
Ron Coleman	Archie Noone
Professor Colm Cunningham	Irene Oldfather
Jenny Douglas	Ann Pascoe
Simon Harry	Brian Pepper
Agnes Houston MBE	Jean Pepper
Donna Houston	Dr. Martha Pollard
Andy Hyde	Kate Swaffer
Dr. Nick Jenkins	Karen Taylor
Jan Killeen	Paul Thomas
John Killick	Dr. Dot Weeks
Nancy McAdam BEM	Professor Heather Wilkinson

I would also like to thank my colleague Damian Murphy for working closely with me on this project; my colleagues, for their very helpful comments on drafts; and, of course, the Life Changes Trust for seeing the value in capturing these stories, and for funding this project.

Key sources

There are a number of sources which have been used extensively and are therefore not referenced at every point. These include:

- Alzheimer Scotland website⁴, and in particular the SDWG webpage⁵
- The DEEP website⁶
- Dot Weaks' book 'Perspectives on Ageing with Dementia'⁷
- 'The Perspectives of People with Dementia: Research Methods and Motivations' Edited by Heather Wilkinson⁸

Some words of caution

Readers should be aware that this is not a research study. To build the stories, the author has drawn on a wide range of documents (both online and hard copy) and on the interviews and discussions that have taken place – all shaped by the Perth event described above. Despite our best efforts, not all those who were suggested as potential important interviewees were able or willing to take part – their perspective is consequently missing. Occasionally too, memories of dates, events or conversations conflict, and we have done our best to make the most sense out of what we have (especially with regard to pre-internet events).

It is also the case that a handful of individuals feature very heavily throughout the book. This needs no apology. It is partly because of their central role in the story, but also because they were particularly generous in giving up their time and energy to recall many aspects of the story and to search for meaningful documents and other archives. However, it goes without saying that many others have been involved in this story, even if they are only fleetingly mentioned, or not mentioned at all. Again, there is no attempt to record every person, every event and every project.

4 Alzheimer Scotland website <http://bit.ly/2oR8506>

5 SDWG webpage <https://bit.ly/3dU3AGM>

6 DEEP website <http://bit.ly/2MeeudP>

7 Perspectives on ageing with dementia. Weaks, D. et al (2012) JRF

8 The perspectives of people with dementia: research methods and motivations, Ed. Wilkinson, H. (2002) JKP

While all interviewees have given their consent to be named and quoted, we occasionally use our discretion and omit names when that feels appropriate.

Please also note that the focus of the book is on people with dementia themselves and what they have done. For this reason, unpaid carers/care partners have only been interviewed in relation to their role in supporting an activist. No attempt has been made to tell their story – though this is of course hugely important in its own right.

Accessibility

Readers may wish to read the whole book in one go, or perhaps to dip into chapters which are of particular interest.

There is an accessible summary on page 1.

Please also note the Glossary of Acronyms in Appendix 1 at the end of the book.

2. Early days

Laying the foundations

Dementia activism doesn't just pop up out of nowhere in Scotland at the turn of the century. It is quite a long time brewing! Even in the 1980s and '90s, narratives are starting to shift. In the wider world, both the Kings Fund and WHO (World Health Organisation) are calling for action on dementia. The first books containing the testimonies of individuals living with dementia also appear around this time.

It is important to understand the development of the key dementia organisations in Scotland. Until 1987, Scotland effectively comes under the Alzheimer's Disease Society (an organisation founded by English carers in 1979, with its headquarters in London), through the Edinburgh Branch. The latter is founded in 1981 by Glenda Watt, a progressive and influential psycho-geriatric nurse. By 1983, Edinburgh has its own development officer, Annette Forster. The 1985 annual conference of the (then) Alzheimer's Disease Society is held in... Edinburgh! However, Evelyn McPake recalls that one of the principal speakers unfortunately referred to events 'occurring here in England'... to the lasting indignation of the secretary of the Edinburgh Branch.⁹ And, according to Evelyn, this underlying attitude is surely a factor in the subsequent separation of Scotland from that organisation in 1987.

Meanwhile, SAD (Scottish Action on Dementia) has been formed in 1985. The brainchild of *"a group of angry professionals and carers"*¹⁰, SAD is supported and initially hosted by ACS – and funded for ten years. It comes about following an ACS conference in 1984 which includes carers as guest speakers (not people with dementia yet), on the topic of 'Coping with care of ambulant people with dementia'. This event raises many issues, including the need for care standards, education and training, stigma and discrimination, lack of legal support and the micro – and macro – costs of caring.

9 Three into one McPake, E. (2004) Alzheimer Scotland <http://bit.ly/31PbCdP>

10 Quote from Mary Marshall

Mary Marshall recalls:

“It led to people asking – Well what are you going to do now you’ve opened this can of worms?!”

Once Alzheimer Scotland (AS) is set up, it comes onto the board of SAD. For a brief period AS and SAD work together in a triangle with the new Dementia Services Development Centre (DSDC) at the University of Stirling. Each has clearly identified roles and remits, with SAD working on policy and campaigning, AS on service provision and DSDC on training and research. Then in 1994, AS and SAD amalgamate into one organisation, known firstly as Alzheimer Scotland – Action on Dementia (ASAD), but soon as Alzheimer Scotland. DSDC remains as an independent body.

It is clear from the accounts of this time that the focus of the main organisations is primarily on the needs of the family carer (as opposed to the ‘sufferer’, to use the terminology of the time). Dementia is not yet recognised or diagnosed until the very late stages. The predominant narrative is also still very much of the ‘medical model’ i.e. it portrays people as disabled by their impairments or differences, and focuses on what is ‘wrong’ with the person and not what the person needs. This model creates low expectations and leads to people losing independence, choice and control in their own lives. With little if any voice directly from those with the lived experience, the dementia world is at this time lagging well behind the wider disability world. In the latter, the civil rights movement in America of the 1960’s and 1970’s has been inspiring disabled people themselves to take direct action against discrimination, poor access and inequality.

However, Stirling's DSDC stands out in Scotland for its early exploration of more radical perspectives and its promotion of the social model of disability. This model says that disability is caused by the way society is organised, rather than by a person's impairment or difference. It looks at ways of removing barriers that restrict life choices for disabled people, so that they can be independent and equal in society, with choice and control over their own lives.

As Mary Marshall, the first director of the DSDC, recalls:

"We taught the social model from the off. It was certainly counter-cultural."

Jan Killeen

Jan Killeen joins Age Concern Scotland as a training officer in 1981. As part of her induction period, she visits the new Specialist Dementia Day Hospital at the Royal Edinburgh Hospital. Here, with encouragement from Glenda Watt, Jan learns about best practice and attends a carers' support meeting. These experiences make her decide that the quality of life for people living with dementia has to become a priority. ACS agree to make the care of people with dementia (or, in the jargon of those days, 'the confused elderly' living at home) the theme for Old People's Week in 1984. Their annual conference, organised by Jan as training officer, is the first to be held on dementia in Scotland, with carers speaking on the platform making a huge impact (and leading to the formation of SAD, as described above).



It is in the early 'nineties that we hear of the first person with dementia in Scotland to speak at an event. By this time early symptoms of dementia have started to be recognised. Jan organises various symposia at Crieff Hydro near Perth, and is now committed to finding someone living with dementia to speak about their experiences. Dot Weeks, one of the few specialist dementia CPNs, suggests Min Inches. In 1992, Min becomes the first person with a diagnosis to take the platform, speaking to 400 delegates from across the professions, including Directors of Social Work and Chief Executives of Health Boards...

Dot reflects that: *“No-one thought that someone with dementia could present at that time. But Min proves them wrong – speaking eloquently about her feelings and emotions, of living with certain symptoms, and about the specific help she needs to help her carry on her work. Evelyn McPake recalls that Min’s “advice to the caring professions about the importance of being given the diagnosis and about her support needs... made an outstanding impact.”*¹¹

And Jan Killeen recalls: *“The event was fully covered by the media, with a double page spread in The Scotsman featuring Min with her dogs. Min made a profound impact on everyone who heard her and helped to raise the public profile that it is possible to live well with dementia.”*

It is a breakthrough moment – though it will be several years until a similar thing happens again. It is fair to say that the voice of family carers dominates the agenda at least until the start of the 21st century.

However, in the mid-nineties, attention really starts to focus on human rights. In 1996, Jan leads a campaign for law reforms, to promote and protect the rights of people living with cognitive disabilities. Many people with dementia and unpaid carers/care partners contact the First Minister in support. The successful campaign secures full legal rights in 2000 under the new ‘Adults with Incapacity (Scotland) Act’ – and surely shows the potential of activism. Jan continues to monitor the effectiveness or otherwise of the Act, and is seconded to Scottish Government to lead on a programme to improve it.

Jan Killeen sums up her approach: *“The principles of empowerment have always informed my practice at whatever level, seeking to create change that really affects people’s lives.”*

¹¹ Three into one McPake, E. (2004) Alzheimer Scotland <http://bit.ly/31PbCdP>

In 1996, the importance of hearing the voice of people with dementia is highlighted by Malcolm Goldsmith at DSDC (actively supported by Mary Marshall) in his book 'Hearing the Voice of People with Dementia'¹². Written for all those concerned with providing services for people with dementia and their families, the book explores the idea that communication is not only possible, but also vital, to the understanding and the development of services. Based on a series of interviews with people with dementia and also professionals working in the field, on an extensive literature search, and on a consultative document which was sent out to over a thousand people, the book discusses ten key points:

- the possibility of communication
- the disempowering experience of dementia
- the different ways in which people are affected
- the need to respect people's sense of time and place
- the importance of knowing a person's 'life story'
- the effect of environmental and other factors on the process of communication
- the non-verbal ways in which people with dementia communicate
- the means of communicating through 'challenging behaviour'
- possibilities of group work
- the value or harm of sharing a diagnosis

12 Hearing the Voice of People with Dementia: Opportunities and Obstacles Goldsmith, M. (1996) JKP

Practical advice and suggestions based on the research into these key areas are offered to help professionals gain a greater understanding of dementia and develop skills which aid communication.

By the turn of the century, some people with dementia are already being involved on interview panels and in providing feedback on services. In 2000/01, Jan Killeen develops ASAD's Involvement Policy, which gives recognition to these forms of involvement. Jenny Douglas is instrumental here, and the policy leads to people with dementia getting places as board members.

With hindsight, we can see that all these developments lay the foundations, both for the formation of the SDWG and for the development of activism more widely. The ducks are starting to line up!

James McKillop

James McKillop is a key figure – indeed the ‘father figure’ – in the development of dementia activism in Scotland. He recounts:



“I joined the Civil Service in 1959. I went where I was sent, and after a few years in England, found myself in Glasgow in 1971. Where I worked, females outnumbered the males by at least ten to one. It was a great place for a single man to meet a possible wife, and so I did; marrying in 1973. Four children followed. Life went on, and then it changed. I was taking longer and longer to do my work. It wasn’t rocket science or brain surgery, just clerical work. The work was routine and you did the same work on the first of January, as you did a year later on the 31 December. And the same again the next year.

I ran a small team and I checked their work. It had to be correct when it left me, otherwise the customer would suffer another day’s delay. I was doing my work correctly, but frequently had to consult my work’s manual to get it right. This meant staying behind unpaid, to keep up with my workload. I did not mind this, as being correct was so important to me.

My supervisor noticed I was not coping, but instead of being asked if all was well and being helped, I was castigated. If I had had a drug or alcohol problem, all sorts of help and counselling were available, but there was nothing for an employee who had given his all since leaving school... and now at age 55, was...

..now experiencing some sort of problem. There was no mention of being referred to anyone who could look into the situation. Note, I did not have a diagnosis of dementia at that time. But I was struggling. The pressure mounted on me and took a toll on my health with absences for high blood pressure. I ended up off for some months. The day I went back I had such a harrowing interview with my supervisor I had to go to the work's nurse. My blood pressure was so high she said I would die if it stayed at that level. She sent me home in a taxi, and I never worked another day there. I took a retirement package, before I was pushed out or died from the high blood pressure. What a way to end your lifelong career! Normally at retirement there is a 'do', presents and speeches. No one in my group knew I had retired, until a month later and that was by accident. If I had been offered a job at the level below me, my work would have been checked, with no disadvantage to the customer.

At work I was in charge of people and one time I noticed a very good worker, a widow, was not coping. I spoke to her gently, pointing out she was not up to her usual standard, and was there anything I could help with. She had problems with a lodger that were affecting her sleep and her finances. She refused to show him the door, as she could not do that to somebody's son. She took my advice to buy him a one-way ticket back to the Islands. Her work rate immediately improved and she looked and sounded better. I looked after my staff – but I wasn't looked after by my employer when it was me who needed help.”¹³

¹³ Blog posted 30 Sep 2016 by Age Scotland. <https://bit.ly/3hh8gIT>

Four years after having to stop work, at the age of 59, James is diagnosed with multi-infarct dementia. It is the very end of the last century – November 1999. By this time, he is forgetting the names of people he has known for many years:

“I went in for a brain scan and learned I had been getting TIAs (transient ischaemic attacks – mini-strokes)... At the time of my diagnosis, it [dementia] was a death sentence. People were given only a couple of years to live. There was also the stigma of being diagnosed with dementia. Up until the [new millennium], people with dementia were regarded as non-citizens. People would pat me on the head and ask, ‘How are you? How can you talk?’ I’d reply: ‘I learned as a boy!’”¹⁴

14 Article on The Caregiver’s Voice website: Avadian, B. (May 2017) <http://bit.ly/31Z4zQ9>

Starting to make connections

After he is diagnosed James can't find anywhere he feels welcome – *“there's nowhere for people with dementia to go, to just sit and be themselves.”* He recalls going along to various mental health meetings after his diagnosis, looking for support, information and company:

“I was ostracised from the start. Nobody would listen when I tried to explain that dementia was a mental health issue. After all, it affects the brain, and it is hard to learn anything new... Everyone looked askance at me when I mentioned dementia. When I tried to speak, I was firmly told that dementia did not belong there, and I had to go elsewhere. Nobody had heard of it and they certainly did not want to discuss it. They had their own agendas. I was cold-shouldered, they didn't want to know me. I was a lone voice crying out in the wilderness, and I had to fight hard to get heard, wherever I went. I was never asked any questions, there was simply no interest. After that I was blanked, so I moved on from the hostile atmosphere. This was a part reason to later set up a group of people with dementia, where we could meet and talk openly.”

But soon after James' diagnosis, Brenda Vincent, a support worker with Turning Point, visits, to assist him in applying for Disability Living Allowance. Then she asks him to help at a Christmas party. At this time, James' family relationships are very tense:

“Being unaware of my condition had led to a very difficult lifestyle and family tensions, and the scars still oozed blood. I was in my own wee world comparable to Dante’s Hell, completely bewildered and unable to make sense of anything going on around me.”

So he really enjoys having some company, and Brenda becomes a key person in his story. James reflects:

“I was fortunate in meeting Brenda... who, using her own time and influences, steered me towards a fresh start in life... Brenda brought me back into the community and I am now contributing to society. If it was not for her, I would be a big burden to the state... I might still be staying behind my four walls.”

Around the same time, in 2000, James becomes involved in a research project run by Heather Wilkinson¹⁵. He also contributes to the work on the Government’s Learning Disability Review ‘The Same As You’. He recalls:

“It was the early days, and I was still reeling from the impact of the diagnosis... I was the only voice of people with dementia at that time. I had to fight my way into these meetings... At that time, I did not know (nor did the experts) that some people with learning disabilities had a higher risk of developing dementia, such as people with Down’s Syndrome. [I went] to highlight those with a newly developed dementia.”

15 Tell me the Truth Pratt, R and Wilkinson, H. (2001) Mental Health Foundation <http://bit.ly/332UoKg>

James is not named in the resulting report¹⁶. However, it contains a number of references to dementia, over which he may well have had an influence.

By now Alzheimer Scotland has initiated its ‘Candlelight’ support groups for people recently diagnosed with dementia. Neither the first group, for men only, nor the second, for women only, lasts for more than a few weeks – it is not clear why. After some thinking, and trepidation, they put on a mixed group. It is so successful that it runs for over a year, until progression of the illness and death of members eventually closes the group. James is enjoying meeting others in the same boat – he recalls:

“I was a member throughout, and enjoyed it. But it was a support group only, and we never campaigned. We visited places as a group, and had lunch.”

So after going through *‘the usual depression after diagnosis’*, James now picks himself up and is keen to get involved and to make a difference. After a year of ‘nagging’, Brenda persuades him to do IT training – which will stand him in very good stead as he becomes an activist.

But people with dementia are not yet always welcomed into public events. James remembers being turned away from a dementia conference in 2000 – because he has dementia! However, Brenda drapes a large camera round his neck and, undaunted, he manages to blag his way in as an official photographer (he is actually an amateur photographer)! James notes that the next year he is a speaker at the same event!

16 The Same As You, Scottish Government <http://bit.ly/2oheNfO>

Getting busy

Things now really start to change. James realises that he must choose one of three paths to follow:

“First, the status quo. I could have kept blundering around my shrunken world deeply depressed, as I had been decisively excommunicated from a misunderstanding society. Next, I could have simply given up and been watered, fed and lived in limbo until my dying day. Finally, I could stand up to the condition. How dare it think it can control me?”

He opts for the third path and gets busy!

“I decided to try and ensure that there was material for others to clutch at in their time of need. So I go round doctors’ surgeries and hospitals in my local area, leaving posters and help-line cards. I also leave them anywhere else I can, for example in some churches, community halls/centres and public notice boards. Nowhere is sacred! To me it is senseless telling someone they have dementia and then leaving them guessing what comes next.”

In October 2000, James presents some of the findings of Heather Wilkinson's research project¹⁷ at an event for carers, policy-makers, and practitioners. He recalls:

“My first talk, Heather asked me to do – I don’t know why I did it... At that time, it was unheard of. Brenda rehearsed me – I wasn’t a public speaker. But then I began to get this feedback from people coming up and saying they enjoyed it. It made me see things differently and changed my mind about things... People appreciated you doing the talk and said how brave you were. [It made me think] I can speak for others with dementia who cannot speak for themselves...”

I never was a public speaker, though I had muttered the odd word at meetings like PTAs [parent-teacher associations]. Suddenly I was up there speaking to a group of discerning people and operating an OHP [overhead projector]. What on earth possessed Rebekah [Pratt] and Heather to allow me platform time? Where had the confidence come from to permit me to give a talk? They certainly went out on a limb, putting their heads on the chopping block if it had gone pear-shaped, and both must be highly commended for their foresight and risk-taking stance.”

17 Tell me the Truth Pratt, R and Wilkinson, H. (2001) Mental Health Foundation <http://bit.ly/332UoKg>

James' diary soon fills up, with meetings about living wills, transport, dementia friendly communities and much more. In June 2001, he writes an article to the local paper, in which he decries *“hurtful, demeaning and derogatory terms like dementia sufferers, suffering from dementia, demented and other suchlike vile terms...”* The article is never published. But many years later, at an Alzheimer Europe conference, James speaks about the issue loud and clear: *“I surprised myself by my boldness.”*

Jenny Douglas

Jenny Douglas is another key player at this time. She runs a project with people with dementia called 'Having our Say' – the first piece of work Alzheimer Scotland undertakes with the aim of hearing direct from people with a diagnosis. It looks at what is important to them, their experiences, what they feel has been helpful or unhelpful to them, and what they want to change to make a positive difference. Up to this point the views or needs of people with dementia have in the main been expressed by proxy through carers, family and professionals. Jenny – who is described by Jan Killeen as *“a very effective group worker... always very well appreciated by the group”* – recalls:

“I worked directly with a small group of people (two are still members of SDWG now) in both a group work setting and individually, with one-to-one conversations using a fairly fluid semi-structured interview. Group members contributed to the name of my project and publicity material, shared views around their experience of getting a diagnosis (mostly poor) and talked about what made a difference in their lives and what was important to them. Everything was written up (and always shared with the participants). At this stage we were not yet talking directly to policy-makers, service providers or professionals – we were still feeding views into the organisation to use in its policy, service development and campaigning strands. The views and words though were those of people with the diagnosis.”

Between 2001 and 2012, Jenny is employed by Alzheimer Scotland in several different posts to support user voice, involvement, activism and campaigning. She also works for a short period of time as a sessional worker, supporting people to attend meetings of both Glasgow and Scottish Dementia Working Group during 2003/4.

The birth of the SDWG

Now that their paths have crossed, Heather Wilkinson and James McKillop are both questioning why there is no specific group for people with dementia. Heather draws on her knowledge of the disability movement and social action, and James on how people treat him once they are aware of his diagnosis of dementia.

So on 22 June 2002, Heather organises a conference in Dundee, focusing on different aspects of dementia. It is still very unusual to have both professionals and people with dementia at the same conference, and it is here that the idea of a group for people with dementia *“to get our voice heard”* is endorsed. James comments:

“Up to then we had been ignored and cast aside... People with dementia did not meet together [before then]. For some reason, we were segregated and kept apart; what did people fear in us getting together?”

A small steering group is formed, to explore the feasibility of creating a group for people with dementia, run by people with dementia. Heather invites Dot Weaks – who has been appointed as Scotland’s first nurse consultant in dementia in 2006 – to be involved, first of all on the steering group, and later as a co-opted member and professional advisor of the committee. James McKillop sums up Dot’s role as being there to *“ensure they don’t pull the wool over our eyes!”*



Dot Weaks

James describes the early meetings:

“So, Heather had the idea and I did too, and she managed to come up with funding for a room and sandwiches to get us started. Many were enthusiastic and signed up. We hadn’t a penny. It was only by the goodwill of Heather and Brenda that we got a room and a cup of tea.”

As Dot notes, there is a very strong team spirit at this time:

“In the early meetings, as the group was forming and finding an identity, one of the great strengths was the coming together of people with dementia and professionals from different backgrounds, and from a wide geographical base, including Turning Point in Glasgow, Joint Dementia Initiative in Falkirk, Katrina Balmer and Liz Taylor (Dementia Community Psychiatric Nurses) in Edinburgh, Anne Mason, a nurse lecturer in Inverness, and Alzheimer Scotland with their director of Public Policy, Jan Killeen, collaborating closely with Heather and James in facilitating the voice of dementia to be heard. These early days forged a really strong team spirit, with fond memories of it being really exciting times for all concerned. People with dementia in the group enjoyed the support of many different agencies, including voluntary, local authority and NHS to ensure that meetings could take place.”

From these early beginnings, the SDWG grows steadily in number, stature and influence. James recalls:

“I became an advocate of the idea of people with dementia meeting up on their own. And, when the SDWG came into being, I was exhilarated to be among people with a desire to make the world of dementia better, for those who would follow in our footsteps. I had found kindred spirits.”

As some of the members find reading difficult, James records the minutes of each meeting onto a CD which is sent to them: *“That was us thinking about the people that couldn’t manage.”*

James and the others have lots of ideas – and they are totally free to follow them up – with support as needed. With Brenda’s help and encouragement, he applies to the Millennium Commission for a grant to produce a thousand free 2003 calendars for people with dementia. Brenda sends them all round Scotland. James also has a lot of problems with money in shops, so he brings out a Help Card¹⁸. He agrees on Alzheimer Scotland getting involved, as they have greater Scotland coverage and he has no funds to post the cards out. The card is still in use today.

<p>Using this Helpcard</p> <p>Do show it to staff or officials, so that they can help you – for example in shops or on buses.</p> <p>Don't show it to strangers who could take advantage of you.</p> <p>Do call the Dementia Helpline free on 0808 808 3000 if you need advice.</p> <hr/> <p>Alzheimer Scotland, 160 Dundee Street, Edinburgh, EH11 1DQ. www.alzscot.org helpline@alzscot.org</p> <p><small>Registered in Scotland 149069 • Scottish Charity no. SC022315</small></p>	 <p>I have an illness called dementia. I would appreciate your help and understanding.</p> <p>See inside this Helpcard for more information on how my illness can affect me and how you can help.</p>										
<p>My name is _____</p> <p>Due to my illness I sometimes: (Tick any of these that affect you)</p> <table style="width: 100%;"> <tr> <td><input type="checkbox"/> get confused</td> <td><input type="checkbox"/> can't manage money</td> </tr> <tr> <td><input type="checkbox"/> feel lost</td> <td><input type="checkbox"/> need help crossing roads</td> </tr> <tr> <td><input type="checkbox"/> forget things</td> <td><input type="checkbox"/> mistake the time or day</td> </tr> <tr> <td><input type="checkbox"/> can't make myself understood</td> <td><input type="checkbox"/> panic</td> </tr> <tr> <td></td> <td><input type="checkbox"/> other _____</td> </tr> </table>	<input type="checkbox"/> get confused	<input type="checkbox"/> can't manage money	<input type="checkbox"/> feel lost	<input type="checkbox"/> need help crossing roads	<input type="checkbox"/> forget things	<input type="checkbox"/> mistake the time or day	<input type="checkbox"/> can't make myself understood	<input type="checkbox"/> panic		<input type="checkbox"/> other _____	<p>I like to be independent, but sometimes I need help. Here's how you can help me:</p> <ul style="list-style-type: none"> • Be patient and try to understand me. • Ask how you can help me. <p>If I seem very confused or distressed, contact:</p> <p>Name: _____</p> <p>Daytime phone: _____</p> <p>Evening phone: _____</p> <p>Mobile phone: _____</p>
<input type="checkbox"/> get confused	<input type="checkbox"/> can't manage money										
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<input type="checkbox"/> forget things	<input type="checkbox"/> mistake the time or day										
<input type="checkbox"/> can't make myself understood	<input type="checkbox"/> panic										
	<input type="checkbox"/> other _____										

Help Card

¹⁸ Help Card <http://bit.ly/2VjvzY4>

During National Dementia Awareness Week June 2003, James is invited to be a keynote speaker at a conference on early diagnosis and support services, organised by Jan Killeen. By now he is well-prepared:

“We wanted to appear professional to the world. As we were now being approached by the media, we had media training in Edinburgh, by a professional, with mics and cameras. I think this may have happened twice – perhaps with new people? Lots of things we did ‘back then’ are not currently replicated.”

But not all media activities turn out well. James remembers being interviewed for radio, with Doreen Cairns, and being asked ‘indelicate questions’ about his sex life. But, he says wryly, *“I managed to avoid them!”*.

Joining Alzheimer Scotland

As the group grows rapidly, it has to decide whether to become a free-standing charity or to accept an invitation from Alzheimer Scotland to come under its umbrella. At a landmark meeting in September 2003, the majority of members vote in favour of the latter. Jan Killeen writes a paper for Alzheimer Scotland Executive Committee on 31 October 2003¹⁹ which records this meeting:

At its national meeting on 1 September 2003, a vote was taken by the group members (excluding support workers and facilitators) on the direction the group wished to go. Two presentations were given setting out the pros and cons of the group either becoming a separate organisation or coming under the umbrella of Alzheimer Scotland (the latter given by me). Information had been sent out in advance to members, including a short paper I’d written about Alzheimer Scotland and how we could help.

¹⁹ Document provided by Jan Killeen

After a great deal of discussion, the Group voted 10 to 2 in favour of joining with Alzheimer Scotland. It was made clear that this was on the basis that the basic principles of the group would be met, i.e. Alzheimer Scotland would facilitate the group to:

- set its own agenda and priorities in line with their aims and objectives
- construct its own budget and be supported to manage that
- hold meetings and organise other activities by providing funding/seeking funding through our Trust Manager
- be the voice of people with dementia in Scotland within the wider organisation by empowering individuals and supporting the development of local groups

At the meeting, the Group elects seven members to form a committee, with James McKillop as chairman. Jan Killeen recalls that the main rationale of the decision is in order to be free to campaign, and not to be bogged down *“seeking to survive and constantly fundraise.”*

There is a now strong sense of optimism. James feels that joining is a good decision, and he describes the SDWG as *“the independent voice of people with dementia within Alzheimer Scotland, a marriage made in Heaven”*. While it will be working within Alzheimer Scotland’s constitution, the group develops its own rules on membership, decision-making and priority-setting. Jan facilitates early meetings to help the group recognise and use their collective skills. She also serves as Treasurer, working with the Committee on their plans and budget, *“as no one else wanted that role.”* Sylvia Rossi supports the two members who have agreed to act as secretary to the group.

It is the group itself which eventually decides to bid for funding for a coordinator. They are involved in writing the application to Comic Relief and in drawing up the job description. This leads to the appointment of Phil Bryers as the first coordinator. Jan Killeen describes Phil as:

“Brilliant! His community development background meant he had really strong skills in empowering the group, and his later experience with social work at a senior level meant he knew the maze and power structures they needed to influence.”

Dot Weaks recalls the strong spirit of ‘can-do’ collaboration which continues at this time:

“Jan (Killeen) helped with the Constitution. Jim Jackson, who was chief of Alzheimer Scotland, was like a benign father. Philip (Bryers) and Jan worked really well together. Philip had such a stature amongst the group. He enabled, encouraged, facilitated with such integrity. He was so the right person for the role, and humble with it.”

Another great advocate for people with dementia at the time is Anne Naylor, who regularly brings a ‘crowd’ down from Aberdeen to the SDWG meetings.

From the early days, people with dementia are involved in interviewing people applying for jobs in Alzheimer Scotland – another radical step. James recalls being on the panel which selected Phil Bryers, and later, panels which selected Martin Sewell (a subsequent coordinator) and Jim Pearson (Alzheimer Scotland’s Director of Policy & Research).

Once the SDWG is set up, James gets more and more involved. He acts as Chair for six years, with Doreen Cairns as the first Vice Chair. Both are speakers at Hawker's annual Scottish Dementia Congress in Edinburgh in 2003. James recalls:

“It was very unusual, in that both Doreen and I stood up before an audience and spoke. I stood beside Doreen as she talked. She was shaking with nerves. It was brave of Richard [Hawker, the conference organiser] to invite us. It was a leap in the dark, an act of faith, and held a gigantic risk for him, if we floundered. Happily, we both managed to do well, and I gave her a big hug at the end...”

“It was common at that time for people to believe that people with dementia were incapable of doing anything. You had lost your human rights, and your rightful place in society. I call the start of the Millennium ‘the Dark Ages’.”

For the first three years, the SDWG receives funding for group expenses and for the coordinator post from Alzheimer Scotland, in partnership with Comic Relief. This dual funding then continues for another three years, allowing the staff group to grow to include a part-time development officer and part-time administrative support. An office base is provided by Alzheimer Scotland in Glasgow. Around 2004, Alzheimer Scotland change their constitution to allow a person with dementia to be on their council.

Nancy McAdam

The Central Belt isn't the only place where things are happening. Nancy McAdam from the Black Isle – previously a preschool coordinator and a community development worker in Merryfield, Glasgow – is diagnosed with dementia in 2003, following a number of strokes: *“Then a CPN visited. After a couple of years, she'd had enough of me!”*. But Nancy



and another person with dementia, Alan, connect with Sheila McEver at the Inverness branch of Alzheimer Scotland.

Nancy has always been a campaigner – or as she calls it, ‘an oddball’! She has campaigned on GM crops on the Black Isle (and was arrested and held in a cell for eight hours), and has taken part in a rent strike when the high rise estates in Merryfield flooded: *“I like to take action... I'm still up to my eyes in work!”*

Nancy recalls being very willing to talk about her condition – and about how to stay healthy:

“In 2007 [the paper] did a big middle page spread of me. I thought it was important that people realised you can keep up your CV [cardio-vascular], grow veg, dig the soil... It's the cycle of life.”

Nancy becomes increasingly involved with SDWG and goes to many of the conferences with James, Agnes and Ross. She also chairs the Transport Sub-group for many years, as she travels a lot, and she presents on their work at the Alzheimer Europe conference in Slovenia.

The group's influence continues to grow, with members speaking at a variety of events and responding to consultations from government and the NHS. Members prioritise campaigning around early diagnosis, respite provision and access to medication, as well as drawing up a ten-point plan with their vision for 2010. Alzheimer Scotland goes on to appoint four Involvement Officers across Scotland, to work with both carers and people with dementia. Jenny Douglas has the post for Argyll & Clyde Region, based in Paisley. Her recollections of this time illustrate the philosophy and skills underpinning this work:

“I set up a network where people could feed their views in (for people who did not want to or could not come to groups or take a more active role). A local action group for people with dementia in West Dumbarton (a very small local version of an SDWG) supported a small number of people to take part in local planning groups and Public Participation Forums, (very early stages of local authority/health trying to engage with people using their services with various levels of success) and a small number of other groups to make them more dementia friendly. They also supported carers to participate as speakers at a conference, and arranged for health and local authority staff to join a meeting with younger people with dementia and their carers to hear directly from them of their experience of getting a diagnosis and difficulties in accessing support that met the needs of a younger age group. This was an opportunity for people making the decisions about services (consultants and planners) to hear directly from people as well as getting the write up from the report. I also held two focus groups with people further on in the condition attending day care, to share views around sheltered housing which was written up and given to local authority housing staff. I supported several people to attend SDWG meetings.”

When the four-year funding for the Involvement Officers comes to an end, the posts become Dementia Advisors, with involvement and engagement now being seen as everyone's responsibility within the organisation, rather than as the work of a small number of staff.

In 2005, June Andrews arrives at the Dementia Services Development Centre in Stirling – initially for a two-year secondment by the Scottish Government, though she ends up staying for ten years. By this time, it is almost obligatory for key people in the dementia field to make connection with the SDWG, as June recalls:

“It was soon made clear to me that I was expected to go and meet them – something my predecessor had obviously done. So I was ‘summoned’ to appear. The first time, to be honest, I was slightly scared, being aware of my own accountability and being somewhat ‘put on the spot’. But I understood that and it was right too. The first time I went people understood that I was new in post. It was clear that everyone’s voice in those meetings was heard. Some had supporters with them.”

Jenny also recalls the important work that SDWG does around this time with NHS Quality Improvement Scotland (NHS QIS), campaigning for the National Institute for Health and Care Excellence (NICE) to allow those in early stage dementia to continue to retain access to the drug Aricept. People with dementia join carers to testify as to how valuable their medication is in improving the symptoms of Alzheimer's disease. Jenny comments:

“This was very important, and as powerful in impact as large numbers of names on petitions and written evidence of value. There is nothing as strong as hearing directly from the voice of experience.”

Summary

The coming together of several determined activists, supportive advocates, enlightened academics and forward thinking policy-makers in the early years of this century leads to the founding of a unique and highly influential group. The SDWG quickly becomes a central force in bringing the voices of people with dementia in Scotland to the attention of policy-makers, academics and practitioners. Its members also find new meaning in their lives and their connections, which helps them to overcome initial feelings of despair following diagnosis.

This early story is a powerful example to more recent (or potential) activists of how a small group of people with dementia can forge alliances and get their voices heard. Yet this in no way diminishes the challenges that the early activists face. There is still a very long way to go in changing attitudes, developing a better understanding of dementia, and calling out discrimination in so many areas and at so many levels. SDWG is off – but dementia activists still have many mountains to climb.

The next chapter explores the growing influence of activism as things move up a gear.

3. Moving up a gear

Over the next few years, SDWG grows steadily, both in number and influence. One key figure to come onto the scene, in 2007, is Agnes Houston.

Agnes Houston

Agnes has been a nurse, serving in Hong Kong in the Queen Alexandra's Royal Army Nursing Corps (QARANC). She is diagnosed at the age of 57, in 2006, while caring for her father who has dementia. She now takes the job of manager at a chiropractic practice, as she can no longer cope with the responsibilities of being a nurse. She recalls:



“My boss said I might have a brain tumour and made me go to my GP. My best friend then said she'd been worried, but didn't know how to broach it... There was a period of withdrawal. They sent me to a psychiatric unit. Those were the dark ages of dementia – no cafés, no advocacy, no rehab. You were diagnosed and sent home. It was all negative. Nobody knew how to treat us, they would cross the road, they didn't know how to cope. They would talk to Donna [my daughter] instead – it was fear-based.”

One day Jim Clarke (a manager at Alzheimer Scotland who is at the time supporting her father) asks Agnes how she is... and she bursts into tears. He suggests that joining a group might be helpful, and he introduces her to SDWG:

“I went not knowing what to expect. [When I got there] I didn’t know who had dementia! There was laughter as well as work. I thought I was in the wrong place, we’re supposed to be depressed!”

Agnes joins SDWG in 2007, and James – at that time Chair – takes on the role of mentoring her. She recalls:

“I wanted what James had, I became his puppy. I questioned and questioned him. One day he told me I must take control of my own dementia – wise words from a wise man. I knew I could live with dementia if I could bottle this and take it morning, noon and night. But it’s a campaigning group, so I had to become a campaigner. And I lost my anonymity. I don’t remember the meetings, I just knew I left feeling good. They encouraged me to try.”

The first time Agnes speaks publicly is in a lecture theatre at Edinburgh University. Lynda Hogg, who is also diagnosed in 2006 and becomes an ADI Board member, is speaking too: *“She seemed self-assured but she got me to go first.”* Agnes is terrified, but she takes a deep breath and gets on with it... with Dot Weaks massaging her shoulders to relax her while she speaks. She receives a standing ovation.

Like James, Agnes tries hard to get interest from user-led mental health movements. She spends several years (from around 2010) with VOX, Scotland’s national voice on mental health²⁰. She makes the point that, if dementia is part of mental health services, its voices should be included in organisations such as VOX and the ‘See Me’ campaign²¹ which aim to end mental health stigma and discrimination, and which *‘were strong and had big money behind them.’*

²⁰ <http://voxscotland.org.uk/>

²¹ <https://www.seemescotland.org/>

But eventually she decides to put her energies in other directions. Ironically, Ron Coleman is also involved with VOX at that time, though it is only much later, when he joins DEEP, that he and Agnes realise that they have met a number of years before.

In 2013, Agnes is awarded a lifetime achievement award from Alzheimer Scotland. She chairs SDWG for two years from 2013, and feels she tried to push the boundaries, for example by visiting people in care homes.

“I loved being Chair. It was hard work, but I asked James for advice and he helped me. I had to put my own passion [the sensory challenges of dementia] on the back burner. I liked to make sure everyone had a say, we had fun and did work. I got acceptance and humour to laugh at myself.”

In time Agnes occupies many high-level policy and advisory roles. She is a founding member and then vice-president of the European Dementia Working Group (EDWG). She is also on the Board of Dementia Alliance International.

In 2015, Agnes is awarded an MBE, and the following year a Winston Churchill Memorial Fellowship. The latter enables her to travel to Canada and Ireland to seek out examples of best practice relating to sensory challenges and dementia. As Agnes has experienced visual disturbances and effects to her senses of taste, smell and hearing, this has become one of her driving passions – and one which in due course leads to a series of co-produced research and publications.

Connecting with government

The SDWG is growing stronger, and the Scottish government is also becoming more aware of dementia. In 2007, the Scottish National Party (SNP) make dementia a priority in their manifesto. Irene Oldfather plays a key role in moving things forward at a political level.

Irene Oldfather MSP

Irene's awareness of dementia is first awakened by a 'constituency case', Mary, who has dementia and cares for her son who has Huntington's disease. One day, Mary collapses in the street and is taken to hospital. But all she can think of is whether her son is alright alone at home. Irene reflects:



“I became very aware of the hard lives some old people were struggling with. I got her an assessment and two weeks later she was smiling. For me that set a standard – we will treat everyone like Mary, we will push the boat out. I met many more Mary’s... We wanted the new Parliament to be different from Westminster, more open. But I never saw people with dementia petitioning and campaigning like other groups. I felt they didn’t have a voice. I started to table members’ debates and raise awareness of these quieter voices.”

Not long after Irene becomes aware of Mary's case, her own mother is diagnosed with dementia. Irene begins to meet a range of organisations, and sets up the Cross Party Parliamentary Group (CPPG). She recalls:

“I had to demonstrate added value and lobby to find members. There were only four at the first meeting! But we worked hard, tabled lots of questions... When I left in 2011, there weren’t enough chairs in the room.”

Once the Scottish government makes dementia a priority, their contacts with SDWG increase to two to three times per year. Nicola Sturgeon, then Minister for Public Health, sets up an advisory group, the Dementia Forum, to guide the development of dementia as a national priority. Two members of the SDWG are invited to join this influential group. During a visit by the then First Minister, Alex Salmond, they discuss the importance of challenging public stigma and misconceptions of dementia. And these discussions lead to major political initiatives, which turn out to be world-leading.

The Charter of Rights

In December 2008, Irene urges the new Scottish Human Rights Commission to make older people and people with dementia a priority. As Irene recalls:

“I pushed for a Charter of Rights... It wasn't that easy... Mary Scanlon [MSP] was inspiring – she kept us going. There were so many strong women, who had experience of caring and of their constituents' stories.”

The work starts with another ‘first’ – a series of roadshows held all over Scotland in partnership with Alzheimer Scotland, to ask people about the challenges that they face. Around a thousand people take part. During this period, Jan Killeen and Jim Pearson also run a series of workshops on the human rights of people with dementia and carers.

The following summer, Irene sets up a sub-group while Parliament is in recess, which meets at the Scottish Human Rights Commission. They distill all the information collected at the roadshows and produce three report versions.

They choose the most accessible version, based on a human rights-based approach known as the 'PANEL' approach, which is endorsed by the United Nations. PANEL is an acronym which emphasises the rights of everyone to:

- **P**articipate in decisions which affect their human rights
- **A**ccountability of those responsible for the respect, protection and fulfilment of human rights
- **N**on-discrimination and equality
- **E**mpowerment to know their rights and how to claim them
- **L**egality in all decisions through an explicit link with human rights legal standards in all processes and outcome measurements

SDWG are part of the whole process, with James, Agnes and Edward all involved. As an MSP, Irene isn't allowed to directly finance or resource a campaign, so she hands the Charter to Alzheimer Scotland to produce. Then, on 8 October 2009, she tables a members' business debate. Irene recalls positioning a poster by the stairs in the Scottish Parliament and asking members to physically sign it before they go into the debate. The Charter of Rights²² is endorsed by all the parties – with minutes to spare! Irene recalls:

“We worked hard, wheeled and dealed, to get them all. The Conservatives signed up because I said it would save them money. Shona Robinson, Health Minister, only agreed five minutes before. Everyone [supporting] was up in the gallery – I gave them the thumbs up. I was so proud, it meant so much to me. We told people's stories and we won people over. That changed hearts and minds. It demonstrated the power people have, when they get together.”

²² Charter of Rights <http://bit.ly/2MfNdYx>



Charter of Rights

Growing strategic impact

By this time, Agnes Houston is deeply involved with SDWG. She recalls:

“We were now moving and shaking at government level. We were almost grateful for having that voice – but we were travelling beyond our limits. Sitting with high profile people gained a lot of respect. We were professional, well-read. We wanted change in action. James taught us how to gain respect. We had a name for being respectful.”

Impact case study 1

The first Scottish Dementia Strategy

The first Scottish Dementia Strategy, which is launched the following year in 2010, is a notable example of direct impact of activists on policy change.

The Charter of Rights is central to the development of the strategy, which focuses on improving the quality of dementia services through more timely diagnosis and on better care and treatment. Ten members of the SDWG are involved in the development of the Strategy, two participating in each of the five workstreams. They are also partners in running the consultation events. The SDWG Chair at that time, Edward McLaughlin, writes in his foreword:

*“It is something our members have wanted for a long time. And we have been very pleased with the way our members have been involved with the development of the Strategy from the start, as representatives on the five workstreams and as a partner in running the consultation events. We are particularly grateful for the time the Minister for Public Health, Shona Robinson, gave to meet with us to discuss our priorities.”*²³

After its publication, three members of the SDWG sit on the programme board to oversee the implementation of the Strategy.

In June 2011, Nicola Sturgeon, while addressing Alzheimer Scotland’s Dementia Awareness Week conference in Glasgow, describes caring well for older people and those with dementia as *“one of the most sacred duties of any civilised society”* – unusually strong words for a politician. She also announces that Scotland’s chief nursing officer will oversee the implementation of standards of care for people with dementia – based on two major new documents. ‘Standards Of Care For Dementia’²⁴ sets out how people with dementia should be treated, and ‘Promoting Excellence’²⁵ is intended to ensure the standards are met by staff.

23 <http://bit.ly/336dNdc>

24 <http://bit.ly/2LNT3RL>

25 <http://bit.ly/337TxYG>

The influence of the SDWG on the highest level of policy-making is very clear.

In recognition of this, the Scottish Government hosts a celebration reception at the Scottish National Gallery in 2012. Nicola Sturgeon, by this time Deputy First Minister, speaks in praise of their work, and highlights just how far the group has influenced the shift in attitudes in Scotland:

*“Development of the Dementia Strategy included the close involvement of Alzheimer Scotland and the Scottish Dementia Working Group, both of whom endorsed our approach. It has been vital to me that, in implementing the strategy, they have both been at the heart of the large programme of work, providing expert advice and input on the services to which people are entitled, and influencing the implementation of the various strands of the strategy.”*²⁶



The Scottish
Government

*Nicola Sturgeon MSP
Deputy First Minister and
Cabinet Secretary for Health, Wellbeing and Cities Strategy*

requests the pleasure of the company of

James McKelvey

*at a reception to mark the tenth anniversary of
The Scottish Dementia Working Group
at The Scottish National Gallery
on Thursday 28 June 2012*

*7.30pm
Business Attire*

RSVP details overleaf

James' invitation from Nicola Sturgeon

26 Dementia in Scotland, Issue 75, p.3, (March 2012) [5.1]

Broadening connections

The SDWG is now well-established, with a committee of 18 and many more ordinary members. As the group gains confidence in its abilities to campaign, the workload increases. There are many invitations to contribute to dementia-related work, not only in Scotland, but throughout the UK. These include commenting on and being part of research projects, supporting professional training and responding to consultation documents and government strategies.

In 2012, SDWG celebrate their tenth anniversary, receiving greetings and good wishes from individuals and organisations around the world. The group meets to review their campaigning work and decides to focus on three main areas: building a stronger SDWG, raising awareness of dementia within the transport sector, and GP training. The latter has long been an issue. James recalls a meeting in around 2007, in Glasgow, which was targeted at the medical profession, mainly GPs:

“I must confess some of the things the GPs said, and their bedside manner, made me cringe. They had no idea of dementia.”

In 2013, Agnes becomes Chair, and the group continues to go from strength to strength. An independent consultant, appointed by the group to carry out a review with a view to future development, describes the SDWG as *‘a successful, influential and highly regarded group achieving the majority of its aims and objectives, especially across campaigning and awareness raising’*. The review suggests a more strategic approach and the priorities for the coming three years are agreed as: a well-trained workforce; early diagnosis; and good post-diagnostic support.

The Life Changes Trust

During this period, another very significant player comes onto the scene. The Life Changes Trust is established in April 2013 as an independent Scottish charity, with a £50 million endowment from the Big Lottery Fund (now the National Lottery Community Fund) to be spent over ten years (around half on dementia). The Trust is soon funding many exciting and innovative projects. Their emphasis on enabling a stronger voice for people with dementia is central to their mission statement, which states:

‘What is clearly needed is a shift in how people affected by dementia are perceived, how they are treated and how they are supported and empowered. We want to play a significant role making sure that this support is put in place, and enabling people affected by dementia themselves to have a strong voice about matters that affect them. We are committed to driving change in how people with dementia and their carers experience everyday life. We know how important it is to see the whole person, ensuring that he or she is central to decisions that affect their life, and we will invest our resources so that people affected by dementia are empowered to identify their needs for support and have choice and control in how these needs are met.’

The Life Changes Trust is clear that the influence of the activists on their thinking and their funding has been significant. The views of people with dementia have also played into the Life Changes Trust’s more recent decision to fund a School of Leadership (to be known as ‘BOLD’) and a new National Forum for Dementia Policy and Practice (to be known as ‘About Dementia’) – as announced in March 2019. Both are being delivered collaboratively by Age Scotland, the University of Edinburgh and Queen Margaret University, and aim to support and validate people with dementia and carers to become experts, leaders and influencers in Scotland.

Continuing SDWG impact

The second Dementia Strategy (2013-2016) focuses on improving post-diagnostic support and strengthening integrated and person-centred support. It takes a human rights approach to ensure that high quality, person-centred care is provided from diagnosis to end of life.

In 2015, Henry Rankin takes over as Chair. The SDWG is now having real impact, working with many influential institutions such as the Mental Welfare Commission, NHS QIS, GMC (General Medical Council), BMA (British Medical Association), Colleges of Nursing & Midwifery, Social Work and Allied Health Professional training, research institutions, Police Scotland, the ambulance service and many more.

One notable example is the work with the Care Inspectorate. Agnes, James and Anne MacDonald are the first people with dementia to support the Care Inspectors, from around 2016. Unsurprisingly Agnes highlights sensory issues in her visits, pointing out how people not wearing hearing aids or glasses are excluded and isolated. She recalls:

“It was breaking barriers, boundaries. But it was hard to fit the inspections into a busy schedule.”

In 2017, SDWG members Pat McGonigal, Henry Rankin and George Woods take part in the short Life Changes Trust-funded film ‘Living and Learning with Dementia’²⁷, to show that people with dementia can continue to learn new things after their diagnosis. Henry Rankin is recognised for his hard work by getting a Lifetime Achievement Award at the Scottish Dementia Awards. Vice Chair Carol Hargreaves continues to represent the group on the EWGPWD (European Working Group People With Dementia) and travels to meetings in Brussels, Berlin and Luxembourg.

²⁷ ‘Living and Learning with Dementia’ film <http://bit.ly/30JTUAU>

The third Dementia Strategy (2017-2020) maintains a focus on improving the quality of care for people living with dementia and their families through work on diagnosis, including post-diagnostic support; care coordination during the middle stage of dementia; end of life and palliative care; workforce development and capability; data and information; and research. Crucially, within this Strategy, there is a recognition of the importance of taking a person-centred and flexible approach to providing support at all stages of the care journey. But the third Strategy is much lighter on human rights, only mentioning them in connection to inappropriate prescribing of antipsychotic medication. Some people are concerned that the strong human rights focus of the first Strategy is now being watered down.

The Alumni

In 2016 there is another new development, as several members of SDWG set up a new group called the Scottish Dementia Alumni. There is a range of motivations. James says:

“We felt [there were] some things we wanted to discuss that weren’t discussed... We need meetings to discuss things that concern us... SDWG draw up a list of priorities every year – but they seem to be the same. Why not move on? [Alumni] is very informal. Not official. There’s no conflict of interest with SDWG.”

Agnes recalls:

“It was needs-driven. We needed our voice still to be heard, but our needs were different and we were being suppressed. We wanted to talk about our emotions more than campaigning. All groups will need this... We need a safe place to talk. Donna gave up her time and we found a room. We don’t want any help... I’m now regaining Agnes back. I’m campaigning for what I want now. I want to do it in a safe environment.”

Nancy is also a founder member of Alumni, retiring from SDWG in February 2018:

“The days of Agnes and James and Edward were wonderful – the heyday. Because they had charisma. Since then the meetings are not the same... I feel sixteen years was enough to give to [SWDG]. I prefer to go to local things now.”

Nancy remains part of the Highland group, which she set up with help from one of the advisors, Geraldine Ditta.

The Alumni’s biggest project to date is their own research on what self-management means to people with dementia (see chapter 5).

Summary

As the SDWG beds in, and grows in confidence and credibility, important connections are established. These gradually bear fruit in terms of real influence on policy. Scotland's rights-based approach is justly feted, and it seems that each success fuels determination to keep moving forwards.

Inevitably some activists outgrow the structures they have themselves created and move off in different directions, and into new partnerships. The Alumni group builds on the many years of experience of its members and their confidence to follow their own priorities. The entrance of the Life Changes Trust onto the scene now brings many more opportunities for the voices of people with dementia to be heard, and arguably greater 'license to be free,' as Agnes desires.

We have yet to mention the increasing reach of the DEEP network, and we address this in the next chapter.

4. DEEP in Scotland

Background

DEEP – which stands for the Dementia Engagement and Empowerment Project – begins as a one-year project in 2011. It is funded by Joseph Rowntree Foundation (JRF), managed by Mental Health Foundation, and supported by Innovations in Dementia, a UK-wide social enterprise. The aim is to find out how many ‘involvement groups’ of people with dementia there are in the UK, and to know how the groups work. At the end of the project 17 involvement groups and activities have been counted – including SDWG, which is one of the most well-established and well-known.

From 2012, the DEEP network starts to take shape across the UK, hosted by Innovations in Dementia. DEEP connects groups to each other to magnify the views, hopes and intentions of people with dementia. It supports groups to share learning and skills and to increase confidence. By the end of 2015, there are 50 DEEP groups. This phase of DEEP²⁸ is funded by JRF (and, from 2013, Comic Relief). A national user movement of people with dementia is being built.

DEEP in Scotland

In October 2015, the Life Changes Trust joins Comic Relief and JRF as a funder of DEEP, giving more momentum to the work in Scotland. At this stage there are 13 DEEP groups in operation or development across Scotland.

From the start of DEEP in Scotland, the need to work closely with Alzheimer Scotland, and the SDWG in particular, is recognised by Innovations in Dementia and by the Life Changes Trust. At a teleconference with SDWG in January 2016, DEEP is explained to the group, and some probing questions about the rationale for expanding DEEP into Scotland are answered.

²⁸ Developing a national user movement of people with dementia. Litherland, R. (2015) York: Joseph Rowntree Foundation

Interviews for the coordinator are held with SDWG at the offices of Alzheimer Scotland in Glasgow, and SDWG inform the application pack, as well as the questions to be used at the interview. The interview panel in April 2016 comprises a majority of people with dementia from SDWG.

Paul Thomas is appointed as the Scottish coordinator, having spent four years as chair of the Scottish Independent Advocacy Alliance. Entering this field of dementia activism is an opportunity to complete the circle, since Paul's very first job as a 19-year-old was as a care worker in a care home. He recalls:

“People with dementia were always at the bottom of the pile – they have historically been dehumanised.”

So how do the long-term activists in Scotland see the arrival of DEEP?

Paul remarks that, although Agnes and James have been ‘on the scene’ a long time before the DEEP network is established in Scotland, they both intuitively understand its aims and values:

“...Agnes... knew exactly what it was about. In fact, Agnes has taught me what DEEP is about!”

Agnes also recalls how she gets involved with DEEP:

“We didn't know if we could trust DEEP. It took us a year or 18 months... Scotland was getting big and a well-deserved international name. But I wanted to know about others in the UK. I was popping over to England... I liked what I was hearing...”

“... I will never forget the first meeting about DEEP. I met some beautiful people. They strongly didn't want support from the Alzheimer's Society – and I couldn't understand it. [But] it's been such a privilege to see how powerful and right they were to remain a network, and true to their own individual values. They proved me wrong. That inspired me to turn round and say, let's find our own way.”

James is also very positive right from the start. He has long had wider connections with the rest of the UK (and beyond) and he also wants the freedom to address more local issues in Scotland:

“I thought it was very good. Alzheimer Scotland had cornered the market but weren't doing groups. It gave people a chance to discuss local issues that Alzheimer Scotland wouldn't take up.”

With Paul's support, groups across Scotland start to connect with DEEP, to be in touch with other groups, to attend DEEP events and to access DEEP grants so that they can carry out small projects that they prioritise.

The DEEP Gatherings

At the core of DEEP's identity are the Scottish Gatherings, which are always led by people living with dementia, and which connect them (and sometimes their unpaid carers/care partners) across geographic and demographic boundaries, to build on their own priorities. By involving people living with dementia from across the network, local issues can be addressed from a wider perspective, and people from remote localities can share their own life-affirming work with each other.

Between March 2017 and September 2019, nine DEEP Gatherings are held – in Hawick, Inverness, Aberdeen, Glasgow and Evanton Woods, as well as two each in Edinburgh and Stornoway.

Many who come to DEEP Gatherings report the experience as 'life-changing'. The peer support, the fun and the social elements, as well as the serious 'gathering' style discussions, empower people to experience life changing circumstances, together. Nancy particularly values the more social and 'fun' emphasis of DEEP Gatherings:



DEEP Gathering in Hawick

“I had a great time with Paul [Thomas] at Edinburgh Murrayfield. I did a little bit on mindfulness. And a fantastic session by a guy doing dance stuff. Then we took the train and had fish and chips. We [also] went to Stornoway. Then DEEP did Aberdeen – why didn't I go? I like DEEP Gatherings, I thought, why didn't I go to more?”

Other members testify:

“DEEP doesn't tell you about dementia, they want to hear what YOU want to say.”

“I can't believe, in just two magical days in Inverness – the difference in both our ways of looking at and dealing with things.”

Agnes feels that DEEP offers the opportunity to function as part of a team:

“I’m delighted [with DEEP], it gives me great pleasure, my heart soars. It’s like your child has a gold star. We’re part of a team, we celebrate every win. It’s what campaigning is about, it’s about supporting one another.”

For Ron Coleman, his first Gathering, in Aberdeen, is a life-changing moment:

“You guys changed my life. I took my head out of my arse. I was down when I came, but not when I left. It proved my depression was normal and reactive – as soon as you find hope you come out of it.”

Paul Thomas’ assessment of the power of the Gatherings model is this:

“DEEP – through its principles, values and influence – has opened the door to many professionals to welcome people with dementia into an equal dialogue... The Gathering model is totally inspiring. It enables people with dementia from across the whole of Scotland to connect face to face. People with dementia won’t be put back in the bottle. The life-changing experience of some people at these Gatherings is priceless... totally inspiring.”

There are also more tangible outputs from the Gatherings that include:

- a visual map about what DEEP means to people
- several themed Dementia Diaries Live Performance scripts
- an end-of-life resource, produced with the carers organisation **tide**²⁹
- priorities for post-diagnostic support³⁰
- consultation about DEEP resources, including the website and DEEP Update
- a Gathering for facilitators to support each other with common challenges (Glasgow, June 2019)
- a list of priorities for Scotland (see below)

Priorities of activists in Scotland

These are the priorities that people with dementia who participate in the DEEP Scottish Gatherings have come up with:

- We have the right to get out and about.
- We want to work to reduce stigma.
- We want a better experience of getting a diagnosis.
- We want to address issues of bullying and intimidation.
- We have the right to support throughout the dementia journey.
- We want to use technology, creativity, community and gatherings to reduce isolation and loneliness.
- We have the right to be supported to live independently in our community.

29 End of Life Care and Post Bereavement Support – Shifting the Conversation from Difficult to Important (2018) Tide and DEEP <http://bit.ly/2kSTM9w>

30 A Guide to Psychosocial Interventions in Early Stages of Dementia Guss, R. et al (2014) The British Psychological Society <https://bit.ly/3feamHv>

- We have the right to do normal things, the things we want to do.
- We support the use of cultural and creative opportunities to help people to speak, whatever their background or circumstances.
- We have the right to clear and accessible information about all aspects of all forms of dementia.
- We have the right to initiate and lead research, not just be research subjects.

Reports, including photos, of all the Gatherings can be found here³¹. Innovations in Dementia have also made short films of the Gatherings in Stornoway³², Glasgow³³ and Aberdeen³⁴ which convey their unique flavour.

Some challenges for the ‘DEEP model’

Establishing DEEP in Scotland has not been without its challenges. For a start, travel, accommodation and rural transport issues raise many barriers to national and even local networking. Supporting people properly takes a lot of skill, experience, care, time and emotional input. Nevertheless, there have been many successful Gatherings, even in areas as remote as Stornoway. And the commitment to testing out technology to enable remote meetings is proving very fruitful (though it can exclude some).

Some Scottish organisations have found it harder than others to understand DEEP’s different approach. DEEP is young, is not a formal, separately constituted organisation (it’s just a network), and is specifically about amplifying the voices of people with dementia themselves. Its funding is spent mainly on events and project grants, and very little goes to its minimal staffing (in Scotland this has never been more than one part-time coordinator). As such it offers freedom for the groups within the network to develop a proud sense of independence regarding their own work and their own voice.

31 <http://bit.ly/35ePImG>

32 <http://bit.ly/2mcUHly>

33 <http://bit.ly/2miwB9j>

34 <http://bit.ly/2kAfCyK>

To sustain this, DEEP in Scotland needs to remain light on top-down management, and diverse and rich in grassroots experience and expertise. Paul Thomas believes that:

“The emerging and free voice of people with dementia in a network across the country is something un-tamable... To control these emerging voices would be like herding cats!”

It must also be remembered that the growth of activism described so far in this book follows decades of traditional approaches and services, which, albeit often well-intentioned, have tended to reinforce dependency. Twenty years of an emerging and growing voice of people living with dementia is still a relatively short time. So, while the DEEP network can complement and add value to the work of others, taking the step of joining it requires the enthusiasm of someone with vision – whether that be a person living with a dementia or a facilitator.

Some of the activists also say that, while the loose network and support which DEEP offers feels enabling, they can feel excluded from the political channels that can really make change happen. Agnes sums up this challenge:

“I see SDWG as the national campaigning group. But in Scotland it’s only the national voice that’s being heard. I’d like to work... to get that changed. I want DEEP’s voice at the table...”

The activities and impact of DEEP groups

Between October 2015 and September 2019, one third of the DEEP ‘involvement grants’ are ring-fenced for projects in Scotland. The availability of small grants has been a good way of connecting with groups that are interested in influencing and enabling people with dementia to have their voices heard. It also means that groups are able to carry out projects and work that they own themselves.

The SDWG, for example, uses its DEEP ‘involvement grant’ to buy iPads to connect individuals and help communication. Nancy McAdam, who does not live near any other group members, is able to use the iPad to connect with the meetings in Glasgow. The iPads are passed around the room so that, using the FaceTime app, Nancy can see people as they are speaking. Nancy describes the experience as *“fantastic... just wonderful”*. Members of the SDWG can also now ‘attend’ other meetings without travelling great distances. Agnes also uses her iPad to connect with a meeting in Luxembourg while sitting at her kitchen table. This meeting generates ideas about how people with dementia from across Europe can connect and take part in conferences and events using technology. Here are Agnes’ reflections:

“SDWG joined DEEP and got a grant for iPads. I got my iPad and that was my lifeline, because it was intuitive. That was the window. My way of connecting and finding out. Another person with dementia, Brian Malone, taught me how to Tweet, at a conference – on a piece of paper! I use [my iPad] for photos too and as a memory aid.”

The peer support and empowerment that are built on the solid foundation laid down by the pioneers within and around the SDWG, and generated at the DEEP Gatherings (see below), enable more people to speak out. Many of the DEEP groups now proactively seek to influence local and national policy and practice, and demonstrate increasing confidence in doing so. There are many examples of practical impact, including:

- DEEP groups in Haddington, North Berwick, Cockenzie, Dunbar and Mussleburgh help to develop principles for working with Meeting Centres
- the Alumni participate in the Fife Church of Scotland conference ‘Dementia and the Church’ at Edinburgh Festival Theatre
- people from the Western Isles and Edinburgh support the development of a DEEP initiative at Edinburgh Festival Theatre
- some also attend the Cross-Party Parliamentary Group, though travel expenses are not covered, making this difficult for many

In addition, the guides and other materials available on the DEEP website are regularly accessed by many in Scotland. These are highly regarded, and contribute to many events and practices across Scotland. DEEP’s bright yellow ‘I Want to Speak Please’ cards are particularly ubiquitous!



DEEP card

Ron Coleman

Ron Coleman is one example of the more recent activists on the scene in Scotland who are honouring and learning from the more experienced activists, and stepping up to the plate.



Ron, who is in his early sixties now, is a survivor of abuse. In his twenties he spends ten years as a psychiatric ‘client’ – over seven of them as an in-patient. Ron hates his diagnosis of schizophrenia:

“I became quite rebellious against the whole system. I was considered ‘non-compliant’”.

But then, in the early ‘90s, he gets involved in the Hearing Voices Network, set up by the Dutch psychiatrist Professor Marius Romme. When he *“gets out of the system”*, Ron has a crazy few years in his thirties, *“learning to live”*. He finds his voice and becomes the first national coordinator of the ‘Hearing Voices’ movement – only resigning when the movement gets funding: *“I would never make an employee”*. By this time there are around 200 groups in the movement.

Ron is inevitably *“at loggerheads”* with many professionals, but also sees many people as allies – including his wife-to-be (or ‘partner in crime’ as she prefers) Karen Taylor, a mental health nurse, who he meets in the late ‘90s. Ron moves from Runcorn to join her in Gloucester... and they have their first child Rory the following year. By this time, he and Marius are great friends and Marius even ‘adopts’ Rory as his grandchild. Karen and Ron start working together, and Karen encourages him to charge properly for the training he is now doing.

They also set up many different recovery projects over the next twenty years, including ‘recovery houses’.

Karen also brings her experience of working in acute and community mental health, but, before that, of being a young nurse on a dementia ward and feeling very angry at the way the patients were treated (tea, milk and sugar all in one jug, as an example).

In 2003/4, the couple are commissioned by Gregor Henderson (Director of the Scottish Government’s innovative and internationally renowned National Programme for Improving Mental Health and Wellbeing) to help set up the national Recovery Network – and since then work internationally in countries such as Australia, Canada, New Zealand, USA, France and Italy. Around the same time, they move to Scotland and have a daughter, Ron’s first – and last – Scottish child!

It’s now about three years ago and they are living in Port of Ness on Lewis. Ron’s daughter notices he is forgetting things, falling asleep, getting lost, leaving the gas on etc. He is also losing his ability with figures (he is a trained accountant). He is diagnosed with mild cognitive impairment. Ron starts contacting third sector organisations, but none respond. But when he sees the Memory Clinic Nurse, she puts him in touch with Alzheimer Scotland in Stornoway, and with DEEP. This leads to contact with Paula Brown at An Lanntair and gets Ron and Karen to the Aberdeen DEEP Gathering in August 2018. Karen recalls:

“The moment he met other people, he came away feeling really alive. He got on Twitter and started talking to them. He could see he was still capable – he hadn’t lost who he was... He loved the Dementia Diaries too... he was really fired up.”

This is the start of Ron’s involvement as a dementia activist... or ‘do-er’.

‘Do-ism’

Ron Coleman describes how the paternalism of current structures, as he perceives it, is frustrating progress:

“In Scotland there is the idea that we should be passive recipients, not active players. You face a hierarchical structure. We’re so used to everything being done for us, not by us. There’s no malice – they’re really nice – but people should care about you, not for you.”

In a powerful Dementia Diary³⁵, Ron elaborates on the concept of ‘Do-ism’, which is founded in the civil rights campaigns:

“I remember at a Union meeting many years ago, listening to my dad argue that we should strike in support of dockers, and refuse to allow any material into the factory that came from the docks. In this moment my dad taught me the importance of Do-ism. The meeting we were at was meant to show solidarity with the dockers, by sending them a letter of support. Instead we took action to support them.

Being an Activist is about doing things, not just talking about it. We cannot expect others to do the action for us. If we do this, we allow our agenda to be colonised by others, who may have very different thoughts about what we need or want. In the fifth strongest economy in the world, our lives should not be constrained to just campaigning for our needs, but also demanding a fruitful and self-determined life. The right to a life is a fundamental human right and we should not just accept what the system tells us we need...

35 Dementia Diaries <http://bit.ly/2JBGFVT>

“Do-ism is about taking back power and not accepting a dialogue of silence that is the norm from service-land and its deeply held delusion that they are the experts. To do this we must understand that power is never given, it must be taken. It is important we learn the lessons from those who have struggled to have their voices heard in the past.”

“The great activist movements of the past had Do-ers who practiced Do-ism to win their campaigns. We should ask ourselves who gave women the vote? Was it men? No, women took the vote through the actions of the suffragettes and suffragists. Who gave black people their civil rights? White people? No, it was the actions of the Do-ers like Rosa Parks who, when she sat on that bus on a white-only seat and refused to move, took power that was instrumental in winning the civil rights battle. Who gave gay people the right to love? Straight people? No, they took that power by coming out and being proud of who they are.”

“In the light of history, do we really expect the system to passively give us our rights as full citizens in a society based on privilege and individualism, when we are seen as less than equal because of an illness? The answer must be NO and will be NO unless we actively fight our own fight. So, like those other campaigners in the women’s civil rights and gay movements, we no longer allow ourselves to be victims, and become victors. The question is not ‘to do or not to do’, the real question is when do we do? The answer is now.”

The DEEP network feels it can play an important role in this broadening out and normalisation of grass-roots activism – or ‘Do-ism’. Ron gives a nice example of how peers in the network support each other across the UK to take action on issues that affect them. When the local evening bus to Port of Ness is threatened with closure, Howard Gordon (from Sheffield) sends Ron information on his rights under the UNCRPD:

“Howard is focusing on the right to a life. He gives me confidence in preparing a letter and challenging them. That’s what peer work is. Most people forget we have had a life. We know how to do teamwork, as well as be mavericks. You can’t achieve it on your own, that’s one of the hardest lessons. That’s what makes activists out of someone. That’s when you know you have allies as well as peers. I’ve not lost my skills and my ability to do an analysis of what I’m facing and to come up with a solution.”

As the third decade of the 21st century approaches, DEEP in Scotland enters a new phase. The Life Changes Trust’s funding finishes in October 2019 and coordinator Paul Thomas retires. However, the National Lottery Community Fund funds DEEP for four more years (until September 2023) as part of the next phase, to be known as ‘Dementia Voices’.

Ron sees DEEP as *“becoming a movement bit by bit, not a network”*. People with dementia could be leading the Gatherings and taking more control. In September 2019, several activists – and a number of supporters – get together at a seminal meeting in Stornoway, to discuss the way forward for DEEP in Scotland. There is laughter, cake, craftwork, singing... but then they ask all the people who are not living with dementia to leave the room, and they come up with their ideas.

They want to challenge the status quo where one dementia organisation dominates the narrative – effectively excluding most DEEP members, individual unaffiliated people with dementia, and those not in the Central Belt. They want Scottish groups in the DEEP network to find a model which could enable them collectively to have greater influence, and allow them to choose their future and greater autonomy while retaining DEEP support and connections. They want to test out how technology can help to connect and involve more members, and explore how those who are less tech-savvy can access support e.g. to join ZOOM meetings.

They also want to ask the Cross-Party Parliamentary Group for funding to enable people with dementia who are not in SDWG, and/or who live in rural areas i.e. beyond the Central Belt, to participate in their meetings (framing it as an access/discrimination issue). As Agnes puts it: *“We’ve earned the right to be invited. How can we make them understand there are lots of voices around Scotland?”*

Agnes summarises the change that is being asked for:

“It’s the right time, it’s time we stand up and take the lead in Scotland. It’s not for the faint-hearted. But we’re not alone, we’ve got allies who will make us strong. Scottish voices need to be much more inclusive. We’ve got the passion. We’re older, but we’ve still got the energy to make it happen.”

Summary

DEEP in Scotland connects many groups across the whole of the country, including the remoter parts of the Highlands and Islands. The groups are all very different, but they share a sense of belonging and connection which is highly valued by those involved. Many members identify important outcomes in terms of their own sense of wellbeing and belonging. The DEEP Gatherings enable them to meet physically as often as possible, another aspect of DEEP which is much prized. They also benefit from cross-fertilisation with other groups across the UK – and vice versa of course.

As time goes on, many more voices are being heard, and in many different ways. Another important outcome is the number and range of projects which the groups themselves come up with (often funded through small DEEP grants) and which are increasingly self-led.

In the next chapter we discuss how people with dementia in Scotland have, over the past twenty years, become increasingly involved in research – to the extent of leading their own projects on the things that matter most to them.

5. Involvement in research

It is only relatively recently that people with dementia have been included in research studies, even as research participants. It has probably been assumed that they do not have the capacity to consent... and/or that they do not have anything useful to say! Consequently, carers or professionals have often been asked to act as their proxies.

So there will be very few examples of people with dementia advising on, or carrying out their own, research before the turn of the century. In this respect, people with dementia have been lagging behind many others in the disability movement. Heather Wilkinson, who comes to Stirling University in 1998 from a background of care and research with people with learning disabilities, recalls that she *“came with certain expectations of involvement [and] was very surprised in the early years that this wasn't the case for people with dementia... then they all went through a massive learning curve.”*

Advisory roles

‘Patient and public involvement’ (PPI) is now a prerequisite for most large research/academic funding bodies. This means there is an imperative for universities and academics to ask people with dementia to get involved in their research processes from an early stage. This is organised with varying degrees of intention and success, although good practice is beginning to emerge, including partnership building between academics and people with dementia, consideration of accessibility issues, financial recompense and appropriate feedback cycles³⁶.

People with dementia often express enjoyment and satisfaction in having dedicated roles to influence and shape research agendas, and to work in a direct way with academic researchers.

³⁶ Litherland, R. et al (2018) Reflections on PPI from the ‘Action on Living Well: Asking You’ advisory network of people with dementia and carers as part of the IDEAL study. *Dementia*. 17(8): 1035-1044.

They say they feel valued and more empowered – and hopefully an increased confidence also has impacts in their day to day lives. One example is the ‘Dementia Enabled National Symbols’ project³⁷, which involves the Positive Dementia Group (Aberdeen) and CEARTAS (East Dunbartonshire). They are assessing the strengths and weaknesses of commonly used universal symbols, identifying domains where symbols are a priority for people with dementia, and exploring and identifying any ‘missing’ symbols that would be helpful for people with dementia and the wider community. Ron Coleman, one of the contributors, testifies:

“I loved working... on the Symbols project. It made me feel I was getting an opportunity to make some changes. And I’ve become friends with the people I met on ZOOM.”

These developments also bring people with dementia more in line with the wider disability field, where increasingly people who use services, rather than professionals, have control over the whole research process.

So in the past twenty years it becomes increasingly common for researchers to invite people with dementia to act as guides to the research process, often as members of project advisory groups. Dementia activists in Scotland have been involved in numerous research projects as advisors, either representing SDWG or as individuals. An early example of this is a project on the topic of telling the truth about diagnosis³⁸. As soon as Heather Wilkinson – one of the researchers – connects with James McKillop through this project, it becomes clear to her that people with dementia really want to be heard. This connection leads directly to the formation of the SDWG (see chapter 3). James himself becomes involved in Edinburgh University’s CRFR (Centre for Research on Families and Relationships) when Heather moves there – and later with the new centre ECRED (Edinburgh Centre for Research on the Experience of Dementia).

37 Life Changes Trust <https://bit.ly/2Yp19FE>

38 Tell me the Truth Pratt, R and Wilkinson, H. (2001) Mental Health Foundation <http://bit.ly/332UoKg>

Another example is a study³⁹ into the effectiveness of Talking Mats for people with dementia – both James McKillop and Ross Campbell are on the JRF Project Advisory Group. This important work opens up a new method which has the potential to enable people at a more advanced stage of dementia to voice their views.

Over the years, Agnes Houston advises on many projects (including JRF's UK-wide programme 'A Better Life'⁴⁰), is involved in research with HammondCare, and becomes an Exchange Fellow with ECRED advising on various projects, including a major project about post-diagnostic courses. Agnes reflects:

"I like being involved in ECRED. I go there monthly and I find it good to hear the young PhD brains. It lifts me up."

Principles for involving people with dementia in research

By the start of the new century, Heather Wilkinson and James McKillop are thinking together about whether and how people with dementia should be more involved in the research process. In her book published in 2001⁴¹, Heather and a number of other researchers share what they are learning. The book focuses on three key questions: Should we be including people with dementia in social research on dementia? Can we include them? What still needs to be done to facilitate work in this area?

39 Using 'Talking Mats' to help people with dementia to communicate' Murphy, J. et al (2007) JRF <https://bit.ly/2Aqzz20>

40 A Better Life: valuing our later years Blood, I. (2013) JRF <https://bit.ly/3fl5yQV>

41 The Perspectives of People with Dementia: Research Methods and Motivations Wilkinson, H. (2001) JKP

James has his own chapter in the book – an important step forward in itself. As Heather explains:

“Not only do these chapters illustrate yet another way in which people with dementia can be included, they present powerful and articulate examples of the necessity and importance of ensuring such inclusion.”

As things begin to change, it becomes clear that researchers need to understand better what involvement really means and how it can best be supported. In 2004, James and Heather publish a joint paper for researchers on interviewing people with dementia.⁴²

We have already described, in chapters 3 and 4, many of the research projects in which the SDWG is involved. As more and more requests come in, they set up a research sub-group in August 2013, made of around 14 members. The sub-group considers each request, and also ensures that people with dementia are meaningfully involved in research (James says that he and the others sometimes said no *“if we felt we were being used.”*) In the following months, supported by four Scottish academics – Sarah Keyes, Nick Jenkins, Dot Weaks and Liz Taylor – the sub-group also develops a set of six core principles for involving people with dementia in research⁴³. This document proves very influential.

Heather points out that there have been, and still are, many barriers to involvement in research. These include the ethics approval system, which can come across as complex, paternalistic and medicalised. However, she reports a recent *“significant shift”* – the Chief Scientific Officer has funded work on how well ethics committees understand incapacity, and the ‘Adults with Incapacity Committee A’ have now invited a researcher who has explored ethics and capacity for people with dementia onto the committee.

42 Wilkinson H, McKillop J (2004) ‘Make it easy on yourself! Advice to researchers from someone with dementia on being interviewed’. *Dementia: The International Journal of Social Research* **3(2)**: 117-25, DOI: 10.1177/1471301204042332.

43 SDWG webpage <http://bit.ly/2LLE5f0>

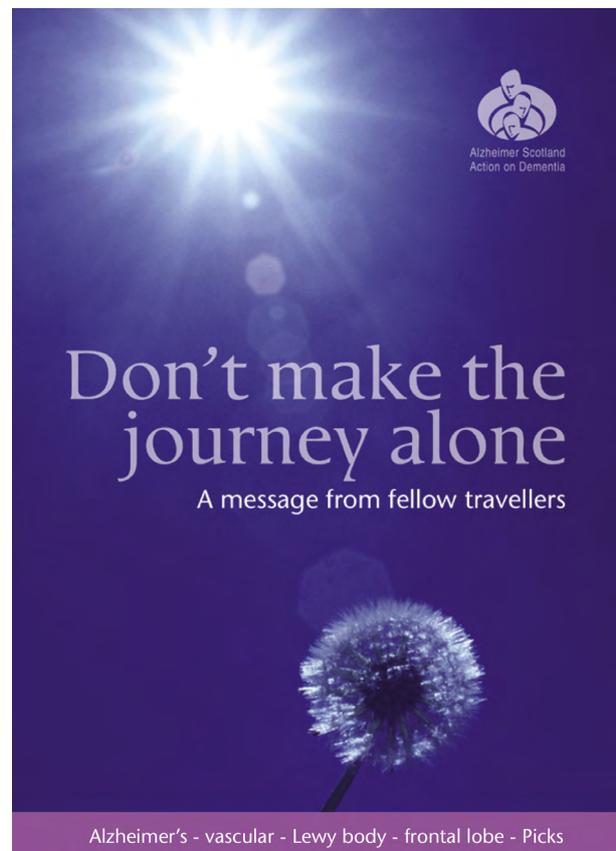
Peer-to-peer projects

One remarkable innovation since the turn of the century has been the development of a suite of peer-to-peer resources, researched and produced by people with dementia for people with dementia.

One of the first is 'Don't Make the Journey Alone – a message from fellow travelers'. This is James McKillop's brainchild, and he, alongside two other SDWG members, Pat and Ian, work on its research and production over many months during 2001. They are supported by Jenny Douglas and Marilyn Dunbar from Glasgow Younger Persons Support Service. James recalls:

“We worked from a very large roll of paper, going round the room we happened to be in at the time. Adding bits each week.”

The booklet is eventually completed, and is published by Alzheimer Scotland in June 2003⁴⁴. James recalls a launch at the Eastbank Centre, Glasgow, attended by the late Jim Jackson and John Killick. This resource could well be the first publication in the world by a group of people with dementia – Jenny describes it as *“ground-breaking.”* The booklet is no longer on the SDWG website, but has been replaced by a newer information sheet on post-diagnosis⁴⁵.



'Don't Make the Journey Alone' booklet

44 Don't Make the Journey Alone – a message from fellow travelers (2003) Alzheimer Scotland
<http://bit.ly/2LMzIQU>

45 <http://bit.ly/31PhIep>

In 2008, a new booklet is published: 'Facing dementia – how to live well with your diagnosis'⁴⁶. It is co-written by Kate Fearnley of Alzheimer Scotland, with many SDWG members⁴⁷. Another early piece of research led by a person with dementia, Lynda Hogg, is about relationships⁴⁸. Diagnosed with dementia in 2006, Lynda becomes a SDWG and ADI Board member. Her study – supported by Sue Venn from the University of Surrey, and staff at SDWG and Alzheimer Scotland – is based on her interviews with eight men and two women.

So far, the projects have been very much co-produced, with either researchers or group facilitators very involved. James McKillop goes a step further and builds a project out of his own experience of having to give up driving. This has been a life-changing issue for him, as he movingly describes in a blog for Alzheimer Europe⁴⁹:

“It is a bitter blow losing your licence and you have no idea just how crippling it is, until it happens to you. Your mobility is turned upside down. Your freedom to get up and go at a moment’s notice is gone. You lose your independence. You may have to rely on others to get about. You feel a nuisance if you ask and are reluctant to bother busy people. You may feel infantilised, taken about like a toddler. Some places are off bus routes and the beaten track and you can no longer travel there, unless someone has the time to take you. It can be humiliating and demoralizing. If lucky, you go in their chosen time, which may not coincide with your chosen time. For example I might want to go for a dawn photograph but the driver is only free in the evening. You are at their mercy...”

46 2008, NHS Scotland – reference not available

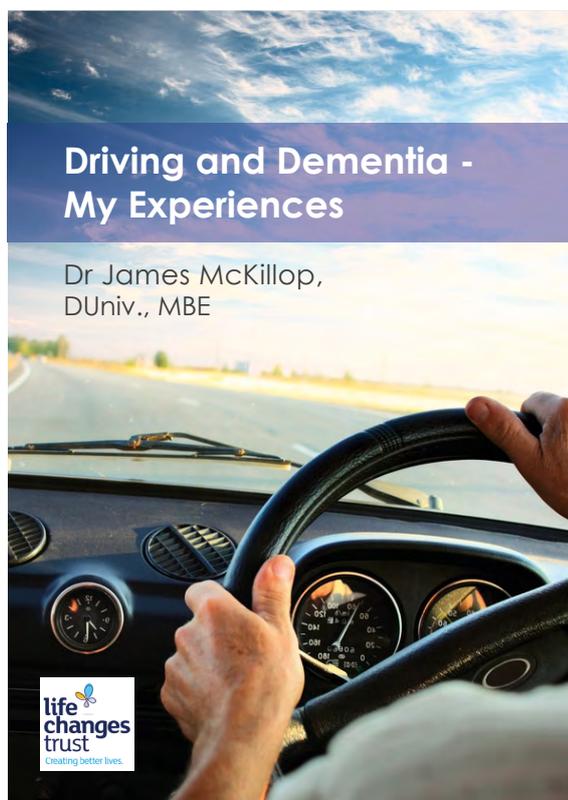
47 including Ross Campbell, Ted Cleland, Lynda Hogg, Agnes Houston, Nancy McAdam, Margaret McCabe, Pat McGonigal, James McKillop, Edward McLaughlin and David Turner.

48 Dementia: Impact on Relationships (2011) Hogg, L. <http://bit.ly/2LQzb0c>

49 Article for Alzheimer Europe (2012) <http://bit.ly/2VelG96>

“... After all these years it still rankles to be a passenger. I still feel I can drive (apart from big roundabouts) and when I sit in a car, I still “drive”. I watch the road, looking out for potholes, cars entering the main road, scanning for pedestrians, especially children and animals. I am always saying (to other’s annoyance) there is someone in the mirror. I am a terrible front seat passenger and get tired on a journey, as I watch the road like a hawk. My feet get sore with driving. Why both feet? The imaginary clutch and brake! I can anticipate other drivers’ manoeuvres and know when they are going to turn, when not indicating. I feel I can still drive, just give me a chance.”

Instead of wallowing in his frustration about not being able to drive, James turns his experience into something constructive. In 2016, with the support of the Life Changes Trust, he produces his own booklet⁵⁰ about driving, which aims to support others with dementia facing the loss of their license.



'Driving and Dementia' booklet

50 Driving and Dementia: My Experiences McKillop, J. (2016) Life Changes Trust <https://bit.ly/2B0ZTAi>

Meanwhile Agnes is realising that the sensory experiences of people with dementia are very under-researched:

“I was at a conference, one of the worst places for a person with dementia because of the sensory overload, the hype and crowd. There were about 35 of us with dementia and we were all at the back of the room, really quite disturbed, and we were thinking, ‘why in this conference is nobody talking about the sensory issues?’ So I said, ‘we’ll go and find funds and write it ourselves’.”

Encouraged by a Scottish carer, Ann Pascoe, Agnes Houston applies for a Winston Churchill Memorial Trust award – and succeeds:

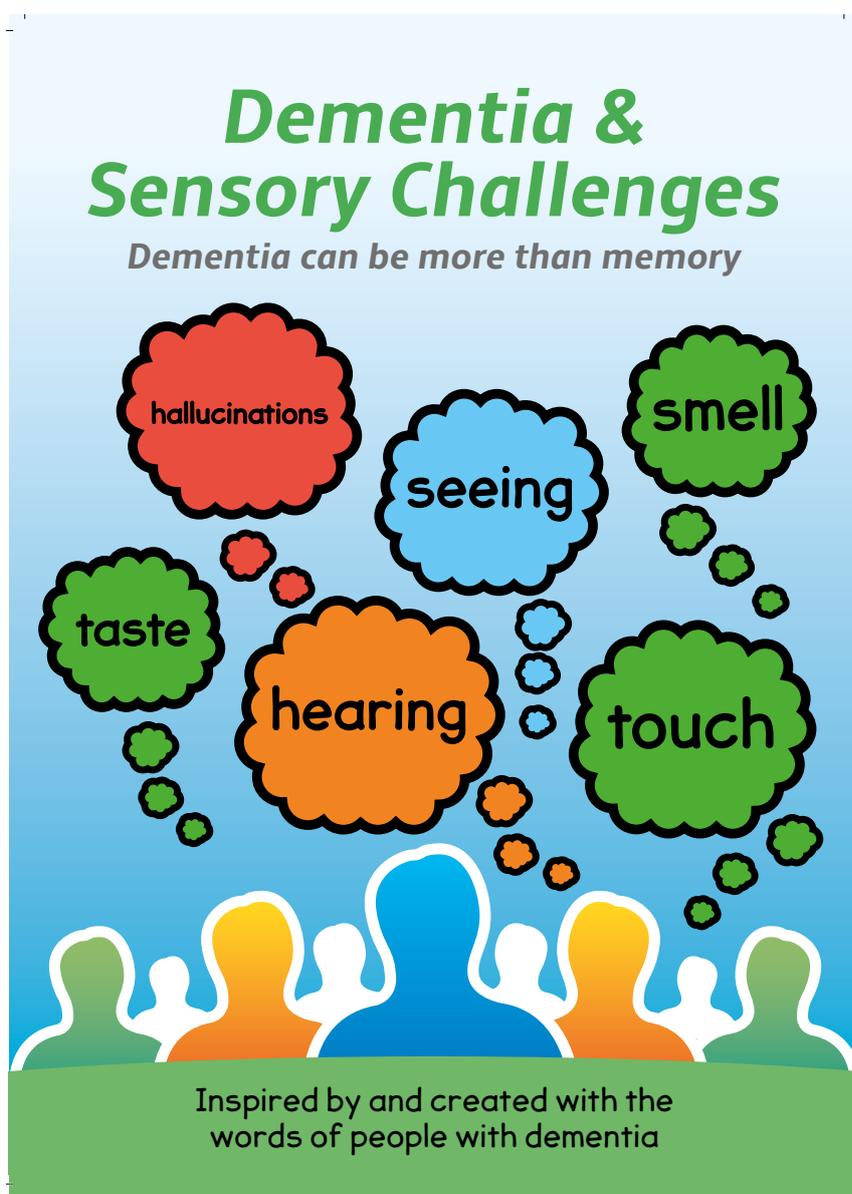
“It was as if I had been given a diagnosis, was assessed cognitively, medication monitored and left to my own devices... Instead, I chose to go on a quest for knowledge to understand what was happening to me. Surely, I was not the only one having these sensory changes? I decided to take dementia out of my world. It led to another journey of me knocking on doors to get help.”

With her daughter Donna, Agnes travels to Ireland and Canada in 2016. When she returns, she develops six case studies that showcase innovation and offer valuable learning to the UK⁵¹. Together with peers from many other countries, she creates a booklet and DVD⁵² which describe some of the impairments and changes that people with dementia experience to each of the five senses, as well as strategies that help.

51 Think Dementia, Think Sensory Houston, A. (2017) WCMT <http://bit.ly/2MknjD3>

52 Dementia & Sensory Challenges: Dementia can be more than memory, Houston, A. (2017) Life Changes Trust <https://bit.ly/3gih8NM>

She then goes on to write a book aimed at practitioners⁵³ with Dr Julie Christie, which is launched by HammondCare in May 2019 at the inaugural International Conference on Palliative Dementia Care (ICPDC) in Belfast. This is the culmination of more than a decade of research by Agnes, driven by her dogged determination not only to bring these issues to wider public and professional attention, but also to teach herself the fundamentals of research practice.



'Sensory Challenges' booklet

53 Talking Sense: Living with sensory changes and dementia Houston, A with Christie, J. (2018) HammondCare <http://bit.ly/336JJy8>

Relationships with, and impact on, academics

It is apparent that academics in the dementia field in Scotland have played a strong role in supporting voice and activism.

Dot Weaks remembers, in the early '90s, a young man with dementia asking her to explain the condition to him:

“I was stumped, and fumbled my way through an explanation. This was pivotal in my development of ensuring people having the right to have a diagnosis.”

This encounter inspires the publication of her study: ‘The Right to Know: Sharing the Diagnosis of Dementia’⁵⁴.

The SDWG is supported right from the start by academics, including Heather Wilkinson, Liz Taylor and Dot Weaks. As Mary Marshall points out:

“She [Heather] was hugely influential, although she would be too modest to tell you herself.”

Not only do activists get increasingly involved in research about dementia, but their activism itself becomes the focus of several research projects. Ruth Bartlett is one academic who is intrigued by what is happening:

“My interest developed when I was awarded a first ESRC grant around 2007. I was aware of the SDWG as the only campaign group led by people with dementia. And that’s very unique. I observed that activism was a growing phenomenon – so I explored why people get involved in campaigning and what are the effects on people of doing this...”

⁵⁴ The Right to Know: Sharing the diagnosis of dementia Fearnley, K., McLennan, J. and Weaks, D. (1997). Alzheimer Scotland and the Mental Health Foundation.

“... As a sociologist and a nurse it seemed a very significant change and development in terms of what people with dementia were doing. Yet in the research field no one was writing about it – it was all focused on care and care homes. I thought, we need to look at this and find out what’s going on. I recruited several people from SDWG, because so many fitted my inclusion criteria and they were all in one place (mainly Glasgow). So it was a way to access people... It really felt like cultural politics, which really excites and stimulates me.”

Ruth analyses the development of dementia activism in several articles⁵⁵
⁵⁶ ⁵⁷ published between 2010 and 2014. As part of her work, she arranges two residential meet-ups with people with dementia (including Agnes and Nancy) in the Lake District. Ruth reflects:

“It was a very equalising experience. We shared the same space, ate and cooked together. Agnes did yoga in the morning.”

This leads to an article⁵⁸ about the importance of ‘privileging place’ – *“of where, as well as how”* – in which Ruth concludes that *“by privileging place, a more equitable, productive, healthier, and respectful way of involving people with dementia as collaborators in research dissemination could be realised.”*

55 Campaigning for Social Change: Understanding the motives and experiences of people with dementia: A brief report of the findings. Bartlett, R. (2010) Unpublished report, University of Bradford

56 The emergent modes of dementia activism. Bartlett R. Ageing Soc. 2014a;34(4):623–44.

57 Citizenship in action: the lived experiences of citizens with dementia who campaign for social change. Bartlett R. Disability and Society. 2014b;29(8):1291–304.)

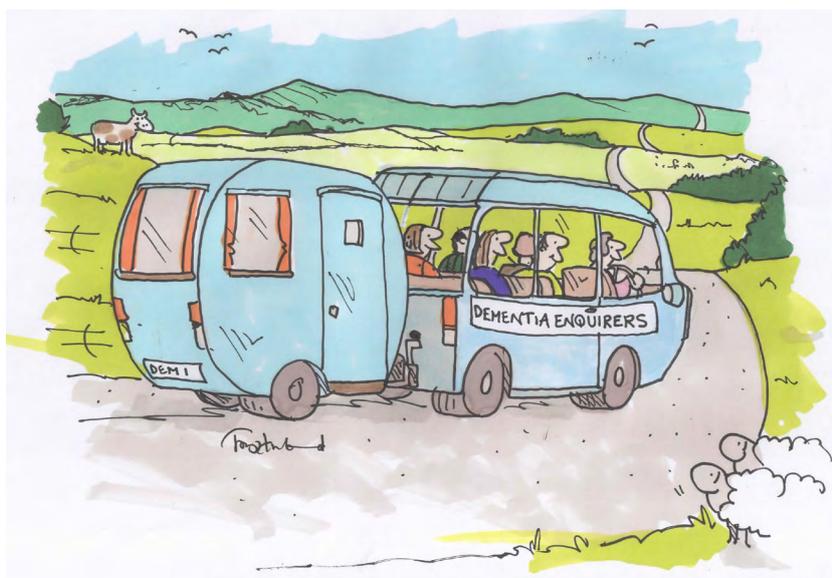
58 Bartlett, R, Hick, C., Houston, A., Gardiner, L and Wallace, D. (2015) Privileging Place: Reflections in Involving People with dementia in research. Dementia: International Journal of Social Research and Practice. 14, 6, 788-799.

Moving into the driving seat

Building on some of the early notable examples already cited, more people with dementia are starting to take on the role of researchers themselves. One of the stated priorities emerging from the Scottish DEEP Gatherings is ‘to lead and initiate our own research’. The DEEP network provides the potential and capacity for this new approach to research delivery, which is led by people with dementia – who plan and undertake the research, and interpret the findings.

In 2018, the Alumni group starts work on a project about the concept of ‘self-management’. The members select their own research question, and collect and analyse data to produce conclusions. Groups in the DEEP network from many parts of Scotland – and beyond – contribute to the project, the final result being the booklet ‘Dementia and Self-Management’⁵⁹, published on the Life Changes Trust website. It’s worth noting that it has been 16 years or so since the SDWG started work on its first research project, ‘Don’t Make the Journey Alone’.

The same year, 2018, sees the launch of another important initiative – Dementia Enquirers⁶⁰. This UK-wide project, funded by the National Lottery Community Fund, aims to equip the DEEP network to be more confident and capable of defining, planning, delivering, evaluating and demonstrating the outputs and outcomes from their own research. Professional researchers may be brought in as advisors or have specified roles within the project – but people with dementia will be ‘in the driving seat.’



59 <https://bit.ly/2TAzcJp>

60 <http://bit.ly/2oXYtk0>

Agnes Houston joins the Dementia Enquirers as one of its six ‘Pioneers’, the project’s Research Interest Group, which is made up entirely of people living with dementia. They will be heavily involved in providing oversight throughout the project and in helping to define what a new research involvement framework looks like. Working with allied researchers and evaluators, they are also developing resources to help selected DEEP groups to ‘think research’. This includes running webinars and seminars, working to produce guidance and templates, and critically considering the step by step approaches of conducting research. They will make sure all processes are accessible to people with dementia and fit with DEEP guidance and expectations.

Agnes reflects that she likes Dementia Enquirers *“because we’re in charge, we’re in control.”* More of her thoughts about Dementia Enquirers can be heard in several of her Dementia Diaries^{61 62 63}.

In Year 1 of Dementia Enquirers, (from summer 2019), a first cohort of DEEP groups submit applications for an action research grant. One of the ten successful bids comes from DEEP Ness, a new group based at the northernmost end of the Isle of Lewis, which is set up by Ron Coleman. DEEP Ness is now being connected with other Dementia Enquirers research sites across the UK through regular newsletters, webinars and events. And the group has already been helped to make links with academics at the Universities of Stirling and Maryland, USA. Ron (see below) reflects:

“Dementia Enquirers allows us to set the question, but also to destroy the mystery about research. When we do our own, we discover the [research] language is rubbish... it’s a power discourse.”

61 <http://bit.ly/2kMYQMO>

62 <http://bit.ly/2khdmvW>

63 <http://bit.ly/2kC3m0I>

Summary

In the past twenty years, the involvement of people with dementia in research has moved relatively quickly through a number of phases:

- being ignored, being excluded, or being spoken for/about by proxies
- being involved as research subjects
- contributing to the understanding of researchers as to how to do research well: *“From a University perspective, we’ve had to learn to work in different ways – it’s not just an academic agenda anymore.”* (Heather Wilkinson)
- being involved in advisory groups
- being employed as co-researchers, or as fellows of research bodies
- designing and leading their own research projects on their own topics

This has not of course been a completely linear progression. And indeed, people with dementia are still regularly omitted from research about wider issues, such as later life or chronic disability – or even from non-health and social care related research.

So what will happen next? Will we see people with dementia commissioning their own projects as part of programmes they have designed? Will they set up their own ethics committees? Will they be published as a matter of course in peer-reviewed journals, and present on their own work at academic conferences?

In the next chapter we look at how creative approaches can help many more people to have their voices heard.

6. Creativity and voice

For many people with dementia, finding and using their ‘voice’ (in the broadest sense) is much easier said than done. The organic process going on in the brain means that being able to keep up with a swift-moving discussion; knowing when and how to ‘chip in’; articulating a point clearly; remembering the right words and phrases, and the important point you wanted to make two minutes ago; and sometimes losing vocal capacity almost completely... all can be daunting in the extreme, and explain to a great extent why so many are not heard.

However, the story of activism in Scotland is rich with examples that not only help compensate for these difficulties, but also build on individual strengths to ensure views are still being expressed and voices heard. Below we describe some amazing creative collaborations between artists, activists, academics – and funders.

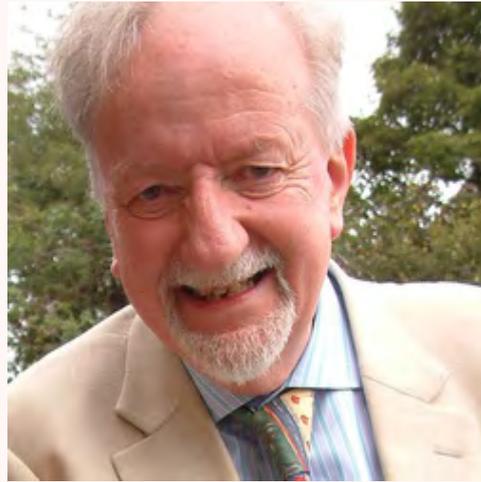
Poetry and ‘playfulness’

John Killick is one of the pioneers of creative methods to hear the voice of people with dementia – methods that are fun.

John Killick

In an interview for Eldercare⁶⁴ John explains his approach – which is worth quoting at length:

“When I gave up teaching full-time I began doing writing residencies, first in a women’s prison and then in a hospice, listening to the lives of residents and writing down their stories. A year in, working for a private healthcare company and they asked whether I would do this with people living with dementia. At this time, 25



years ago, dementia care was a little discussed topic... There was nothing really in the papers about dementia or on the TV and most people didn’t know anything about it. The healthcare company sent me to a care home where many of the residents had dementia and the manager said I would get ‘nothing out of anyone here’. But three months in, I had a meeting with the company, who decided I was onto something... Not everything is a problem to be solved... and people with dementia haven’t lost their sense of humour or fun. They made me a writer in residence and, along with a grant from the Arts Council of Great Britain, I worked there for ten years with those with dementia, writing their words down and sharing them back with them. Word got out about the work I was doing, and people started writing articles about it and it was even on the radio...”

⁶⁴ <http://bit.ly/2IsrF9T> undated

Subsequently, as writer in residence at the Stirling DSDC between 1999 and 2004, John conducts work exploring communication with people with dementia through a wide variety of arts activities. Let's go back to his interview:

“The common theme [of my work] is communication – it has underlined everything I have written, from the first book to the latest. With dementia, communication is low on the priority list for many people – at the bottom, even. In care home after care home you see it; people often getting little more than two and a half minutes a day to speak with another person. Most of the time, care in such circumstances is very task-oriented. People in their own homes have much more of a chance to communicate with family carers, but even then, those carers are often at a loss as to how to do it, so they need a bit of help.”

John recalls that Agnes Houston once requests his help to write a poem. They spend a day together and Agnes says she'd like it to portray the real feelings of living with dementia. John takes it away and works on 'tidying it up' before sending it back. A while later he receives some blunt feedback from Agnes: *“Rubbish!”* John recounts how she rewrites the poem herself and – in his view – massively improves it... *“getting across the strength of emotion, using a powerful and consistent metaphor.”*

His work teaches us that people need a 'license to be free' – a concept he and Agnes develop together in a further joint collaboration (also involving psychologist Kate Allan)⁶⁵. That's what he gives Agnes by writing a 'rubbish' poem about her:

“It's that 'license to be free' that has further emboldened so many people with dementia to ask questions and to challenge the status quo.”

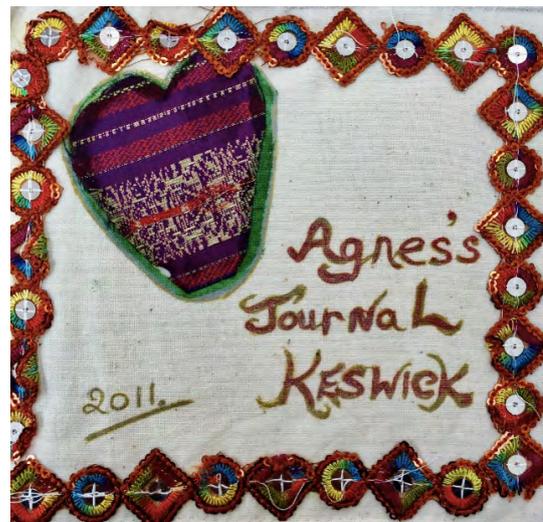
Like many of the activists' supporters and allies, John has learnt that, when you really engage people, and resist imposing any agenda, they can take it a step further themselves.

65 Playfulness and Dementia – a practice guide Killick, J. (2013) London: JKP

Banners

Banners are a classic symbol of activism, protest and a call for change. When the SDWG is formed, James designs a logo of a banner held aloft on a pole, which he envisages *“marching into virgin territory, where no man had ever been before.”* Though he is disappointed that it isn’t produced exactly the way he wants, James feels this banner really represents the essence of activism.

Later, Ruth Bartlett, whose research interests lie in involving people with dementia, citizenship, ageing, disability and inclusive ways of working, comes to work with Scottish activists – including Nancy, James and Agnes (see chapter 5). Ruth works alongside a social scientist, a curator, an installation artist, and research participants using art, specifically textile banners and documentary film, for an exhibition based on original research on dementia activism. Most of the work is developed during a short residency in the Lake District, in spring 2011. This leads to the creation of an exhibition called *No Limits – Reimagining Life with Dementia*, which explores the individual and collective strength of people with dementia. The exhibition tours Bradford, Glasgow and Liverpool, and the film, directed by Anne Milne, is screened at the International Documentary Film Festival in Amsterdam.



Agnes' journal from the Lake District residency

Fine art

When Edward McLaughlin, an internationally esteemed engineer and amateur artist, receives a diagnosis of dementia in 2002, he retreats for a long time into inactivity and depression. But, as he eventually takes up art again, he discovers to his amazement that he now sees the world, and, in particular colours, quite differently. His vibrant portraits contrast markedly with his previous meticulous pencil drawings, and are lauded as a vivid insight into the inner life of someone with dementia⁶⁶.

Edward sums up this transformation like this:

“Dementia: you could see it as a gift or a curse. To me it’s a gift. It’s opened up a wonderful world to me.”

His work is widely exhibited over a number of years, including in Ayr, at the Iris Murdoch building in Stirling, and in Edinburgh at the Festival Theatre and at the 2019 Festival. Edward also speaks at the ‘Shifting Paradigms for Dementia’ seminar series in May 2018, alongside film-maker Christeen Winford and Jennifer Souter.^{67 68}

Ann Pascoe, a Helmsdale-based community activist, also finds art to be a great way for her husband Andrew, who has dementia, to express deep emotions. She recounts:

“Andrew was a brilliant photographer, and at one point he made a painting of one of his photos. I told him I thought it was rubbish and to stick to the camera. When I discovered that creativity is something that remains intact for many people with dementia, I tried to get him to start painting again. The only way I could was to do it with him...”

⁶⁶ Blog for DSDC website. Henriette Laidlaw (Dec 2016) <http://bit.ly/2MhrWxt>

⁶⁷ YouTube <http://bit.ly/2Optnwy>

⁶⁸ YouTube <http://bit.ly/2AHwys>

“... He painted a picture of one of our favourite photos from Goa – an idyllic beach scene. It was all dark and black. He claimed it was at night. When I asked where the moon and stars might be, he said ‘there are no moon and stars in my world’... It was a real sign of his mood. He made the same painting several times subsequently, and each time it got brighter and brighter. It’s now used as a case study. Andrew is now regarded as an artist, not as a man with dementia, and that is great. So we both benefitted from that learning.”

Film and video installations

Many films have been made starring Scottish dementia activists. Anne Milne makes a film of Agnes and Nancy talking about their friendship⁶⁹, which is shown at the Scottish Mental Health Film Festival Edinburgh 2011. Agnes also features strongly in ‘The Power of Words’, a JRF film⁷⁰ made in 2015 to highlight the risks of negative media coverage and thoughtless language (and which echoes James’ much earlier work on negative terminology). In the film Agnes declares:

“Since my diagnosis of dementia, words hurt more than they did before. It’s like prodding a wound. They should choose their words with care!”

She adds:

“Words can empower people to live well.”

69 <http://bit.ly/2IopQeg> Milne, A., Bartlett, R. and Hicks, C. (2011)

70 <https://bit.ly/3cQK2S7>

The Life Changes Trust awards Edward McLaughlin and Christeen Winford a grant to convert their short film ‘Things I like about Dementia’ – in which Edward talks about his life, ideas and works – into a video installation.⁷¹ This can be displayed at exhibitions, and provides an effective, and non-traditional, way of amplifying the voices of people with dementia. The first showing of this exhibition takes place in June 2017 at the Festival Theatre Studio in Edinburgh. The funding is also used to create another video installation, capturing reactions to a series of pictures Edward calls ‘The Fog’, which sparks much discussion. The video features testimonies of other people diagnosed with dementia, and offers shared experiences, stories of hope and coping strategies. The film is intended to be shown alongside Edward’s artwork to help create a deeper understanding of the condition and those who live with it. It is yet another fantastic example of using creative methods to enable us to hear the voices of more people with dementia.

Photography

James McKillop is an enthusiastic amateur photographer. When artwork made by the Candlelight group is displayed at the Alzheimer Scotland conference in June 2001 in Glasgow, it includes six of his photos. In the same year, James produces a calendar for people with dementia – again featuring his photography. James recalls rather wistfully: *“We had lots of ideas for other things, but no money.”*

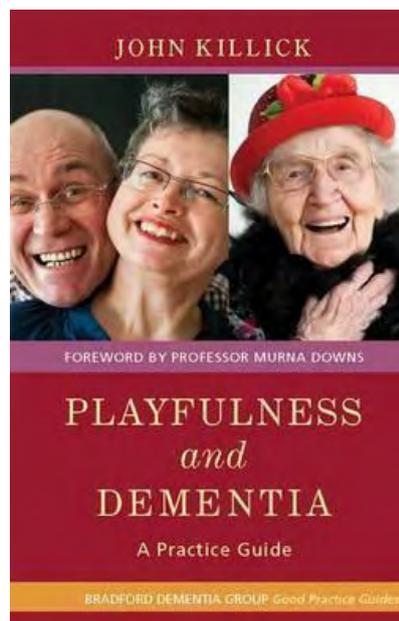
In the coming years however, James is delighted that Alzheimer Scotland often use his photos for leaflets, Christmas cards etc. Some are also used for one of John Killick’s books, and others are displayed at the Alzheimer Scotland main office. This is a great example of activists playing to their own strengths, using their talents and interests to convey their messages.

⁷¹ <https://bit.ly/3cUZ4X0>

Drama

Two more examples – this time of people with dementia taking ownership of the medium of drama – offer another indicator of the ‘license to be free’. The first is from 2010, and the second from 2019.

In 2010, John Killick organises a series of ‘Funshops’ across Scotland – in Glasgow, Dundee, Aberdeen, Forfar and Stonehaven. The idea is for a brief drama workshop for people with dementia in which the emphasis is on humour and companionship. But Agnes and her peers are less keen on improvisation and say they want to write their own plays. The ideas for these come from members of the group and John helps to shape the finished pieces, creating half a dozen humorous ‘Dementia Monologues’⁷² which they then perform at the Scottish Care Congress.



72 Playfulness and Dementia – a practice guide Killick, J. (2013) London: JKP

Nancy McAdam's 'Dementia Monologue'

Everything in the Garden

'So what's wrong with me, doctor?' I asked. 'You lack vitamins in your body,' he said. 'Eventually your mind will be affected. Like leaves falling from a plant, your mental faculties will shrivel and fail.'

I was alarmed. 'What can I do to ensure some more fruitful years?' I asked. 'I prescribe Baby Bio at your root twice daily. Then your stem will be strengthened and a green old age will be assured.'

Well I set about it at once. I swept all the decaying matter from my life, planted out my faculties in neat rows, and mulched them in vigorously. I feed them faithfully night and morning, prune them regularly, and give any slugs that dare to come near short shrift.

And now you see me in my harvest time. My branches are overloaded with fruit. Here, pick one, have one, there's more than I can eat. All that discipline, that regular effort, has paid off. I am self-sufficient. I dine on my own produce.

I hardly dare consider the consequences if I had lost the plot, and let it be overtaken with weeds and thistles. My simple message to everyone is 'Grow Your Own!'

In the second example, and nearly a decade later, the Stornoway arts centre, An Lanntair, premieres a new play written and produced by Isle of Lewis resident and activist Ron Coleman. This starts as an installation, but Jon Macleod at An Lanntair encourages Ron to turn it into a full play. Funded by DEEP and An Lanntair's Cialanas Project (see below), the play 'Caught in this Moment of Time' *"delves into family relationships, personal emotions and imagines the future of Artificial Intelligence. Gritty at times, exploring the injustice and pain of facing the future with dementia, Ron's play is ultimately hopeful, and features poetry, live dance, folk singing, and a local waulking song. By exploring what it is to be a machine, we discover what it is to be human..."*⁷³

The play receives high acclaim when it is first performed in September 2019. Ron is now planning a tour to start a new conversation about dementia, and hopes to perform it at Edinburgh Fringe Festival 2021.



Ron Coleman's play, with his wife Karen Taylor as Alexa

73 Programme 'Caught in this Moment of Time'

Traditional arts in remote places

Cianalas is a Gaelic word meaning ‘a sense of belonging’ – and it is the name of a pioneering initiative (formerly called Arora) on the remote Isle of Lewis. The programme upholds the rights of people living with dementia and unpaid carers/care partners to be included, involved and to make valuable contributions to the community together. The numerous and very innovative *Cianalas* projects include an intergenerational photography project, quilt-making, vinyl murals, a ceilidh trail across the islands, Memory Boxes, film tablets and traditional storytelling.



Boat mural, Lewis

Over to the East coast, another creative project also involves quilt-making. Evanton Community Woodlands near Inverness supports couples who are living with dementia to produce Memory Quilts in the woodland cabin. People's stories are shared, drawn, and distilled into images, which are then sewn and embroidered onto quilts. Ian Mowat's quilt features his sheep and his sheepdog Glen, a key part of his identity. Ian's wife Annik reflects:

“The quilt encouraged Ian to start talking and get involved. Before he was sitting isolated – but afterwards he became animated and told us his story. It was like day and night.”



A memory quilt, with Annik Mowat and Lizzie McDougall

Summary

Since the turn of the century, Scotland's activists, researchers and creative innovators have found many ways to collaborate in order to enable the voices of people with dementia to be heard loud and clear. From poetry to fine art, film and video to photography, quilt-making to bird sculptures, plays to banners... the list is very impressive.

But, although we should note the contribution of forward-thinking academics in this sphere, the contribution of creative approaches has not only been in their use as research methodology, but in enabling those whose voices are not heard to have them heard.

Is this activism? Well, maybe not if we see activism only as campaigning, marching, networking with politicians, using the media, working on strategies and charters... But, in a broader sense, surely activism means finding a way to express our views and experiences in a medium that suits us, and that has the potential to influence the outside world? These creative approaches are enabling many more voices of people with dementia to be heard in Scotland in recent years. Do they not effectively represent the 'license to be free' that Agnes, James and others tell us they seek? Is it not their activism and their calls for recognition that have got them to this place, and have led to all these opportunities for self-expression?

In the next chapter we move beyond Scotland to consider the impact of Scottish activism on the wider world, and vice versa.

7. Scotland and the wider world

For many years, Scottish dementia activists have been making their mark around the world. Connections have been forged at international conferences, through study tours, personal invitations, and, more recently, virtual meetings, usually using the ZOOM video-conferencing platform. In this chapter we look at some of the most prominent areas of influence.

Impact case study 2

The impact of Scotland on Japan

Scotland, and the Scottish user movement, has arguably had its greatest influence on a country that is over 5,000 miles away and which has a very different culture – Japan.

It is in 2004 that Kyoto first hosts the ADI conference. 16 people with dementia from Japan participate, plus five from overseas – including Christine Bryden from Australia, Peter Ashley from England and Doreen Cairns from Scotland. But Japan really only starts to connect with Scottish activists through Kumiko Magome, a well-respected translator and dementia advocate, and her husband Yuji Kawamura, a director for Japan's NHK television. By 2010, Kumiko has already translated a book by Christine (and another by her 'spiritual guide' Professor Elizabeth McKinlay, on spiritual reminiscence method, that includes a lot of quotes by Christine). Kumiko asks Christine what she knows about dementia activism. She recalls:

“[Christine] said I would do better to go to Scotland than Australia, because there's a group there growing, up to about 125 people. I couldn't believe it. We decided to research Scotland. But the earthquake in 2011 stopped things for a couple of years.”

The first actual contact between Alzheimer Scotland and Kumiko happens at the ADI conference in Taipei (2013) when she meets Jim Pearson (their Director of Policy & Research):

“[I noticed] a tall blonde Scottish man, left in an almost empty tearoom area, quietly sipping his tea. We started talking. I understood him about 80%! He gave me a USB stick containing documents about the Scottish Five Pillars model, the National Strategy and their guaranteed post diagnostic support.”

Kumiko becomes very interested in the work of the SDWG, and she shares the documents with her partner, Yuji. Intrigued, he decides to go to the UK in December the same year. A very positive visit, including discussions with Jim Pearson and SDWG members, especially James McKillop and Agnes Houston, leads to Yuji producing two TV programmes about Scotland, which are aired in Japan in September 2014. The first, about Scottish Dementia Link Workers, features on prime-time NHK news, and receives substantial attention, especially from professionals. The second, ‘Nothing About Us, Without Us!’ – a documentary about SDWG – has a very big impact indeed as it is on-air the day after the Scottish national referendum when the Japanese people are hearing the country name over and over. It is seen by between two and three million viewers. The films make a big impact in Japan and greatly increase the confidence of emerging activists. Within a few months, three representatives of dementia advocates – Kazuko Fujita, Masahiko Sato and Shigenobu Nakamura – form their own Japan Dementia Working Group (JDWG). They meet the Minister of Health, Labour and Welfare, submit a proposal, and ask the government to give more respect to the perspective of people with dementia in the national strategy. All by January 2015.

James and his wife Maureen are now already well known in Japan from the NHK programmes. The following Autumn (2015), NHK Public Welfare Association invites them to Japan, with Kumiko coordinating the speaking tour. James is the main speaker at two forums, to an audience of 800 in Tokyo, and 400 in Osaka. There is also TV and magazine coverage. James recalls the trip like this:

“They had a huge poster of my face up! Like a popstar. Then I met Tomo [Tomofumi Tanno, another activist] and he was encouraged by me and he came over once or twice [to Scotland, later on]. I loved it... but I didn’t eat the food! They were very impressed by SDWG and surprised. They’ve got their own group now.”

This story is beautifully described in a blog for Alzheimer Disease International (ADI), authored jointly by James and Dr Mayumi Hayashi of King’s College London⁷⁴. It begins:

‘As Glaswegian James McKillop strode towards Arrivals in Tokyo airport last November, he read the customs sign. Had he anything to declare? Yes – he had a positive message of hope and the strong belief in the right to live well for almost 5 million people with dementia in Japan...’

The blog goes on to describe how James shares this message under the heading of ‘A new dawn – people with dementia mapping out their destiny’ at two forums in Tokyo and Osaka. At these forums two founding members of the Japan Dementia Working Group also speak. The blog eloquently highlights some of the direct impacts of Scottish activism in Japan:

“Tomofumi (41 and living with Alzheimer’s Disease) created the ‘Orange Door’ in his hometown of Sendai to provide a welcoming meeting place by and for those living with dementia, offering a listening ear, guidance and a sense of hope. Kazuko (Fujita, 54) launched a local support group ‘Clover’ in her region Totorri, working for and with people with early-onset dementia... Their actions remind us that people with dementia are agents for change and improvement. By cashing in on their lived experience, they are leading the way towards a better life for their peers and a more dementia friendly society by influencing policy.

⁷⁴ Blog (Jan 2016) ADI website <http://bit.ly/30TVPJn>

Kumiko Nagata, a panellist, said that dementia is everybody's business now. In Japan, 1 in 5 will have had direct experience of dementia by 2025. She emphasised the need for meeting people with dementia, if only to hear their voices and aspirations."

With the foundation of the JDWG, people with dementia in Japan quickly start to make demands! In 2015, Japan's Orange Plan is adapted to include 'the perspective of the people with dementia'. JDWG becomes a social corporation in 2017 and holds its first general assembly in June 2018. It soon has around 20 active campaigners.

In April 2017, Kyoto again plays host to the ADI International Conference, attended by 3,000 delegates from over 70 countries. Speakers with dementia from JDWG and others present on their experiences and other topics. The opening ceremony is followed by an introduction to the conference by Tomofumi, who speaks about his journey over ten years since his diagnosis of dementia – from fear and anxiety to his active role as a dementia advocate with the support of Alzheimer associations in Japan and Scotland.

Connections between Scottish and Japanese activists and advocates continue – though the money, health, time and energy needed for physical visits make them few and far between. However, Tomofumi has since visited England and Scotland. Agnes recalls:

"Tomo-san came to visit. I love his smile. I met him in Glasgow and we made a film with Philly in a darkened room, telling about how he was supported at work. Then I used it to show at a big Trade Union event the next week...We still connect by Facebook. But I've never been to Japan, because of illness".

Kumiko Magome reflects on the impact of Scottish dementia activism on Japan and sums it up below:

“Scotland has been a frontrunner of the post-diagnostic system and self-advocacy of people with dementia – these are the two big things that have inspired Japan. We are also still very interested in the human rights-based approach, and in the practice coordinators for people at later stages.”

Kumiko senses the relationship may now be changing – with some Japanese professionals feeling they have learnt enough from Scotland. Although still keen to know more about support for people with dementia and dementia friendly initiatives, she says *“they realise not everything in Scotland is that rosy”*. Nevertheless, the relationship is special and still developing. For example, Health and Global Policy Institution, the Japanese government affiliate organisation, invites dementia professionals from Scotland in March 2019, to foster mutual information exchange.

Scotland and Australia

Another strong relationship has been with Australia. In the early years, some connections are made between Christine Bryden, and activists from Scotland such as Doreen Cairns, James McKillop and others. More recently, one of the crucial links has been with Kate Swaffer. Diagnosed at the age of 49, Kate is a dementia activist who has played a significant role in bringing the rights approach forward at organisations such as the WHO and the UN. Kate has also played a vital role in empowering new dementia advocates globally, inspiring the development of numerous new Dementia Working Groups. She is the co-founder, Chair and CEO of Dementia Alliance International (DAI), a global charity for people living with dementia.

Kate recalls her first encounter with SDWG:

“I didn’t know anything about Scotland’s activism until 2012. Christine Bryden encouraged me to submit abstracts for ADI 2012 [conference] in London. It turned out this was SDWG’s tenth birthday, so in true Scottish form they celebrated. Maybe 20 or 30 of them were there, and we were invited to their birthday party. I found their feistiness really motivating. The SDWG really sent me home to Australia with a bee in my bonnet about setting up a DWG Australia. At that time, we had five consumer advocacy groups – for policy, aboriginal, research etc. – so why haven’t they got a group for people with dementia? I advocated for that... from April 2012 I just did not let up!”

Kate reflects that, when she reads about care in Scotland, she is under the impression that it leads the world. However, when she meets people from Scotland, they tell her this is not necessarily the case.

Another very strong link between Scotland and Australia has been through Agnes Houston and Colm Cunningham.



Kate Swaffer

Colm Cunningham

Originally an A&E nurse/social worker, Colm recalls a *'transformative moment'* in around 1993, when, while visiting the Museum of Scotland, he comes across one of his clients who has dementia. The lady is explaining about Queen Victoria's jewellery to her friend. Everybody stops to listen – it is clear that she is an expert on the subject. Colm has never expected this, and the impact is powerful:



"I listened and I felt terrible, I've never forgotten that. It taught me that I was seeing a problem and not a person. All that I heard [before] was everybody's fears."

Colm moves on to take an MSc in Dementia at Stirling (the first course in the world). Within a few years he is director at HammondCare in New South Wales, and also Conjoint Associate Professor at the University of New South Wales in the School of Public Health and Community Medicine. But Colm retains his links with Scotland in his role as Visiting Fellow in dementia design and practice at the University of Edinburgh.

Colm meets Agnes when he is the deputy director at the Stirling DSDC – he remembers her telling the story of caring for her father as they work together on materials for a project. He invites Agnes to Australia as a keynote speaker at the International Dementia Conference in Sydney in June 2016. Colm recalls: *"That conference... people have never forgotten... There's a legacy left by that."*

While there, Agnes challenges him to set up a design school for people with dementia – a challenge he accepts. A year later, in March 2018, people living with dementia and design experts have a unique opportunity to work together at a new design school in Birmingham, hosted by the HammondCare Dementia Centre.

Agnes goes on to collaborate with HammondCare on a book of practical ideas for people with dementia and carers⁷⁵ and on another about sensory changes in dementia⁷⁶.

In terms of the impact of Scottish activism on Australia, Colm reflects:

“People in Australia talk much more about rights these days. That may well have come from Scotland. The work they were doing on standards in research is directly quoted and referenced here. The guidance on driving [by James McKillop] is also referenced regularly in Australia.”

Scotland, the UK and Europe

While many of the Scottish activists understandably focus their energies on Scotland, some are very engaged across the UK and very much see themselves as part of a UK-wide movement. James recalls speaking at a Royal College of Occupational Therapists conference in the North of England as long ago as June 2004. In subsequent years he, Nancy, Agnes, Ron and others have been involved in many UK wide projects, including Dementia Enquirers, Dementia Diaries, Dementia Adventure, JRF’s ‘A Better Life’ programme... and many more.

Over the years, Scottish activists attend many conferences in Europe, spreading the word and sharing ideas. Venues include Rome, Luxembourg, Oslo, Vienna, Malta, Budapest and Slovenia.

Early in 2012, Alzheimer Europe and its member associations launch the European Working Group of People with Dementia (EWGPWD) – an idea which is first suggested in a letter from James McKillop five years earlier. Alzheimer Europe’s website acknowledges the direct impact of Scottish activism on its own endeavours to put people with dementia closer to the heart of its work:

75 My Home, My Life: Practical ideas for people with dementia and carers (2018) HammondCare <http://bit.ly/2Ioxnd2>

76 Talking Sense: Living with sensory changes and dementia Houston, A with Christie, J.(2019) HammondCare <http://bit.ly/336JJy8>

‘In 2012, inspired by the work that had been done in Scotland, we set up a working group of people living with dementia.’

The first EWGPWD meeting is held in Vienna in October 2012, and the SDWG are invited to address it. They are introduced by Jean Georges, CEO Alzheimer Europe, as a *‘particularly successful example’* of a campaigning group run for and by people with dementia.

SDWG then takes a major role in hosting the important Alzheimer Europe conference in Glasgow 2014 – at which the Glasgow declaration⁷⁷ is launched. The Declaration calls for the creation of a European Dementia Strategy and national strategies in every country in Europe. The signatories also call upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

Agnes Houston serves as Vice Chair of the EWGPWD until 2016. She recalls EWGPWD as *“amazing, a delight.”* Carol Hargreaves is also on the group.

The SDWG’s influence on the foundation and work of EWGPWD is clear. Irene Oldfather also notes that collaborators at Age Platform Europe *“are always very interested in the Charter [of Rights], and look at us with envy.”*

Ruth Bartlett, who is now a Professor in Oslo, reports that the Norwegian government is very influenced by Scotland and involves people with dementia in their Dementia Plan (2015-2020): *“It’s had lots of ripple effects.”*

In addition, the EFID network⁷⁸ (European Foundation of Initiatives in Dementia) brings Scottish activists together with a number of European countries. An Italian project, Rifugio Re Carlo Alberto, spends a holiday exchange with Alzheimer Scotland’s North Lanarkshire project ‘Dementia is Everyone’s Business’, and this leads to reciprocal projects in Slovenia and Slovakia, as well as a new Eastern-Central Europe network.

⁷⁷ Glasgow Declaration <http://bit.ly/2VeLG96>

⁷⁸ <https://www.efid.info/>

Scotland's global presence

It is clear that Scottish dementia activists have played a key role in building relationships with other countries to promote new ideas and mutual learning.

Against quite a bit of opposition, SDWG presses for the involvement of people with dementia on the board of Alzheimer's Disease International (ADI). Eventually Scotland is the first country to have a person with dementia – Lynda Hogg – on the ADI board, in 2003.

Dementia Alliance International (DAI), launched in January 2014, is an independent self-advocacy organisation of people with dementia, which works in partnership with ADI. DAI is set up by eight people diagnosed with dementia, representing three countries (USA, Australia and Canada). Although Scottish activists are not involved in founding DAI, both James and Agnes become actively involved as board members, and Agnes features alongside nine others in a DAI film 'The Many Voices of Dementia'.⁷⁹ In 2019 the DAI awards James the Richard Taylor Memorial Advocates Award. The account of this on their website makes James' global impact very clear⁸⁰:

“James has been a Pioneer dementia advocate, having been diagnosed himself with dementia in the last Century! DAI is indeed honoured and privileged to work and walk beside him, and our members find him a constant inspiration. He motivates us all to keep going, and is always a source of great wisdom and wonderful Scottish humour...”

⁷⁹ YouTube <http://bit.ly/2ALEOXy>

⁸⁰ DAI website (21 Sep 2019) <http://bit.ly/2kHlnL2>

“... Since joining DAI, James has continued his work locally and nationally, as well as being a very active DAI member on occasions representing us internationally, travelling with his dear wife, Maureen. James became a DAI board member some years ago, and continues to co-host the UK peer to peer support group on a Monday morning, which now also meets on Thursdays. Congratulations from us all James. Thank you for all that you have done, and continue to do.”

So what has been Scotland’s impact globally?

It is clear that Scottish dementia activists have played a key role in building relationships with other countries and acting as a channel between them for cross-fertilisation of ideas and mutual learning. They have been willing to travel to the other end of the world and cope with jet-lag, interpreters, strange food and cultural differences with open minds. They have been incredibly generous with their time and their encouragement (and have seldom if ever been paid for their work).

At a European level the SDWG model has been adopted, and SDWG have also influenced developments overseas, particularly in Japan and Australia. Scottish activists have also successfully lobbied to get people with dementia involved in ADI and Alzheimer Europe conferences. Individual activists have made a huge impression on many across the world and no doubt have influenced in ways that can never be fully evidenced. Nick Jenkins reflects that:

“There should be real pride in the shift in rhetoric and how we see dementia globally. The rights-based discourse in the WHO, for example can be threaded right back to Scotland... The G7 [The Group of Seven international intergovernmental economic organization], the WHO [World Health Organisation], the OECD [the Organisation for Economic Co-operation and Development] have all increasingly adopted a rights-based citizenship approach first championed in Scotland.”

And Jenny Douglas reflects:

“SDWG Members have been role models, mentors and inspired peers from Europe and beyond. They (and the carers from NDCAN⁸¹) now play an active role in Alzheimer Europe. There has always been a major Scottish presence at conferences in Europe and beyond... Members were highly regarded and highly active within both Alzheimer Europe and Alzheimer Disease International.”

81 National Dementia Carers Action Network <https://bit.ly/2UzkoLk>

Bringing learning back to Scotland

Travelling so widely has its own costs for the activists (see chapter 8) – but of course the sharing of ideas has not only been one-way. They are strongly motivated to bring back their learning to Scotland, so that it can influence policy and practice. A couple of examples help to illustrate this:

Agnes Houston's Winston Churchill Memorial Trust award (see chapter 6) enables her and her daughter Donna to travel to Ireland and Canada in 2016, pursuing her particular research interest in the sensory impacts of dementia. Agnes visits Accident and Emergency Departments in Dublin, and, in Canada, a wellness health club, Schlegel Villages retirement villages, and three Alzheimer's Societies. On her return, she distils her learning into case studies and a report. Agnes says she is determined to share her findings and recommendations with her contacts and networks:

“This will enable me to have a UK-wide reach. I will also share this report with the individuals and organisations I met through my fellowship in Ireland and Canada. My hope is that this will help to forge new international working relationships that can shape exciting innovation in the UK dementia scene.”

Agnes feels that there is real learning for Scotland from her trip to Canada. In her report⁸² she concludes:

“I feel that in the UK, particularly in Scotland, we must raise awareness of the sensory aspect of dementia and other neurological diagnoses. I was impressed at the multi-disciplinary approach I witnessed in Canada...”

82 Think Dementia, Think Sensory Houston, A. (2017) Winston Churchill Memorial Trust <http://bit.ly/2VgUjQs>

“... Increased collaborative working between ophthalmologists, audiologists and psychologists would provide greater knowledge and information that is currently not available through mainstream dementia care.”

She follows her work up with a number of influencing activities, creating several publications for various audiences, and presenting at conferences on audiology and visual impairment – areas well out of her comfort zone. But ironically Agnes feels there has been less interest from Scotland in the learning she has brought back than from other parts of the UK. Agnes warns:

“Never say you know it all! I never think I come from Scotland and we’re the best!”

The second example involves a small project funded by SUII (the Scottish Universities Insight Institute) in 2017, which draws upon the connections with Japan, Australia and Canada described above. The aim of the project is to investigate alternative housing-with-care/care home models from overseas through experiential approaches, which enhance the meaningful involvement of people with dementia. The plan is to facilitate cross-sector discussions on lessons to be taken from these models and applied to the Scottish context.

In July 2017, several people who are affected by dementia (Agnes Houston, James McKillop, Archie Noone, Frank Ramsay and his wife Anne Ramsay) meet at the Festival Theatre in Edinburgh. After presentations on small group home models in Canada, Japan and Australia – by and with the people with dementia who have visited them – the group discuss their hopes, fears and wishes about any future move to some kind of supportive accommodation/care home. The project raises questions and challenges that the group would like those in a position of influence to consider. These include:

- How can choice and decision-making be supported?
- How can we understand better the priorities and aspirations of people living with dementia, and also of their families?
- How can planning for the future help us to meet these aspirations?

As one of the group puts it:

“These examples from overseas help to show what we could aspire to in this country. But would we accept the cost?”

... and as another responds:

“But can we afford not to change things? The cost to the ‘human element’ could be more in the long run if we don’t. If it’s not working, let’s look through a different prism. We need choice.”

These questions are included in a briefing paper published later in the year⁸³ which aims to start a new conversation about the choices open to people with dementia who may no longer be able to live in their own homes. It is launched at an event held on 20 September 2017. The event is attended by key policy-makers and representatives from the design, care and voluntary sectors and includes:

- a short film⁸⁴ put together by Liz Taylor and Philly Hare, following a study tour of group homes in Japan earlier that year
- workshops to review the briefing paper and discuss future directions for Scotland

83 The ‘New Dementia’: Widening Choices for our Future Support (2017) Edinburgh University <http://bit.ly/2Mc2Zna>

84 <http://bit.ly/2LMMsqJ>

Yet although the event seems well-received, the activists are disappointed that, as they perceive it, their hard work is not being followed up or built on.

There is some criticism too from other contributors that Scotland could be more open to what it can learn from others. For example, Heather Wilkinson notes:

“[The international connection] always starts with individuals. It seems to be more at the level of activists. The energy seems to sit with them wanting to ‘find their tribes.’”

And Kumiko Magome comments:

“[Scotland’s] practice coordinators for people at later stages... are similar to Japan’s care managers in the long-term care insurance system. Japan can help Scotland on this.”

Summary

There is no denying that Scotland – and in particular Scottish activism – has had a significant impact on developments in other countries all around the world. An impact of which it should be truly proud.

What is noteworthy throughout the last 20 years is that the initiative and innovation, the fantastic connections, the learning and new ideas to share, have very much been created and driven by individual activists themselves.

Yet it seems that these pioneers often struggle to engage and influence Scottish policy and practice with these ideas and connections. This can lead to considerable frustration – something we shall consider in the next chapter when we look at the motivations, costs and rewards of activism.

8. The motivations, costs and rewards of activism

So why do activists do it, what does it cost them... and what do they gain from it? It is all too easy to celebrate what activism has achieved, while overlooking the effort, energy, challenges and costs involved for many activists. The interviews for this book reveal what can sometimes be a high price, in terms of fatigue, ill-health, burn-out, and feelings of exclusion. In this chapter we address these questions, and also look at the implications for those facilitating real inclusion.

Motivations

What is it that encourages people to step forward and stand up for their rights, and the rights of others with a diagnosis of dementia? Ruth Bartlett's interviews with activists⁸⁵ suggests that people with dementia are motivated to take action on behalf of the 'cause' for three reasons: to protect oneself against further decline; to (re)gain respect; and to create connections within the dementia community. Ruth finds that: *"People with dementia take individual and collective action while they still can, and to stay anchored in the present, which is made both compelling and rewarding through activism."*

In the SDWG, it appears that very few members have already been involved in other areas of activism, or join with the sole purpose of becoming activists⁸⁶. Most find their way into the group through hearing about it from professionals, or voluntary organisations that they happen to be involved in because of their diagnosis. Occasionally, people find out about the group pro-actively when looking for more information about their diagnosis.

85 The emergent modes of dementia activism. Bartlett R. Ageing Soc. 2014a;34(4):623–44.

86 Perspectives on Ageing with Dementia. Weaks, D. et al (2012) JRF

Here are a few comments from members who were quite new to the SDWG at the time⁸⁷:

“Primarily, to be among other people who understand really what I am going through, and to try and learn from the group what is in front of me.” (Alistair)

“Coming here today, I like meeting people and getting to know people with the same problems as I have. It gives you comfort, it makes you feel as if you are not alone and the only way we can learn more about this is meeting with a group of people who have got the same.” (Arthur)

“I came to find out what was happening and to get some tips.” (Dan)

“We go to another group in Hamilton and the camaraderie is really good, it gives you a real lift to come. I come along to see what people with the same illness, what is going on with them.” (Rose)

87 Perspectives on ageing with dementia. Weaks, D. et al (2012) JRF

However, activists who have been involved for longer report a change in that motivation:

“When we have been active within the group for some time, our motivation changes. Coming to the group reinforces my own conviction that it’s an illness you can challenge and you can beat. The group destigmatises it and it becomes familiar instead of confusing... you’ve still got the condition but you find a new road and you establish a new life.” (Edward)

“All these lovely people have a common denominator and it is the greatest pleasing thing if I can help somebody else. It gives you a great feeling from the heart; sometimes I get quite emotional about it, to draw somebody out that doesn’t want to talk and all of a sudden they start. That is the therapy of being involved in a group.” (Robert)

“There’s a magic synergy that happens in the room when you get people with a diagnosis together; a synergy I have not seen anywhere else and I have been in many groups and never seen that magic happen... People living their lives fully with this slight handicap called dementia... I thought, well, if I have to do a wee bit of work to just associate and hear their positive words, then I am prepared to do this work which we call campaigning.” (Agnes)

“Coming here was one of the best things I ever did, because all these people were in the same boat as me, doing something useful. And that is probably why I still come, because I am doing something useful”. (David)

Motivation for continuing involvement in campaigning work seems to grow as members become more aware of the issues which need to be addressed. Dot Weaks concludes⁸⁸ that a positive sense of a ‘useful self’ helps to create a different identity and new sense of purpose. More experienced members tend to become role models for newer members, ensuring succession, as Agnes explains:

“When you come in, you are a new member of the group, and then the group helps you to gain your confidence and self-esteem, and you get quite good at the work!”

The same motivations are apparent in the DEEP network. Karen Taylor, Ron Coleman’s partner, recalls:

“The moment he met other people, he came away feeling really alive... He could see he was still capable – he hadn’t lost who he was. It was like igniting a new passion. He could see there was so much work to do!”

And other DEEP members concur:

“People living with dementia can contribute, and can change the world for everybody in the future.”

⁸⁸ Perspectives on ageing with dementia. Weaks, D. et al (2012) JRF

“Through a network like DEEP, we can share.”

“What is happening now is what should be happening everywhere – you are listening to people living with dementia.”

Tiredness and effects on health

But however strong these motivations, activism does take its toll. Many of the key players in this story have worked tirelessly for many years. Heather Wilkinson has learnt that:

“There are lots of practical costs – campaigning is very tiring, as is fitting into non-accessible events... There is also the pressure (often self-imposed) to do as much as they can while they still can – the future is always looming.”

Jenny Douglas reflects:

“I do very much remember the hard work individual members put in to developing the National Dementia Strategy, attending the working groups that informed the first content. I remember the long hours and huge amount of time that people put in – some members worked as long or longer than I did in a week. I can only guess how mentally and physically tiring input is for those doing the work. Each member has given a bit of themselves in a very personal way by sharing their experiences, which we also should not forget...”

“...Some of the meetings were very hard to participate in. Membership of those groups has [since] changed the way meetings are run to some extent, to enable a more productive participation.”

Travel can be very tiring for people with dementia, but it is very much part of the ‘job’ of an activist. Nancy comments:

“People don’t realise I travel four hours on a bus to get here and then taxis to East Kilbride... it’s a lot of effort.”

Edward also reflects on the demands that activism (and the travelling involved) put on his energy and health: ⁸⁹

“Due to our exceptional campaigning record, members are now invited on to different strategy groups, which often meet in Edinburgh at or near St Andrew’s House, the offices of the Scottish Government. In order to attend these meetings, some of us have to be up before 6.00am to get to Edinburgh for a 10.00am meeting, and this takes its toll. By midday, I nosedive... I’m okay in the morning but I sink in the afternoon. Sometimes you don’t get any warning of it, the shutters just come down. Agnes would say, ‘This is like a fog’, and it can happen any time.”

⁸⁹ Perspectives on Ageing with Dementia. Weeks, D. et al (2012) JRF

Dot Weaks discusses the personal cost of getting to meetings on time⁹⁰. She describes how one SDWG member, who lives in the Highlands, has to leave home the day before to come to Edinburgh for a meeting:

“She was booked into a youth hostel where she endured a sleepless night because of noise and felt ‘wrecked’ in the morning. She had chosen to prioritise the meeting, giving up her place at a Christmas dinner with her walking group in order to attend. Interestingly, she was the only one who had done the requested ‘homework’ which was to be presented by all members at the meeting.”

Dot also points out that preparation for talks takes up a substantial amount of personal time:

“Constructing a speech, learning to deliver it within the allotted timeframe, and rehearsing it often enough to feel confident in front of an audience is a challenge. This is especially the case if it is in a foreign country, with very few of your supporters around, and the audience is made up of thousands of professionals; a daunting task even without a diagnosis of dementia.”

Agnes’ daughter Donna confirms this:

“There were also negative impacts. It was exhausting... but we put the time in because of the positives.”

90 Perspectives on ageing with dementia. Weaks, D. et al (2012) JRF

Activists often talk about the need to ‘hand on the baton’ to those who are more recently diagnosed and perhaps have more energy. Agnes, James and others have worked hard to support newer activists. She reflects:

“... as your condition deteriorates, you then are passing the baton on in helping someone else, and then they step in and it just evolves... We are not unaware that it is a progressive illness, we put strategies in place and we just carry on with life... with a smile on our faces!”⁹¹

And again....

“Passing the baton is hard, but you have to... I’m putting Agnes first now, I need to look after my health. Dementia is only part of me, not the whole. It was a need at the time. Now I need to follow Nancy and her tatties.”

She says more about this in her Dementia Diary posted in August 2019⁹².

The families and unpaid carers/care partners of activists can also suffer. Donna Houston reflects on how the years of activism have affected her own health:

“She [Agnes] couldn’t have done a lot of it without me. The hours of time it takes out of your normal life... It was exhausting, but we put the time in because of the positives.”

91 Perspectives on ageing with dementia. Weaks, D. et al (2012) JRF

92 <http://bit.ly/2ANNGfa>

Agnes is also very aware of this:

“Donna has paid a big price. It’s a sadness for me as a Mum... We feel the professionals never understand how much she did, she was the wind beneath my wings.”

However, Agnes points out that HammondCare, when they become aware of the issue, provide her with a personal assistant.

“Health-wise, I get very tired, so it does cost me a wee bit in extra tiredness, but as long as I get a clear day without a meeting the next day and I can relax... but it does take it out of me in terms of strength, and again, we are getting that wee bit older. I think the benefits to myself of being invigorated by the involvement outweigh the fatigue.”

James also comes to see tiredness positively, finding that the fatigue associated with attending meetings can guarantee a good night’s sleep. He recounts how, after spending the day meeting all sorts of people, listening intently at meetings, and contributing to the agenda, he returns home ‘happily tired’ and feeling he has achieved something. Nevertheless, he now feels that he is coming to the end of his activism years:

“I get very tired now. I refuse early starts. I feel very tired by night time.”

Lack of appreciation

A number of the activists receive very public recognition for their work. Here are a few examples (not exhaustive!): In 2011, James McKillop is awarded an MBE, two years later an Honorary Doctorate from the University of Strathclyde, and then, in 2019, the Richard Taylor Memorial Advocates Award by the DAI. In 2015, Agnes is awarded an MBE and Nancy McAdam a BEM. They, and most if not all the chairs of the SDWG, also receive special Lifetime Achievement awards for their contributions.

Yet in spite of these very public recognitions, many of the contributors feel that the work that activists and their families put in is not always recognised and valued. This is not about gongs and awards, it is more about continuity of contact through thick and thin. This is particularly the case when activists come to the ‘end of their time’ and have to take a back seat. Agnes reflects:

“People disappear – [but] what happens to the campaigners? There’s not enough on transitions. We give our all – and get very little back. We’re thrown out, left to dry.”

Moreover, Heather Wilkinson notes that people regularly question if activists really do have dementia – they ask, if they do have dementia, why are they presenting, writing, travelling⁹³? On one occasion, James is challenged by a relative of someone with dementia as he does not fit with their experiences. He believes his brain scans are proof when there is disbelief about his diagnosis – but there is an emotional cost to this disbelief:

93 Wilkinson, H. Houston, A. McKillop, J. and Taylor, L. (2019) ‘The price of citizenship: the costs and benefits of activism as a route to everyday citizenship’ in – Everyday citizenship and people with dementia. Edited by Nedlund, A. Bartlett, R. and Clarke, C. 2019 Dunedin press Edinburgh

“People feeling they have to show proof e.g. scans to show they have dementia, when else does this happen? i.e. cancer or diabetes, it would not be an issue, they would not be asked for proof.”

Agnes is so affected by these expectations from others that she insists on a second opinion and goes through the whole investigation and diagnostic procedure again. She now thanks people when they express scepticism, and tries to take it as a compliment, but she notes that such scepticism still causes hurt,⁹⁴ reflecting:

“Responding to such attacks has an emotional cost – as does opening up, and sharing your experiences.”

Financial costs

There can be significant financial costs to activism, and people are not always even reimbursed for expenses, let alone offered thank-you gifts or payment. Agnes reflects:

“We were only occasionally paid or given gifts. The first time was a bunch of flowers from a care home, the first time I’d been shown any appreciation.”

⁹⁴ The Price of Citizenship: The costs and benefits of activism as a route to everyday citizenship Wilkinson, H. Houston, A, McKillop, J and Taylor, J in *Everyday Citizenship and People with Dementia* Edited by Ann-Charlotte Nedlund, Ruth Bartlett and Charlotte L. Clarke (forthcoming)

And Donna recalls that, at the first international conference they went to in 2008, she is given no information about how to claim expenses:

“Things have vastly improved since then... It was more our lack of knowledge as well. The assumption from the charity sector [was] that we would know how to do stuff. No regrets at all.”

However, as so often, it is the activists who have taught professionals a better way of doing things. Colm Cunningham has learnt the importance of practicalities, and now insists that people with dementia must be reimbursed for all expenses as promptly as possible:

“When Agnes gets off the train, the cash is in her hand straight away. Organisational procedures have to be flexible to this. The onus should not be on the person with dementia to apply to be reimbursed, they are there to contribute their wisdom, not to be distracted with forms and bureaucracy. That’s harder for organisations. But no more tokenistic stuff.”

In addition, every speaker he invites [to speak at a conference] now has assistance with preparing their paper or presentation, and is also offered a speaker fee and a support package, ‘a buddy’. He has also learnt about valuing contributions not just through money (which can affect benefits). For example, for one activist, he keeps a tally of the work they do and, instead of paying them, ‘gives it back’ as a conference attendance... or through books or launches.

Impact case study 3: Positive impact on individual activists

In spite of all the costs, the activists all feel very proud of what has been achieved and recognise the impact this has had on their own quality of life, social connections and self-esteem. James is very aware of how his activism has changed him as a person:

“I’m proud I was a ‘pioneer’. It’s made me more aware of people with other disabilities. I try to help them if I can. It’s definitely made me more compassionate. I’m always volunteering to help people.”

Many of the activists recognise that they have learnt new skills. Ross Campbell says:

“I learned to become a speaker, and by doing that I managed to empower myself to go out and empower other people and teach them how to handle people with dementia... In 2005, I had the opportunity to do a presentation at the Alzheimer’s Disease International Conference in Istanbul. That was a great experience and really gave me confidence. A few years earlier I would never have stood up in front of an audience and spoken, but I’ve done this a lot since I joined SDWG.”

Jenny Douglas also talks about the confidence that collective activism brings:

“I know there has been a very positive impact for individuals involved. [They] have grown in confidence, found new purposeful roles where others have been lost, been to places they would otherwise never have seen, done things they never imagined they would have done, made new and strong friendships, and found fun, laughter and peer support through taking on this role.”

Some activists are convinced that what they were doing helps to slow the disease process. James, for example, reflects: *“I think being so active has slowed the progression... it’s a big help, along with medication, it’s keeping me from deteriorating”*.

Mary Marshall is also very aware that, for many people with dementia, the window of opportunity to contribute is limited – and they need to be able to access support, encouragement and opportunity. She believes people like James and Agnes and others are flourishing *“precisely because of that love, attention, esteem and opportunity – rather than being ‘atypical’ of people living with dementia. Isn’t everyone atypical?”* Ruth Bartlett’s investigation⁹⁵ likewise raises the possibility that activism can protect against decline amongst people with dementia.

Supporting each other

Donna describes the very positive impact that meeting other activists has had on her mother Agnes:

“When she first went to SDWG she was very subdued, bewildered. She had word-finding problems. James stood out because he said you can learn new things. It gave her immediate hope – and she has passed that on to others. My mum flourished – as if she grew a new brain. She made life-long friends and they know the newer Agnes. She got huge feelings of self-worth and purpose and new skills e.g. public speaking, meeting strangers. She had suddenly discovered a new world and camaraderie. When I saw Tom Kitwood’s flower, I realised Agnes gets all these things from campaigning...”

95 The emergent modes of dementia activism. Bartlett R. Ageing Soc. 2014a;34(4):623–44.

“... That’s why I supported it... Campaigning gives you positive feedback, so you keep doing it. I believe Mum and Dad [Agnes’ husband also lives with dementia] would be dead without the knowledge we got. You can ‘choose the Misery Bus or the Happy Bus’.”

Agnes concurs:

“Being a member of SDWG was my introduction back into society, the first step on a journey and a new beginning, living with dementia. I met other people with dementia... they were the only people who made me feel safe and that I belonged, they gave me my confidence back.”

Activists generally find their peers an enormous source of information and support. Donna Houston reflects:

“If we hadn’t had the SDWG – or social media – we would be in that depressing black hole of ignorance. Because the professionals weren’t expressing any hope at all.”

Dot Weaks reports that there is:

“A strong feeling of supportive friendship and camaraderie within the SDWG. New relationships are formed, and much comfort derived from the understanding and compassionate nature of these friendships. Joining the SDWG can have a dramatic effect on people as they rebuild their self-confidence.”⁹⁶

96 Perspectives on ageing with dementia. Weaks, D. et al (2012) JRF

There is also just a lot of fun! Nancy recalls:

“There was such a camaraderie – when it worked well, it worked well. One year, Larry and Jess came to Perth and Agnes and I stayed with them in the Salutation Hotel. And we all got pissed!”

James says:

“I have met so many lovely people with dementia and have built up a great circle of acquaintances. I know if I am not feeling well, I just need to say and people will be phoning up to check I’m okay. I could go home tonight and have 15 emails from people all around the world that I have met through the SDWG.”⁹⁷

Many members of groups in the DEEP network also testify to the impact that their activism has on them personally. Here are a few quotes:

“Doing our research has also helped me as a person. As a result of meeting with so many people in the DEEP network during our research, I have been able at last to access Self Directed Support and gain control over my life. [And] making our case independently at the Cross-Party Group made a real difference.” (Agnes)

“DEEP is based on respect, it shares across the UK. Everybody gets a bite of the cherry.”

⁹⁷ Campaigning for Social Change: Understanding the motives and experiences of people with dementia: A brief report of the findings. Bartlett, R. (2010) Unpublished, University of Bradford

“DEEP helps us to make connections, and we get a sense of continuity throughout the year.”

“Being part of something helps me to feel more informed and therefore more in control.”

“I feel I’m living now, not waiting for God. I was sitting in the house and vegetating. More and more of us must say, no, we’re not going there!”

Unpaid carers/care partners are also enthusiastic about DEEP. Alison Reynolds says:

“I have often said to [my husband] Pat that he is not alone. But for him to actually see others with the same or similar illness has made a huge difference to him. Last Wednesday night I told you that I caught a glimpse of the Pat before dementia. Well yesterday I heard him laugh so freely! A week ago, he most certainly would have been embarrassed and anxious.”

And Ron's wife Karen describes the first Gathering they went to:

"We didn't know what to expect. Agnes was first to speak – I turned to Ron and said "that's like you!". It was a huge turning point in his motivation. I could see he'd found a new home."

The unpaid carer/care partner of a participant in the two-day 'Welcome Aboard' DEEP workshop, comments (after an evening spent singing at an Edinburgh Jazz Club):

"The workshop was wonderful, but the social side of getting together was just as important. I never expected that X... would be able to contribute so much, she had a wonderful time."

Donna Houston loves the DEEP model:

"It's fantastic, the more the merrier. There's grassroots coming up. People have their own ideas. They are positive about living well."

How far things have come since the 'Dark Ages' described by James and Agnes earlier on!

Summary

It is clear that the costs to those who do become activists can be significant. And we must recognise these costs – mainly to individuals, but also to networks and organisations. Activism is hard work for anybody – the financial costs, the mental energy, the political (with a small ‘p’) tensions, the set-backs, the fall-outs, the unpaid (or late-paid) expenses, the long journeys, the early starts and late finishes – and all these are harder still for those who are living with dementia, who deal with the constant need to adapt to the latest challenge that the disease throws at them.

Yet, for some, if not all, the benefits do seem to outweigh the costs. For those who stay in for the long haul, the sense of achievement and belonging can actually be life-changing. Their activism results in new and important relationships, in the development of confidence and new skills, and in new meaning to their lives.

In the final chapter we assess the impacts of, and learning from, the activism, which need to be weighed against the costs.

9. Reflections on impact and learning

So what does all this mean? What has been learnt and what has been achieved? And, given the resources, time and energy involved, has it been enough?

Raising the bar

Scotland undoubtedly raised the bar by producing the first national dementia campaigning group in the world whose members all have a diagnosis. Jenny Douglas reflects:

“People with dementia have taken the lead and played such an active role themselves – they are true community activists, not token activists in any way. Members were always driving staff in the work. We did a lot of the support, but the movement has been truly user led and a strong solid foundation established.

“They have proved beyond doubt that people want to, and can, very clearly articulate their views and speak out about what affects them directly to a high and professional standard – without losing the genuine human impact that makes the impact of the message so much stronger...

“... Very few people now would not think this was the normal thing to do – it does seem strange thinking back to those early days that people would think otherwise. Now very few conferences or events forget to include people with dementia on their programme or in their audience. This is the legacy of those early pioneers. It is fabulous to find so many stories and videos online now, with so many more opportunities to include the voice of people with dementia in training and awareness raising programmes, or for other people with the diagnosis to relate to on a more personal level.”

Kate Swaffer also feels the early activists should feel proud of having pushed so hard to have a national Working Group: she suspects that *‘the originals like James’* had a much tougher battle than she had [in Australia] to get the national organisation to fund them. She feels that the fact that it took ten years for another one to be set up indicates how hard it must have been.

There is also respect that SDWG has been going for so long, and continues to grow and take on new challenges. Many members have stayed engaged for years and the baton is always being passed on to new people. There is a wide membership, not just a small handful of people engaged – not an easy thing to achieve.

Although many people have been involved in the movement, Dot Weaks and several others single out James and Agnes, not just as influential members of SDWG, but as the de facto leaders of the movement. Dot describes them as: *“absolute warriors – they are outstanding.”*

Paul Thomas likewise reflects:

“Agnes and James are two remarkable people who have made a massive impact... We may never see another Agnes or James. Clearly the times – the Dark Ages as James refers to them – needed someone as formidable and unique as Agnes and James.”

Donna, Agnes’ daughter, adds:

“The campaigners moved us on from ‘telling your story’ (just anecdotal) to finding the commonalities. The argument for people with dementia has been won – most of the time! They won’t be able to put people with dementia back in the bottle! We’ve won many, many battles. The barriers are coming down.”

Political influence

Nick Jenkins, from the University of the West of Scotland, has worked with the SDWG and he describes their impact as *“seismic”*. He cites in particular the Charter of Rights and the first Dementia Strategy, both of which involved a re-framing of the policy landscape and language to *“a social justice perspective, rather than a purely biomedical or paternalistic approach.”*

For Jan Killeen: *“the movement established the fundamental principles of ‘nothing about me, without me’.”*

John Killick recalls the early days of the SDWG and their speedy rise to a position of influence:

“The dementia world would go to their door... I can’t think of any other country where a group of people with dementia were able to have the ear of Nicola Sturgeon (current Scottish First Minister) on a regular yearly basis... If it wasn’t for the SDWG there’s no dementia strategy. When Nicola Sturgeon was Health Minister she knew them all. They have had quite a political impact...”

Jenny Douglas reflects:

“We should be very proud that the voice of people with dementia and carers strongly underpins national Scottish Government strategy and policy, is an integral part of the ‘Promoting Excellence’ training for all professionals and beyond, and has played a major role in awareness raising and reducing stigma around dementia. People with dementia have a place around decision making tables, and their voice is heard in places that matter with people who can really influence the way support and services are delivered.”

June Andrews agrees that there are things that would just never have happened without the involvement and the voice of people with dementia:

“An example is the big changes at governmental level. It is well known that the best way to influence people in power is through the presence of people at the receiving end of services. Policy suggestions around dementia care services were being endorsed by people living with dementia who were brought to the table. It becomes harder to resist those suggestions if you are a politician, for example. It is also harder to challenge that voice, even though the prominent people living with dementia might be atypical of the vast majority of people living with dementia in Scotland.”

Colm Cunningham agrees that the SDWG has significantly influenced politicians:

“They were in their faces. You can’t separate out the policy changes that were happening from the activism that was happening. Dementia friendly communities, post-diagnostic support, Dementia Friends...”

Practical impacts

Many contributors cite very tangible impacts that have come out of, or at least been substantially influenced by, the two decades of activism in Scotland. These include:

- the first Charter of Rights in the world
- the first national dementia strategy in the world (followed by the second and third)
- the spread of ‘dementia-friendly initiatives’ and public awareness in everyday life
- the successful campaign around Aricept
- the right to a year of post-diagnostic support
- a set of co-produced guidelines for researchers
- steadily growing recognition amongst academics of the value of co-production, and greater willingness to use new methods
- a swathe of co-produced peer-to-peer resources
- changes in services. Mary Marshall offers the example of North Lanarkshire *“where those consulted all said they wanted “to carry on doing my stuff”. So they closed all day care and invested in making all areas – clubs, societies, facilities etc. – accessible.”*
- influence over what funders are willing to fund
- international influence
- changes in the way dementia is reported in the media (though this is a work in progress). John Killick reflects: *“The narrative in the Scottish press changed, and any dementia related article would nearly always include a quote from a person living with dementia.”*
- changes in attitudes. Andy Hyde says: *“we’ve inoculated a bit of the design world and changed their misconceptions about what people with dementia can and cannot do.”*

One good example of some very tangible impacts over the years, and continuing influence, is the work around public transport. Early on, James and others are involved in developing the Thistle Assistance Card⁹⁸, with the charity ENABLE. The card and App are developed to make using public transport easier for older people and those with disabilities or illness. It is supported by all seven Regional Transport Partnerships, Transport Scotland, transport operators and disability groups (including RNIB, SATA, Disability Equality Scotland). Notably the card is available to all people who require it, with no eligibility criteria required. More recently, a group of people with dementia are working with railway staff at Edinburgh Waverley station, designing a journey-planning app. There is also significant progress at airports: Aberdeen, Edinburgh and Glasgow all have lanyards for hidden disabilities available, and Glasgow is the first UK airport to host a virtual dementia tour to help staff and other passengers understand the issues.



Thistle Assistance Card

98 Thistle Assistance Card <http://bit.ly/33c86e5>

Making human rights real

Scottish activists have long been at the forefront in framing their experiences of dementia in terms of human rights. James recalls:

“I was at Alzheimer Scotland, making a video for them with ten others, who had been diagnosed with some form of dementia. During a break in filming we got chatting, and found every single one of us had left work under a cloud, as our performance had slipped. We were got rid of. Employers need to be aware that dementia is a disability, and people should be treated under any Disability or Human Rights Acts around. Sadly, there are people reading this article that will go on to develop dementia. Make sure your rights are in place before that happens.”⁹⁹

Yet although Scotland is well-known for leading with a human-rights based approach – and has had its own Charter for over a decade – some question how and why rights have dropped out of the third national strategy. Irene Oldfather reflects:

“I think it was accidental – but it couldn’t have happened in Strategies 1 or 2. Perhaps human rights debates have become almost universal – it’s taken for granted. I’m really worried – we had something so powerful, but we let it drop off the back of the truck. We’ve had HRBA [a Human Rights Based Approach] in place for ten years – and we need to make it real in people’s lives. There’s more work to do! If we could marry this with an enforcement e.g. the Wales Older Person’s Commissioner...”

⁹⁹ Age Scotland blog (30 Sep 2016) <https://bit.ly/3hh8gIT>

“...We have an Older People’s Minister [Christina McKelvie] – but we need some independence. For a while SPSO (Scottish Public Services Ombudsman) were benchmarking complaints against the Charter. We need to reinvigorate the [rights] campaign. We need to re-focus on rights. I’m passionate about continuing to fight.”

It is also essential that human rights are made real ‘in the small places close to home’, to apply the words of the great Eleanor Roosevelt, and this is the link to ‘Do-ism.’ The learning is that, for most people, this is where passion and activism start. Karen Taylor for example calls for a campaign for the right to be able to get out and about to activities and social gatherings, to theatre and the arts. She and Ron are fighting against the decision to withdraw the evening buses on Lewis, fearing it will create isolation and loneliness:

“I do believe that so many people are crying out to belong, to remove the isolation they feel, to connect. Connection or lack of it seems to be at the bottom of most mental distress and also affects physical health. Let’s stop talking about this and start doing, it can only start to happen when we, the people, make it happen.”

Jan Killeen also feels there is much more to do on rights-based issues such as support for decision-making, which *“not everyone sees as a human right.”* She feels that independent advocacy is hugely important to achieve this – and other rights-based matters – but that it hasn’t developed enough over the last twenty years to meet the demand:

“[Advocacy] should be – but is not yet – a major campaign issue on behalf of people with dementia whose voices are not heard for one reason or another.”

Improving the experience of diagnosis

Right back at the turn of the century, James highlights the importance of the process of diagnosis:

“Being told of the diagnosis at the right time, in the right place, by the right person, who has thoughtfully allowed plenty of time for explanations and any questions, is essential. The diagnosis has to have time to sink in and does affect one’s life – for better or for worse. Most people can start to confront a problem once they know and understand exactly what it is. If not told the blunt truth, or if the issue is fudged, you are still in the dark, weaponless, fighting the unknown. Armed with background knowledge, one is able to assess the battleground. The inner one fighting against the diagnosis (it must be someone else’s, it simply can’t be mine...) and the worldly one (the world hasn’t changed but you have). You now have to come to terms with your illness, learn to adapt to your new limitations and be prepared to meet challenges, for they will surely be there.”

There will doubtless be more than a few positive stories of diagnosis since that time. Yet, in spite of all the strategic work of the past two decades, the reality on the ground is that many people with dementia still report awful experiences. As Dot Weaks reflects:

“Thirty years on from a man asking me about his diagnosis, there is not enough attention given to the anxiety experienced around diagnosis – something that is crucial around the first six months. Yet this is so frequently a no-man’s land of input, with people being diagnosed and then being given a follow up appointment ‘see you in six months’.”

John Killick also feels that there should be a greater focus on the process of diagnosis... at the right time, in the right place and in the right way:

“The diagnostic process has to be personalised. We know that everyone experiences dementia in an individual way and that when you’ve met one person with dementia, you’ve met one person with dementia. Well everybody receives the diagnosis in their own individual way.”

Here are the testimonies of several people diagnosed in the past decade. These indicate that the process of diagnosis itself is still inconsistent and often leaves much room for improvement. The first two were collated as part of the national Dementia Diaries project¹⁰⁰ and published in the Mirror:¹⁰¹

Carol Ovenstone lives in Dundee. Initially misdiagnosed, Carol spends a year in a hospital psychiatric unit in 2013 before receiving a diagnosis of dementia. She recalls being admitted to the ward, the door being locked behind her, and her personal belongings taken away before being searched:

“And it was just really, really humiliating and upsetting. I didn’t know what was happening. The unit decided I was having a psychosis and hallucinations. I received medication treatment, but it didn’t work so they increased the medication. After about three months, my own psychiatrist... started doing further tests, and he told me I had Lewy Body dementia, which was absolutely devastating. When you hear the word dementia you think, my god, there’s no cure.”

Anne MacDonald (a member of SDWG committee since January 2015) is diagnosed at age 55 with Posterior Cortical Atrophy. Anne finds the lack of information she receives at diagnosis unacceptable:

“Google helped me through. All I know about Posterior Cortical Atrophy is from the internet. We need to change that... With a diagnosis we should be given facts about our particular strain and what this means for us, how we manage it. Sadly, this does not happen. Most importantly what I would have liked to have been given with the diagnosis was hope. But it was not there.”

100 <https://dementiadiaries.org/>

101 Article on the Mirror website by Myles, P. Ivil, L. Myall, S. (Feb 2016) <http://bit.ly/2AHLN3H>

Ron's 'partner-in-crime' Karen also reflects on his experience. He still doesn't have a firm diagnosis since contacting services in 2016:

“The psychiatrist was awful – he didn’t take Ron’s memory problems seriously, and didn’t put any of his deficits in context with his life story and previous skill levels. The neurologist wasn’t interested in the fact that Ron could ask his voices to remember things – and they would. He looked a bit taken aback, and showed no curiosity in the possibilities of what this could mean for Ron’s autonomy. We felt a bit deflated... The Memory Clinic has abandoned us, and we still haven’t got a firm diagnosis. They said to come back in a year.”

So she and Ron stress the importance of pre-diagnostic support, especially those who have been told by the Memory Clinic (as Ron was) that they have Mild Cognitive Impairment which may become dementia. They suggest having a series of classes on issues that can aid recovery – such as nutrition, brain training, medication, exercise, memory stimulation etc – and that these courses could be run by people with dementia.

Post-diagnostic support and the road to recovery

In response to pressure from activists and others, the Scottish Government is committed to improving post-diagnostic support for individuals receiving a diagnosis of dementia. It endorses a 12-month post-diagnosis support model which uses ‘The Five Pillars’ methodology developed by Alzheimer Scotland, and concludes with a person-centred support plan.

However, the government’s own report published in 2019¹⁰² confirms that, in 2016/17, referrals to dementia post-diagnostic support services were made for less than half (46.7%) of the estimated number of people newly diagnosed with dementia (and of those, less than 84% received 12 months support).

It seems that Scotland’s national dementia strategies are still to fulfill their promise. Some believe there is still a long way to go to meet established targets – not helped by the post-code lottery and lack of resources. Donna and Agnes Houston also feel that Scotland’s strategic vision ignores the needs of those, like Agnes, who have been diagnosed for several years but who are not yet in the later stages (known by some, including the Alumni, as ‘The New Dementia’):

“[The strategy] slipped over those who were neither newly diagnosed or in care homes. There was too much focus on the Five and Eight Pillars. When I tried to get help I had no one to report to. The Five and Eight Pillars didn’t help.” (Agnes)

102 Dementia Post-Diagnostic Support NHS Board Performance 2016/17 (Feb 2019)
<http://bit.ly/2VeTh7u>

Donna adds:

“Nationally we’ve come a long way – but not in individual regions. What’s changed there? The dementia cafés are still full of people traumatised by their diagnosis and with very complex needs.... There are only pockets of good practice. The professionals only see people in crisis or at the severe end. They couldn’t cope with people coping.”

Even for those in Scotland who have been living with dementia for many years, it seems that services – and attitudes – still have a long way to go. James describes a recent appointment (2018) with a psychiatrist about his balance problems which is less than satisfactory:

“By the way he addressed me, he had someone else’s case notes before him. He kept calling me by another name. He also did not speak directly to me, but addressed all his questions to my wife, who always accompanies me, due to my memory and understanding problems... For the first time in my life (78), I refused to go back and see him. I eventually saw another psychiatrist, and wild horses wouldn’t keep me away from her the next time.”

Many are now using the language of self-management and recovery. Even the very early activists understand the need for this, though they may have used different words. Soon after his diagnosis, James realises:

“I’m still in charge; parts of my brain are dead and/or damaged but I can... use the remaining working parts to circumvent many of the problems caused by the illness. And I believe that by taxing your brain daily you can delay its progression. It’s a losing battle in the longer term, but I’ll go down fighting all the way¹⁰³.”

The concept of ‘recovery’ is starting to take root – just as it has with mental health more broadly. Essentially it means a recovery of personhood, of identity, of capacity, of purpose for each individual that has a diagnosis of dementia. Drawing on his work in mental health, Ron Coleman talks about recovery rather than post-diagnostic support – through diet, neuroplasticity training and other methods:

“I was able to see someone quickly, the services [on the Isle of Lewis] are responsive. But is it rooted in recovery? Most places still don’t understand this. I hate the language of carers and service users. My dementia’s not terminal – it’s part of my life. As long as we see it as a terminal illness, we’ll never see a way out of it. It’s about changing things.”

103 Tell me the Truth. Pratt, R and Wilkinson, H. (2001) Mental Health Foundation
<http://bit.ly/332UoKg>

For Karen Taylor, a recovery perspective can ensure the person doesn't lose their voice and remains in charge of themselves. *"It also recognises that, although your memory may have gone, your intellect hasn't."* And she is clear that recovery should include the whole family, including young family members, who, while they may not be primary carers, need to articulate their fears, emotions etc about what is happening to a parent or grandparent.

Power, control and freedom

Many contributors rightly give real credit to Alzheimer Scotland for their role in supporting activism, especially in the early days. It is however understandable that the ever more diverse views and preferred directions of some members – in particular those who have been involved from the early days – might struggle to be accommodated within a large corporate charity. There are questions from some about the perceived gradual loss of freedom for activists to follow their own ideas and express their views totally candidly. Perhaps it is inevitable that some 'outgrow' their host organisation, and, as their confidence and status increase, seek new avenues for impact and greater freedom to pursue their own priorities. And while the 'growing pains' have been very real, one benefit is a much broader range of spaces and platforms for people with dementia to choose from when trying to find their voice.

Heather Wilkinson reflects that it has been an ongoing challenge for Alzheimer Scotland to find a balance between what SDWG offers in terms of visibility and good practice, and allowing them freedom and independence, and sometimes to disagree: *"Some lessons had to be learnt the hard way, and it hasn't always felt they have aligned."*

June Andrews is also aware of this tension:

“...some SDWG members, after a while, expressed some concern and annoyance... at what they perceived as being ‘corralled’ in a way by Alzheimer Scotland, who were now hosting the SDWG. It is an understandable phenomenon when an organisation clearly benefits from involving a group of people with dementia. The tendency and temptation to ‘keep’ such a group grows. Of course, it can then conflict with the wishes and priorities of individuals with dementia – especially those whose progression is slower than others.”

June however stresses that there may be an equal number who don't feel that way and who *“remain thrilled with the platform, the engagement and the opportunity to offer support.”*

John Killick also believes that the SDWG have been fortunate in accessing two very articulate people in James and Agnes. He acknowledges too that this *‘eloquent couple’*, with a perceived *‘license to be free’*, may not always have been received as ‘on message’ since the SDWG has been under the wing of Alzheimer Scotland.

Agnes perceives a gradual shift away from autonomy:

“[In the early days] there was no pressure on us to be anything but ourselves. WE were totally in control. It has changed... but change happens. When I was Chair, I was promised we could always be autonomous. But it depends what that means. In my view it's not as healthy now. We got money and suddenly we had one and a half workers. But now it was Alzheimer Scotland staff leading the group – and driving Alzheimer Scotland issues.”

Dot Weaks also notes these growing pains...

“The voice of people living with dementia is still a whisper. I supported the SDWG as a critical friend. The best time was when Philip [Bryers] wasn’t paid by Alzheimer Scotland. Once fully funded by Alzheimer Scotland there was a conflict of interest...”

Some people feel that, while facilitating SDWG, Alzheimer Scotland has actually prevented a wider range of people from becoming actively engaged and from developing their own ideas.

Mary Marshall reflects on the wider barriers to real involvement, in particular the enduring power of the medical model and of the media. She feels that it is hard to assess the extent of the impact of user involvement and activism, because the medics and the medical model are still *“overwhelmingly powerful”*. Mary adds:

“We will never go back to people with dementia not having a voice at all – but progress has not been what one would have hoped for over the last twenty years. In fact, most people with dementia are not getting a voice.”

Dot Weaks also argues that progress has been hampered by the medical model: *“because dementia is still led by Psychiatry. Psychiatrists are still gatekeeping and psychological services have much less power.”*

Many of the contributors would like to see people with dementia have more power and autonomy. Nick Jenkins would like to see people with dementia setting research, practice and policy agendas, rather than responding to them: *“more of a bottom-up approach – agendas and priorities bubbling up from the grassroots... I hope that activists shape priorities rather than being set by others.”*

Mary Marshall also wants to see:

“A properly inclusive approach [which] is liberating for individuals. What this story we are gathering is showing us is that there is still a danger that this can be stifled by a tokenistic involvement, or by an agenda set by people that does not match that of the people with dementia. It needs to keep going. I feel there is a definite slump in momentum and we are relying on a small group of wonderful people. ‘How many other people are ‘born to blush unseen’?”

Andy Hyde reflects that activism should not just influence him and his work, but service providers before they come to him to work on projects. He suggests that a next step might be to establish some sort of minimum standard of involvement – to move away from tokenistic focus groups.

And June Andrews hopes:

“To see activism and user involvement much better facilitated – essentially well managed – not controlled”.

Activism has to be supported and understood, not controlled or, even worse, manipulated. A caveat from Andy Hyde is that *“it’s alright everyone having a voice and being heard, but what if nothing practical comes of it? What if nothing changes? If nothing changes, perhaps it’s an indicator of tokenism... or continued injustice.”*

A key part of this story is how activism is untameable. People need different spaces to express themselves – activism cannot (and should not) be contained within one organisation. Many of the contributors call for a broadening out and greater normalisation of activism. This also means the normalisation of activism in many places where the concept is never apparent. Jenny Douglas notes that there is much work going on at present around the experience in hospitals and care homes. She suggests this is also an area to look at the challenges of growing ‘user voice’. Finding ways to hear from people less verbally vocal or mobile is also important, but that is also the responsibility of any of us working in those areas to support so there are many diverse voices.

Heather Wilkinson has a similar vision of *“an everydayness – so that activism is not unusual, not always a fight to take part, not an after-thought or an add-on.”* Heather also calls for this to be extended to those at a later stage. Andy Hyde also wants to see many more people involved and agrees that the word ‘activism’ itself may be off-putting for many who would not identify themselves as such. And Nick Jenkins reflects:

“What is needed is more grassroots engagement, where everyday priorities, everyday experiences and everyday lives can set the agenda. Everyone can be an activist. It doesn’t have to be just a select group of experts by experience. Everyone’s experience can add to the provision of expertise which they can contribute. I’d like to see a broader network of activists rather than an elite group of individuals. Something threaded into the everyday experience of living with dementia.”

June Andrews is another contributor who would like to see activism broadened:

“Currently the most prominent people are atypical of the majority. That is not to invalidate their experience – but NARROWS the understanding of what dementia looks like for a lot more people.”

Martha Pollard agrees that activism in the broadest sense could be wider:

“Why is it that some people are deemed worth listening to and not others? It is often those in powerful positions and those who are ‘loudest’ who have the strongest influence. I think we need to promote the infinite value of being human regardless of health, experience and social circumstance, and to take care to listen to those who are quieter; those who in many circumstances have little power. This seems to me to need a shift towards greater awareness of the dynamics of power.”

There is some concern that the very success of activists may be off-putting to others who are living with dementia. Ruth Bartlett comments that:

“We still overlook people with advanced dementia and older people who are not part of this movement, I’m not sure who’s speaking up for them either. One daughter said ‘my mother thought she was doing OK until she saw these other people doing wonderful things – then that set her back! I’m not sure we consider the effects on those who don’t want to be activists. We need to develop more inclusive methods, to redouble our efforts...”

Impact case study 4:

The impact of activists on individual professionals

Quite apart from the impact on strategy and policy, it is clear that both the personalities and the work of the activists has had a profound impact on many individuals. Here are some testimonies:

“It has developed my thinking in practical ways – I’ve made loads of mistakes and learned the hard way.” (Heather Wilkinson)

“I have learnt a lot from people with dementia about how to support them to participate. Though there is still a long way to go, and much to learn about. For example, you know when it hasn’t been organised right or when you’ve got it wrong, and it sticks with you.” (John Killick)

“I’ve learnt about formalising my own requirements and being clear with people providing facilities for me. I know that by recognising and acknowledging the appetite of people with dementia to have a say, get involved and be interested, then this fuels further involvement. So you can take things further perhaps than we originally could have thought. This involvement continually challenges me and we should be continually challenged.” (Andy Hyde)

“I have a background in sociology and my work is anchored in activism, how it is socially organised. I’m interested in marginalisation and exclusion and have seen how people with dementia have been ‘othered’. I feel my own research methods have become more accessible enabling and sensitive to people with a cognitive impairment. Traditionally theirs was a muted or excluded voice.” (Nick Jenkins)

“Any assumptions about what someone with dementia is capable of were brought to my attention. I thought [at first that] they needed more support than they actually did.” (Ruth Bartlett)

Dr Dot Weaks reflects that, after getting involved with SDWG...

“I knew my nurse training was not enough. So I did counselling training – to enhance my therapeutic response. I did a certificate, a diploma and then a masters, which led to a PhD on the ‘impact of a diagnosis on people with dementia’.”

Jan Killeen’s connections with activists show her that *‘decision-making is integral to every aspect of life.’* Their influence is so strong that she undertakes a Winston Churchill Fellowship study, to pursue in much greater depth the issue of support for decision-making.

Martha Pollard reflects that she found it challenging to work in a fully person-centred way in a care assistant role she had several years ago, because of the way the systems worked. However, in a subsequent role with a different organization, the Eric Liddell Centre (ELC), she has felt better able to integrate more of what she has been learning about activism:

“The impact of activism has... enabled me to tap into the wider network of groups, to align myself with an inclusive, organic, collegial way of working. I can bring and share ideas from projects happening elsewhere. I feel that we at the ELC have benefited from being exposed to the DEEP network, and also part of the LCT funded School of Leadership, involving a fruitful exchange with partners such as Age Scotland, ECRED and Queen Margaret University. Things have changed in our work at ELC through the contact with LCT and DEEP.

“I feel I get most from the relationship-based connections, the creative work and the listening. I have begun training as a counsellor, to be able to offer formal counselling, as well as continue in my informal listening roles. Being more involved with activist groups and projects also allows me to bring that into my work at the ELC with people living with dementia and carers.

“Recent visits from DEEP representatives have stimulated new discussions. We have focused very much on highlighting the normalising aspect of our approach.”

Colm Cunningham describes the specific influence of his relationship with Agnes Houston on his own thinking and actions: *“there’s a lot more accountability. And irritation in a good way – and a definite push for more innovation.”* He says he wouldn’t have previously thought of appointing a person with dementia as a consultant. He has also learnt that, if you are working with someone with dementia, you need to support and invest in that relationship, for as long as it takes. For example, HammondCare now supports Agnes with a Personal Assistant:

“This isn’t about procedure or ticking the box, this is about a partnership... You cannot think that you can just do things on one-offs. The reality is that... we are responsible now... I’m not going to withdraw that support... If you’re in the journey, you’ve got to be... responsible... You can’t involve people without committing to a long-term relationship.”

Many of the relationships built are not only close but also reciprocal. Ruth Bartlett reflects:

“Many of the things Agnes and James said were so insightful – rich observations that just stay with you. I read the literature on theory and they would just come up with a phrase that just captures it all! ... Also, they were more experienced than me, older than me – so I found they supported me. They had wisdoms and could see the contribution I was making better than I could. I found that very enriching, to get endorsement from participants – more than from colleagues. I built very close relationships.”

And Andy Hyde is one of several who talks about friendship – a very different model to the one of ‘clients’, ‘customers’ or ‘service users’:

“[I learnt to] share a meal before you even start on a project. It’s vital to connect on a human level. The first meeting at the Festival Theatre was followed by a meal for everyone, including people with dementia, designers and LNER management. It was expensive, but it completely broke down barriers and created real friendships overnight. As a result of this project, the designers and LNER staff gained friends with dementia – not dementia friends!”

Technology and communication

There is much agreement that technology offers many opportunities to support voice and activism, and that its potential is especially relevant to the remote and rural areas. There are already many examples of good work happening in Scotland:

The UK-wide Dementia Diaries¹⁰⁴ offer a platform to those who want their voices to be heard online across the world – without requiring them to move from their own front room! As Agnes testifies:

“Dementia Diaries is in a category of its own. It comes from your heart, it’s honest and true to yourself. That’s a way my challenges are being heard. You can do it in your ‘jarmies’ – it can be 3 am when I’m sometimes at my best. And listening to other people – I almost feel like there’s a chitchat. It’s evolved – it’s more of a two-way thing.”

104 Dementia Diaries <http://bit.ly/2It8Jrv>

However, there are as yet only half a dozen Diarists in Scotland.

Another new opportunity is through radio. Deepness radio station¹⁰⁵, currently being developed by Ron Coleman on Lewis, plays music, but also hosts debates and interviews with interesting individuals. It is committed to *‘providing listeners with alternative views on how we can live with dementia as successfully as we can. We are also committed to creating quality programmes that are relevant to our dementia community. We will involve people with dementia in all aspects of Deepness Dementia Multi-Media and are committed to being owned, controlled and responsive to the ever-changing needs of our community.’*

Virtual gatherings offer another opportunity for connection, support and exchange of ideas. DAI members have pioneered the use of ZOOM technology, and teach Agnes how to use ZOOM when she joins one of their virtual support groups, and later the DAI board. Kate Swaffer explains: *“Without the online space and ability to hold meetings with other countries, we couldn’t do it. It’s been very impactful.”* Since then, Scottish activists have also been at the forefront of using online opportunities to meet. The internet, Facebook and Twitter also have great impact, enabling activists to talk to each other across the world. Agnes for example has benefited hugely from the power of social media platforms to link her to others:

“I got a diagnosis. But I have gained, 13 years later, another family who is there, supporting me, all times of day and night... The friendships I’ve made have been second to none.”

105 Deepness Dementia Radio <https://bit.ly/2MRk2eQ>

She now meets other women with dementia across the UK in a weekly ZOOM-room – they call themselves ‘the Zoomettes’.

Paul Thomas comments:

“There is a broader sense of community, especially through the growing use of technology. Dementia activism has taken up the opportunity provided by the web. This is not being led by services but by activism.”

Artificial Intelligence is another area of great interest. The DEEP Ness group currently has a Dementia Enquirers grant (see chapter 5) to develop dementia-responsive instruction videos on how to make the best use of Amazon’s Alexa Dot Echo. Ron Coleman believes in two kinds of memory – his ‘emotional memory’ (*“living in my here and now”*) and his ‘virtual memory’ (for information, using Alexa for reminders and his Journals). Ron is also planning to develop, and eventually move into, his own Smart home, which will enable him to remain there for life. He says:

“For me the use of technology is the future. Technology is not a ‘carer’ – I don’t want a ‘carer’, I want a PA and it can be virtual... My first Tweet about technology got an amazing response. My job is to meet the need... I hope people will use me for what I can do.”

The right support for activists

The stories we have heard contain many clues about the roles and skills of advocates or supporters. Few, if any, dementia activists would say they want to go it alone, and most are very grateful for the support they have from their allies. But it is apparent that getting the balance right between support and control is vital.

It is worth reminding ourselves at this point of how the skills and commitment of some of the early coordinators/supporters are described in Chapter 3. James says that Brenda Vincent *“using her own time and influences, steered me towards a fresh start in life... Brenda brought me back into the community and I am now contributing to society”*¹⁰⁶. Phil Bryers had *“really strong skills in empowering the group”* and *“knew the maze and power structures they needed to influence”*. He *“enabled, encouraged, facilitated with such integrity”* but was also *“very humble”*. Similarly Jenny Douglas was *“a very effective group worker”* and totally committed to *“hearing directly from the voice of experience.”*

So, to think a bit more broadly, what underpins successful activism? As we listen to these stories, we can pick out many factors which seem key to successful and sustainable activism. We summarise these here:

The foundations that nourish and sustain activism

- ‘A license to be free’: freedom to choose priorities and actions, whether or not the group is totally independent or supported by an organisation
- Skilled facilitators: who are committed and passionate; know how to listen; make people feel welcome and included; allow time and space for social connection and emotional support; avoid taking over; can anticipate and give the practical support people need; and are at the service of the groups (even if accountable to the ‘host’ body)
- Enabling environments and processes: minimal bureaucracy (while respecting safety) and thorough attention to factors such as pleasant accommodation; accessible environments, language and processes; prompt reimbursements or payments; person-centered travel and support arrangements
- Fun, humour, art, music, food: these are not ‘added extras’ but essential components that bring people together on an equal footing, enabling them first to relax, and then to contribute

106 Tell me the Truth Pratt, R and Wilkinson, H. (2001) Mental Health Foundation
<http://bit.ly/332UoKg>

- Time and space: to enable social connection and exploration of emotional issues – if possible, away from family carers
- Networks and connections: especially with peers (and different ways to access these e.g. through technology)
- Channels: a range of different channels and mechanisms for voice, to allow best fit and widest engagement
- Open-minded advocates, advocacy organisations and supporters: who are willing to be challenged; to learn and change their ways when necessary; to engage with each other across their boundaries without jealousy, over-zealous gate-keeping or protectiveness; and to collaborate for the greater good of the people they support
- Funders who take risks and support innovative and creative endeavours
- Opportunities to influence, both at very local levels, and in formal national arenas. Those with power must be prepared to listen with open minds, to make change and to be open to learning from other parts of the world
- Researchers who are willing to give up control and combine their expertise with that of the activists
- Feedback, respect and appreciation for efforts made by the activists

Summary

It is clear that the impact of dementia activism in Scotland on both policy and practice has been significant. The courage and energy of the activists themselves has also inspired many individuals – and in some cases, has influenced their working practices and life courses.

Looking back over the last 20 years, there's clearly so much to celebrate. The period around the turn of the century saw a serendipitous collision of passionate individuals with a diagnosis of dementia; forward-thinking and committed academics; a supportive, accessible and listening government; energetic advocates and supporters... and a well-funded third sector organisation. The emergence of these determined and skilled activists; the power and confidence they find in working collectively; the many achievements of the SDWG in influencing national policy and strategy; the proliferation of 'honest narratives' unmediated by others; the impact on other countries; the development of dementia-friendly (or dementia-responsive) communities; the greater involvement in research methods, topics and processes... and so much more... all contribute to Scotland's reputation for being, in many ways, at the cutting edge.

We must celebrate – but we must also look forward. In spite of all that has been achieved in Scotland, there are still many areas that can and should be worked on over the coming years. There is still a need for the ideas of activists and their supporters/advocates to be nurtured as enthusiastically as they were in the early days. To achieve this, it is clear that key organisations and networks will need to work with each other, to share their learning and applaud each other's successes. It may also be time for Scotland to become more open to learning from others. This will surely help it to achieve its ambitious strategic goals and to refresh its commitment to right-based approaches which have real impact on the day-to-day lives of those living with dementia.

But, to achieve the changes which the activists are calling for, we must all be willing to listen to their stories and their voices, to reflect on what is needed, and to influence whatever is in our sphere of control.

And, if we do, this will surely lead to the creation of a genuine social movement of dementia voices in Scotland. A movement built on hope and recovery.

Afterword

Finally, Agnes Houston reflects on the process of remembering these stories:

“[It’s] made me sad, because I’ve thought of the people who have gone on, the people who have died and not seen the results and the fruits of all their labour... [But] it’s with great satisfaction, that, looking back, I see the fruits of all our efforts and labours...”

“Yes, you’ve got to believe it’s been worth it. I would say a resounding yes, yes, yes!!...”

“For all you people out there just newly diagnosed, please seek out peer support, other groups... and be in your driving seat, do what you want to do, whatever that may be.”

“Dementia is not the end, it’s only the beginning of a different journey.”

Appendix 1

Glossary of acronyms

AAJ	Alzheimer's Association of Japan
ACS	Age Concern Scotland
ADI	Alzheimer Disease International
AE	Alzheimer Europe
AS	Alzheimer Scotland
ASAD	Alzheimer's Scotland Action on Dementia
BEM	British Empire Medal
BMA	British Medical Association
BOLD	Bringing Out Leaders in Dementia (School of Leadership)
CPN	Community Psychiatric Nurse
CPPG	Cross-Party Parliamentary Group
CRFR	Centre for Research into Family Relationships – Edinburgh University
DAI	Dementia Alliance International
DEEP	Dementia Engagement and Empowerment Project (The UK Network of Dementia Voices)
DSDC	Stirling Dementia Services Development Centre
ECRED	Edinburgh Centre for Research on the Experience of Dementia
ELC	Eric Liddle Centre
EWGPWD	European Working Group People With Dementia
G7	The Group of Seven international intergovernmental economic organisation
GM	Genetically Modified food
GMC	General Medical Council
JRF	Joseph Rowntree Foundation
LNER	London North Eastern Railway
MBE	Member of the Most Excellent Order of the British Empire
MSP	Member of the Scottish Parliament
NDCAN	National Dementia Carers Action Network

NHS	National Health Service
NHS QIS	NHS Quality Improvement Scotland
NICE	National Institute for Health and Care Excellence
OECD	Organisation for Economic Co-operation and Development
QARANC	Queen Alexandra's Royal Army Nursing Corps
RNIB	Royal National Institute of Blind People
SAD	Scottish Action on Dementia
SATA	Scottish Accessible Transport Alliance
SDWG	Scottish Dementia Action Group
SNP	Scottish National Party
SPSO	Scottish Public Services Ombudsman
SUII	Scottish Universities Insight Institute
TIA	Transient Ischaemic Attack
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organisation

Appendix 2

Some practical tips for newer activists and their advocates and allies

- ▶ Try to find others who are ‘in the same boat’
- ▶ Share your stories. But then move on to find common issues
- ▶ Then work together to try to make a change
- ▶ Making connections with other groups and joining a network can be helpful
- ▶ Make the most of everyone’s skills and life experience – share jobs and activities around
- ▶ Explore if and how you can do your own research on something that is important to you
- ▶ Gradually find allies – advocates, friends, academics, local companies, policy-makers, practitioners, councillors/MPs, local media (between you, you will know some already)
- ▶ Don’t let others take over. Set your own agenda and priorities in line with what matters to you. Keep your ‘license to be free’

▶ Leave time and space to socialise, and to discuss emotions as well as action through ‘peer support’

▶ Meet in a nice, quiet, enabling environment

▶ Agree some basic rules and ways of working. But keep bureaucracy to a minimum, and language simple

▶ Make sure anyone who is travelling is confident, and has a clear travel plan (and support if needed)

▶ Keep things light and fun. Humour, games, art, music and nice food can enable everyone to relax, and then to contribute

▶ Respect all voices and experiences

▶ Maybe focus first on smaller/local issues – leave the bigger/national ones for a while

▶ If possible, meet separately from family carers (this can make it easier for people to talk openly)

▶ If you have a group facilitator, ensure they have the ‘right’ skills and values – and be clear about mutual expectations

▶ See if technology can help to connect and involve more members

▶ Try out creative methods to enable as many people as possible to express themselves (and to have fun!)

▶ Make connections beyond Scotland – in the rest of the UK, in Europe and maybe even further

▶ Enable more experienced members to buddy up with and support newer members

▶ Look after your health – don't take on too much, and keep space between meetings and events to enable you to recover

▶ If you are invited to take part in an event, ask for all expenses (at least) and (maybe) a fee

▶ Don't be afraid to ask others for help – for funding, for a room, for media coverage, for technical help... for whatever you need

▶ Keep a note of what you do and celebrate every achievement, however small

▶ Learn as much as you can from the stories of those who went before

About the author

Philly Hare BA (Hons) MSc CQSW is a co-director at Innovations in Dementia CIC. She currently leads on external influencing, and her projects include Dementia Diaries and Dementia Enquirers. She often works with groups in DEEP, the UK Network of Dementia Voices.

Philly is Honorary Visiting Researcher at the University of Bradford and a Fellow of the School of Social Entrepreneurs. She is also Knowledge Exchange Fellow at the University of Edinburgh (ECRED). In this role she led the ESRC-funded research project 'The Impact of Dementia Activism' with ECRED, and is a partner on the Alzheimer's Society funded project 'Beyond the Margins'.

Previously, Philly was Programme Manager at Joseph Rowntree Foundation. She led JRF's major programme 'Dementia without Walls' for 4 years, from initial scoping and commissioning to its fruition in December 2015.

Philly's particular interests are the empowerment and inclusion of people with dementia, and the application of research evidence to practice. As a qualified social worker, she has experience within the NHS, Local Authorities and the voluntary sector in many areas of adult social care. In the 1990s, she managed the Scarborough/ Ryedale Kings Fund Carers Project and later set up the Princess Royal Trust Carers Resource.

Philly has a first degree in English and Philosophy (Exeter University) and an MSc in Applied Social Studies (Oxford University).



Getting in touch

If you have any queries or wish to share your views and ideas, you can contact the Life Changes Trust in a number of ways:

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