Perspectives on ageing with dementia

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Agnes

> *We, the people in this action group, don't want to be seen as suffering from dementia, this is a term we really do not like. We are living with it and getting on with it with laughter and love and that makes a difference. We are being heard and our opinions valued.*
>
> ***(Agnes Houston, Chair, Scottish Dementia Working Group)***

This paper explores the formation, development, challenges and benefits of nearly ten years of the Scottish Dementia Working Group, through the views and experiences of people living with dementia.

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Introduction

This paper draws on the experiences and views of the Scottish Dementia Working Group (SDWG) over the past 10 years. It explores the challenges faced by those living with dementia and the ways in which the SDWG has worked to increase awareness.

In their own words, SDWG members explain why they are proud to be part of a group that campaigns to improve the lives of people with dementia which has achieved significant policy changes and while providing support, friendship and a sense of camaraderie for people living with dementia.

Cover photo: Jo Hanley

About the author

I'm Dot Weaks and prior to my recent retirement I was a nurse consultant in dementia (the first to be appointed in Scotland). I have worked with people with dementia for most of my professional career (over 30 years) and was awarded an OBE for services to dementia care in 1998. In 2006 I gained a doctorate for my study entitled *Living within a limited freedom: the perceptions and experiences of early dementia from the perspectives of people with the diagnosis and the diagnosticians* and for ten years I have been involved with the Scottish Dementia Working Group (SDWG), first on the steering group and then as a co-opted member and professional advisor of the committee.

Heather Wilkinson, who has worked on this paper as co-author and editor, is proud to be a founding member of the SDWG. She has worked in the field of dementia research since 1998 and is currently based at the University of Edinburgh, heading a programme of social research, teaching and knowledge exchange activities focusing on the experience of dementia.

This paper has been prepared in partnership with Heather and many other group members, with Chair Agnes Houston and vice chair James McKillop being heavily involved.

Agnes Houston

My name is Agnes Houston and I was diagnosed with dementia of the Alzheimer's type about five years ago. I am Chairperson of the SDWG and a member of the Alzheimer Scotland Council. I believe that the SDWG has helped me to live a more full and happy life with my diagnosis of dementia. I have represented the group at international, European and national conferences.

James McKillop

My name is James McKillop and I was diagnosed with vascular dementia in 1999. Since then I have been very active in establishing the SDWG, was Chair for the first six years and am currently Vice Chair. I am a member of the Alzheimer Scotland Council and their International Committee. I am interested in tackling stigma associated with dementia as well as advocacy, ethics and training professionals. I was awarded an MBE in the New Year's Honours List 2011 for my services to people with dementia.

Participants

Conversations with SDWG members were recorded at two meetings, one in Glasgow and one in Dundee, and members were also contacted by email. The paper also draws on three DVDs made by the group and some 84 past presentations, from which some of the quotes below are gleaned in order to give as broad a perspective as possible.

Since 2001, the SDWG has notched up an impressive national and international reputation for enthusiastic and fearless campaigning. Working tirelessly on behalf of the people of Scotland who have a diagnosis of dementia, we try to improve their lot and lobby for service improvement for those coming behind them. What might surprise the onlooker is that each of our members has a diagnosis of some form of dementia. Indeed, some members have had a diagnosis for as long as twelve years.

Here we explore, through our views and memories, the formation, development, challenges and benefits of almost ten years of the SDWG.

Foundation of the Scottish Dementia Working Group

So, how did the SDWG and subsequent campaigning begin? It was all really down to the meeting and ensuing synergy of two like-minded people. In 2001, James McKillop, who had been diagnosed with dementia, become involved in a research project led by Heather Wilkinson, at that time employed by the Centre for Social Research on Dementia at the University of Stirling. Two participants in that study went on to present some of the findings at a conference for carers, policy makers, and practitioners. One of them was James:

> My first talk, Heather asked me to do, I don't know why I did it, 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.
>
> *(James McKillop, Vice Chair, SDWG)*

Heather and James had both been thinking along similar lines about the need for a group to be formed; Heather drawing on her knowledge of the disability movement and social action, and James from observations on how people treated him once they were aware of his diagnosis of dementia. Both had begun questioning why there was no specific group for people with dementia.

In summer 2002, Heather organised a conference in Dundee, focusing on different aspects of dementia. It was very unusual to have both professionals and people with dementia at the same conference and it was here that the idea of a group for people with dementia was endorsed.

A small steering group was formed, to explore the feasibility of creating a group for people with dementia, run by people with dementia. James describes the early meetings:

> People with dementia did not meet together. For some reason, we were segregated and kept apart; what did people fear in us getting together? 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.
>
> *(James McKillop, Vice Chair, SDWG)*

From these early beginnings, the SDWG has grown in number, stature and influence.

The creation of such a campaigning group had only become possible against a context advocating an early diagnosis for people with dementia in the late 1990s. 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.

It became clear that the key questions emerging were around how and should a national group of people with dementia go forward in a sustainable way. The group, which grew rapidly in both number and strength of commitment, had to weigh up two different options:

- Option 1: to become a free-standing organisation with charitable status;
- Option 2: to accept an invitation from Alzheimer Scotland to come under its umbrella.

At a landmark meeting, from which the professionals were banned, the majority of members voted in favour of accepting Alzheimer Scotland's invitation. While working with the Alzheimer Scotland constitution, the group would have its own constitution or working rules on membership, decision making and priority setting.

The decision on that day changed the status of the group and the members really took ownership of the direction of the group and had a strong debate between them in taking a decision to come 'under the umbrella of Alzheimer Scotland'. "I still remember that meeting - it was a very powerful one" (Alzheimer Scotland member of staff). James describes the SDWG as "the independent voice of people with dementia within Alzheimer Scotland, a marriage made in Heaven". (James McKillop, vice chairman)

Funding

For the first three years the SDWG received funding for group expenses and a full-time paid co-ordinator from Alzheimer Scotland in partnership with Comic Relief. Philip Bryers was appointed and served as national co-ordinator for the first three years. This dual funding continued for another three years which allowed 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.

We have managed to generate some income by selling our DVDs and other publications, including a joke book and calendars, and fees from consultancy and training. We are also very grateful for various gifts and donations we have received over the years.

Alzheimer Scotland has assured us that it is committed to continuing funding for the group at its present level.

The SDWG comprises 112 members from across Scotland. Our Chair is currently Agnes Houston, and Vice Chair James McKillop. The group is coordinated by a committee of 18 members, elected annually, and four co-opted members, all professionals with an extensive working knowledge of dementia and related services. All members have a diagnosis of some type of dementia and voting rights are reserved for members only. Open meetings are held every two months in Glasgow and in Dundee. Committee meetings also take place every two months, with an Annual General Meeting each November.

Having a diagnosis of dementia makes life more complex and poses many challenges, both in daily living and in developing and sustaining membership of the SDWG.

Challenges of living with dementia

Diagnosis

One challenge is to get a diagnosis early enough in the disease trajectory that will allow us to make meaning of our life with dementia and plan ahead. Younger members of the group who have had to give up work have felt that they could have continued working with appropriate support, and also highlight the benefits of getting support early enough to come to terms with the diagnosis and move on with their lives.

Getting good quality support early enough to help us come to terms with diagnosis is crucial, and also more cost effective in the long term as it enables us to become more independent and reduces the need for service input.

> It's vitally important to get the diagnosis early because at least then you can try to sort out your future. I went from a confident person earning my own living to a person with dementia who could no longer function at work.
>
> *(Agnes Houston, Chair, SDWG)*

> My supporter, 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 am not getting any support from the services now, but I do get a great deal of support from the members of the group, although it is not a support group per se, but we do support each other, it is vital when we are joining forces to campaign.
>
> *(James McKillop, Vice Chair, SDWG)*

Daily tasks

Activities taken for granted pre-diagnosis can become a bit of a minefield. Here Agnes recounts how she prepares and executes a routine visit to her General Practitioner:

> When I have to visit my GP I need to spend time planning. I plan the questions I am going to ask and practice them. The night before, I do not sleep. On the morning I feel afraid – jittery, a fear of being foolish and taking up time. I put my suit on to make me feel confident; I check my bag over and over and set off feeling determined but anxious. I try to look and feel in control. I even have a speech prepared for when I get to reception, which I try to deliver before one of the questions I dread is fired at me. Sometimes, possibly most times, I would rather remain sick and put up with that than be subjected to the visit.
>
> I get to the face in the little hatch (which sometimes doesn't look up) and before I even start it says "Yes?!" My act feels shaky now but I carry on. I have an appointment with Dr – "Who?" "When?" "Today?" Well now I'm convinced I've got the day wrong and get flustered. Everything goes

> wrong. So much for feeling in control! Even getting into the doctor's room is a challenge. My name is called. Which way do I go from the waiting room? When I find the door, it's closed. Do I knock or wait? Once I'm inside it's better. Being in a quiet, private room makes a difference. I just say, "give me a minute while I get my thoughts together".
>
> *(Agnes Houston, Chair, SDWG)*

Other challenging daily tasks include: counting money, lack of motivation, forgetting familiar names and faces, difficulties making simple decisions like what to wear and even things like remembering if you have already washed your hair or not. Sensory impairment, especially low vision, is a challenge to many of us, as is the ability to filter out background noise. Having to adapt to living with impairment in a noisy, busy world makes socialising much less pleasant.

Independence and relationships

Having to give up driving comes high on the list of frustrations, as does the feeling of loss of independence. Becoming dependent on spouses or trying to reclaim independence when family members try to do too much for us rather than with us, is a common challenge. We are keen that we are left to do as much as we can for ourselves, for as long as we can:

> My husband always wants to help, but I said let me do it, eventually I won't be able to do it at all and then you can do it!
>
> *(Eileen, SDWG member)*

The strain and change in relationships is apparent in many spheres, and never more keenly felt than when a spouse leaves following diagnosis. Two of our members describe their nightmare:

> When I was given my diagnosis, it was truly more than a shock. My mental and emotional world fell apart and I slipped into a very, very dark and painful place. But worse was to come. My wife informed me that she had been having an affair and wanted a divorce. So I sank even deeper than I could have thought possible. I lost all trust and even now have problems in this area.
>
> *(Edward, SDWG member)*
>
> A year ago, a part of my life I thought would never ever happen was the [breakdown] between my family and my wife and me. I have just had to move on and now do a lot of work outside of the meeting.
>
> *(Matt, SDWG member)*

The challenge to relationships and emotional impact of receiving a diagnosis of dementia are well-known phenomena to group members and documented elsewhere (Weaks, 2006; Weaks, McLeod and Wilkinson, 2006; Weaks, Wilkinson and Davidson, 2005).

Maintaining spirituality

A challenge rarely discussed is the difficulty of maintaining spiritual practices. There is a perception that it is not worthwhile for ministers to visit people with dementia. James feels that the group should be spreading the word to ministers of religion that this is not the case.

> I know that my wife's minister has a couple of people in his congregation [with dementia] and somebody said not to go and visit them. I said, "that is the last thing you should do" [not visit] ... their spiritual life is important, and they may forget you but you don't know how long the spiritual benefit is to them, it could last for hours or days.
>
> *(James McKillop, Vice Chair, SDWG)*

We feel that much could be done to improve the situation and that a DVD of services would help people maintain involvement in church life, or simply provide comfort through the familiar.

> I think spiritual needs do not go away. When I have fatigue I can put on my spiritual music and that inspires me and I can go into that spot through meditation or visualisation. I have kept my spiritual life going, but I do like my religious family too, which I have lost.
>
> *(Agnes Houston, Chair, SDWG)*

It seems that religious practice and spirituality is a neglected area within the professional arena. This is not something the SDWG has campaigned about until now, but we feel strongly that this issue needs to be further up the agenda. There is plenty of material from faith communities about meeting the spiritual and religious needs of people with dementia in the latter stages of the disease trajectory, but little on making meaning from an early diagnosis or post-diagnostic perspective.

The work of the Scottish Dementia Working Group

Challenging stigma

One of the main aims of the SDWG is to highlight and challenge stigma, and we have successfully tackled this on a variety of fronts.

A well-known drug company placed an advert in a prestigious magazine portraying dementia in a very negative light. We wrote to complain about this and the advert was withdrawn. The company consulted the group prior to publishing their next advert.

When members speak out about our diagnosis we are confronted with many different reactions, including denial and rejection from friends and family. Sometimes we become very wary of who we share our diagnosis with, for fear of ridicule. Rather than tell our friends we have dementia, we present our diagnosis as 'cognitive impairment' which somehow carries less stigma. Classified as a major mental illness, dementia comes under the umbrella of mental health services and members are often quite shocked to learn they have a mental health condition.

However, some of us feel that by not talking about our diagnosis, we are adding to the problem of stigma.

> I have decided I will speak out about dementia, not hide it away. I believe I have a duty to let the public know that a diagnosis of dementia is not the end, but the beginning of a new life.
>
> *(Agnes Houston, Chair, SDWG)*

This kind of positive attitude undoubtedly plays a large part in the success of SDWG campaigning.

Focusing our efforts

As SDWG successes were acknowledged and we gained confidence in our abilities to campaign, our workload increased. We began to be invited to contribute to many and varied pieces of dementia related work throughout the UK, including commenting on and being part of research projects, supporting professional training and responding to consultation documents and government strategies.

Because of the increased demand on members, and to help find a way forward, an external review of the group was commissioned and completed in 2010. The review suggested that a more strategic approach to planning be implemented, with regard to resource utilisation and work allocation.

In light of these recommendations, and in order to prioritise workload and be more proactive, we felt it necessary to define the SDWG's priorities. After taking time for discussion and debate, we agreed to focus on:

- early diagnosis;
- good post-diagnostic support; and
- a well-trained workforce.

These three priority areas, which we will concentrate on over the next three years, were also included in Scotland's National Dementia Strategy (2010). Underpinning our priorities is the need to build up the strength of the group, help members develop their skills and expertise and expand the membership who undertake the active element of campaigning work, such as presentations and contributing to national strategy.

Working in partnership

We have been working very successfully in partnership with Alzheimer Scotland on many of the above issues and they are an important support, both financially and strategically. However, as can be the case with close relationships, there can be tensions around issues of control and the fine line that is ensuring empowerment, inclusion and independence while under the umbrella and governance of another organisation.

> I remember they were thinking of changing the name of the group once. They felt it sounded a wee bit short term, a working group, but it is the name that is known throughout the world; you can't change a brand name, and we are working, we are not relaxing, we are constantly working. Working is the main part of what we do, work and campaign and strive and we work harder – sometimes it is like working with our hands tied behind our backs.
>
> *(James McKillop, Vice Chair, SDWG)*
>
> The Chief Executive of Alzheimer Scotland comes to see us every three months and we talk about our shared vision, whereas it used to be yearly. We are no pushover, as he knows.
>
> *(Agnes Houston, Chair, SDWG)*

Our motivation

What is it that encourages people like us to step forward and stand up for our rights and the rights of others with a diagnosis of dementia? Recent research by Ruth Bartlett (unpublished) focused on this question and five SDWG members took part in the study. The issue of motivation was also discussed at two subsequent group meetings.

Very few members of the SDWG join with the sole purpose of becoming social activists. 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. A few members have been involved in other areas of activism, such as the trade union movement, but this is a tiny minority.

When asked to give their reasons for joining, these were the responses of some newer members:

> 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, SDWG member)*

> 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, SDWG member)*

> I came to find out what was happening and to get some tips.
>
> *(Dan, SDWG member)*

> 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, SDWG member)*

The motivation for newer members tends to be finding out more about their illness and diagnosis, sharing experience, emotional support and a little curiosity around what the SDWG is about.

However, a different story emerges when that same question is posed to our more experienced or ‘graduate’ members. 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 de-stigmatises 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, SDWG member)*

> 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, SDWG member)*

> 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 Houston, Chair, SDWG)*

> 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, SDWG member)*

Motivation for continuing involvement in campaigning work seems to grow as members become more aware of the issues which need to be addressed. A positive sense of a 'useful self' helps to create a different identity as we find a purpose in the post-diagnostic mists.

More experienced members tend to become role models for newer members, ensuring succession.

> 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! But, 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!
>
> *(Agnes Houston, Chair, SDWG)*

Alongside the motivation to be part of the group, there are both personal costs and benefits to belonging to the SDWG.

Costs and benefits of campaigning

Costs

Due to our exceptional campaigning record, members are now invited on to different strategy groups, which often meet in Edinburgh at or near St Andrews 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 mid-day, 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.
>
> *(Edward, SDWG member)*

Couple the early morning start with the general feeling of fatigue felt by some members, and you realise the personal cost of getting to meetings on time. One member, who lives in the Highlands of Scotland, described having 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.

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.

The extreme fatigue, which is experienced by many of our members, is not always recognised as a consequence of the illness:

> 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.
>
> *(Agnes Houston, Chair, SDWG)*

On a positive note, some members find that the fatigue associated with attending meetings can guarantee a good night's sleep. James recounts how 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.

Benefits

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.

> 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.
>
> *(James McKillop, Vice Chair, SDWG)*

Joining the SDWG can have a dramatic effect on people as they rebuild their self confidence. We take on new roles, develop new skills and benefit from a sense of belonging.

> 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, and by doing that I felt I was speaking for people who could not speak for themselves … 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.

(Ross, SDWG member)

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.

(Agnes Houston, Chair, SDWG)

Dementia is on the increase and I am glad to see it is a problem that is being tackled at the Scottish level and at every level. This is my first year on the committee and I have been lucky enough to meet the lady that runs the NHS [Shona Robison, Minister for Public Health] and she sounded very positive at our meeting. I think we have achieved a tremendous amount … we are not just talking about work, we are talking about a high standard of influence on what is going on for people like us.

(Alex, SDWG member)

There is a great sense of pride among members in what the SDWG has achieved over the last decade, because of, and in spite of, our diagnosis of dementia.

Achievements of the Scottish Dementia Working Group

Political campaigning

Initially, contact with government ministers was through exchange of letters, which progressed to annual meetings. More recently, since the SNP government came to power, the Public Health Minister has requested two meetings per year with group members. Our members have been so successful in lobbying ministers that we are now addressed by our first names. We have even had a meeting with Scotland's First Minister, Alex Salmond.

We feel really listened to and are consulted on all things pertaining to dementia. We feel that the government have taken heed of the group slogan 'Nothing about us without us'. We are involved with the Scottish Government at various levels, including active membership of the Scottish Dementia Forum, a group chaired by the Minister for Public Health who advises the government on dementia related issues.

Along with other campaigning bodies, the SDWG has had a significant impact on policy in Scotland. Over the last two years, the group has been involved in shaping Scotland's National Dementia Strategy, with two members participating in each of the strategy's five work streams. An SDWG representative spoke at each of the consultation events for the strategy, which took place at venues throughout Scotland, including the Isle of Skye.

> I think professionals are lagging behind, some of them don't want to know, the word dementia conjures up something, and all we can do is battle onwards. The government doesn't do anything about dementia without us and I think we have improved the lives of people with dementia and their carers throughout Scotland. We have a lot still to reach but we are slowly and steadily inching forward to improve the lot of everyone in Scotland.
>
> *(Tony, SDWG member)*

Raising awareness

The national and international reputation gained by the group has built up over the years. We rarely turn down invitations to speak at conferences and are willing to travel to far-flung parts of the globe to get our message across. Recently, our Chairperson, Agnes Houston, has given two presentations in Canada. These talks are always tailored to the theme of the conference, with members willing to share both their personal experiences and the wider needs of people with dementia. Again, the focus is on early diagnosis, post-diagnostic support and training of professionals.

Some members were recently invited to address a meeting of health board chief executives and chairmen and present our latest DVD *Through Our Eyes – a life with dementia*, which was made to help raise awareness and educate both public and professionals alike.

Positive feedback is frequently generated from these presentations, which are often described as inspirational and moving.

The SDWG, as the voice of people with dementia, is much valued by Alzheimer Scotland. Members are represented on the organisation's council and standing committees and can therefore directly influence its direction.

Training the workforce

We are regularly involved in the training of both professionals and volunteers, lecturing to nurses, doctors, social workers, helpline volunteers, hospice staff, care home staff and psychology students. Recently, one of our members has been working in partnership with Royal National Institute for the Blind (RNIB) and Alzheimer Scotland on a training pack about the challenges of low vision.

> These sessions have a tremendous impact and feedback is always very positive. Members are told that hearing someone talking from experience is better than dozens of lectures from people who know the textbooks but don't have the experience.
>
> *(Edward, SDWG member)*
>
> Recently, we were doing a session for students in Glasgow and there was five of us, someone with a diagnosis of vascular dementia, Korsakov's dementia, Lewy body dementia, Alzheimer's dementia and Picks disease all presenting – there wasn't two the same – and the feedback from the nurses was, out of their three-year course, it was the best they had ever had, they had learned more from it about dementia than they ever had, they were vibrant, they didn't want to leave the lecture ... they wanted the DVD as part of their course and they wanted us back ... and how did I get that feedback? At my gym the next day!
>
> *(Agnes Houston, Chair, SDWG)*

To enhance our repertoire, members have been involved in the production of three DVDs, which are regularly used in our training sessions and are available for sale from the SDWG office.

Much time and effort goes into the preparation and delivery of training professionals and it is important for members to challenge stereotypes and attitudes. Sometimes professionals have a different picture of dementia than the one portrayed by the SDWG and we are determined this needs to change.

Indeed, it is not just the beliefs and attitudes of professionals that need to be challenged, but of the public in general; something that members continue to do at every opportunity.

Publications

The SDWG have contributed to many publications about dementia, including the booklet *Facing Dementia* which members would like to see everyone getting at their time of diagnosis. Others include *Don't make the journey alone* and a help card for people to carry in their wallets, designed by James McKillop, which Alzheimer Scotland now produces.

Members of the group have also produced a joke book entitled *Why am I laughing?* There is a tremendous amount of humour around at our meetings and members felt it would be good to share some selected jokes with the public and use this as a vehicle for raising awareness. Cartoon illustrations for the book were produced by Edward McLaughlan, a member of the group.

James McKillop and Heather Wilkinson have also had work published in an international dementia journal on the experience of co-producing research.

Recognition

James McKillop, founder member of SDWG, has had many accolades and awards bestowed upon him. The pinnacle of these came in December of 2010 when he was honoured in the Queen's New Years Honours List 2011 and awarded an MBE for services to dementia. Everyone in the SDWG was delighted about this award.

> Everybody round about me was getting excited, I always had the impression that it was for people who worked in their job and were acknowledged through that, but then people started saying it was for what I had done voluntarily and so it is extra special, then I began to think, this is good, not just for people with dementia to show they can still contribute back to society but for all the people who supported me for so long over the years, their efforts, they must feel happy that what I am doing is justified, helping people get their lives back and it's all worthwhile and there is someone with an MBE. I couldn't have done it without the people who supported me over the years, especially Heather, Brenda and Philip.
>
> *(James McKillop, Vice Chair, SDWG)*

A better life for people with dementia: Myth or reality?

Who would imagine that someone with dementia could see this diagnosis as having a positive impact on their life? Is a better life really possible following such a devastating diagnosis? Many of our members think that it is.

Having a purpose and being involved in the work of the group seems of prime importance to unlocking a positive life with dementia:

> I am very proud to be part of the SDWG … It has given me, and others, a new confidence. As a campaigning group it is an outstanding success and doing Scotland proud.
>
> *(Edward, SDWG member)*

> I try to keep myself in a positive frame of mind, although at the time of diagnosis I felt as if I lost my sense of self and purpose. But we, the people in this action group, don't want to be seen as suffering from dementia. We are living with it and getting on with it with laughter and love and that makes a difference. We are being heard and our opinions valued. If you are going to get dementia, get it now, because you can be a pioneer and campaign for services that will hopefully be available for everyone one day.
>
> *(Agnes Houston, Chair, SDWG)*

A positive attitude is another essential element, along with an ability to challenge stereotypical thinking.

> People get to hear the word dementia and it is all lumped together and they think you are finished. You are not finished at all, they think you can't do anything; you can't think for yourself, you can't speak for yourself. So we put together the awareness raising programme, letting people know that we can do things.
>
> *(Pat, SDWG member)*

Challenging these attitudes and indeed challenging ourselves to do new and different things is all part of 'a better life'. Edward has learned British Sign Language, Pat has taken up computing and gained certificates in first aid, Agnes has learned to make glass jewellery, and the list goes on. We are not only learning different strategies for coping with the diagnosis of dementia, but taking up new challenges to prove to ourselves and others that we can learn new things.

> You reinvent yourself ... my brother said, "We admire you" – they were frightened of my diagnosis because of my Dad (who also had dementia), "What can we do?" "How can we help?" – and now they are standing back and say, "We phone Agnes and she is never in, we never know what she is doing, but admire you for how you are handling your diagnosis".
>
> *(Agnes Houston, Chair, SDWG)*

We all seem to be busier than we were in our pre-diagnosis life and the busy life comes highly recommended.

> Keep busy, doesn't matter what it is, at the start of the day I look forward to what I am doing next, and I am working doing everything I can possibly do.
>
> *(Matt, SDWG member)*

Three of us – all more experienced group members – actually say that we would not want to go back to how our life was prior to diagnosis:

> Personally, I would not go back to not having dementia ... I'm quite proud of everybody here. They have climbed a very slippery ladder and are determined to get to the top of it and rather than make it sound all difficult it can actually be quite a lot of fun.
>
> *(Edward, SDWG member)*

> I have the life of Riley; it really is good. I know I have a deteriorating illness and it won't last but I could have died ten years ago if I had been given a diagnosis of terminal cancer, I wouldn't be here and look at all the happiness I've had. I would say, I'm happy with my life, if I could go back and change my diagnosis, no, I wouldn't, I am quite happy living with my diagnosis.
>
> *(James McKillop, Vice Chair, SDWG)*

> I wouldn't swap my life for anybody and sometimes at night I count my blessings before I go to sleep, and I have loads of blessings. We have good quality friends who you could phone and they just accept who you are, and I have my gym buddies, not only do I have my life in the dementia field, but I have a life outside as well. When I was working and looking after my dad, I didn't have the quality of life I have now, so it might not be for a long period of time but the quality is gold-plated, it is absolutely wonderful; you couldn't buy it, but I think we create that.
>
> *(Agnes Houston, Chair, SDWG)*

> I thought I had retired from the SDWG. I joined the group after getting my diagnosis of Alzheimer's Disease in 2006, and was an active committee member. My health got a lot worse, though, and I couldn't get along to the meetings like I used to. But here I am again. I really want to say something today – to say something about moving into a care home and what that is like. I am proud to be here once more, as an active SDWG member.
>
> *(Clarke, SDWG member)*

One of the constant challenges for our group is the recruitment, support and retention of valued members, particularly when they become less able to participate. Many members offer peer support and visit members when they are no longer able to attend meetings, but still want to contribute to the work of the group. One member describes how he still participates following admission to residential care:

Most people who come to the group have not had any experience of campaigning and so we learn as we go along, observing others and being supported in the activities we choose to be involved in. Through this work we regain our self-esteem and confidence and go on to lead very meaningful lives.

James

We leave the last word to James:

> People with dementia can not only be capable of advocating for themselves but can band together to form their own campaigning groups, to be able to run them with a modicum of support and to clamour to the powers that be for recognition and respect; we must earn that respect by our actions. As well as empowering ourselves by finding answers and roads out of despair, we should also empower the professional workers and explain to them that there is life after dementia.
>
> *(James McKillop, Vice Chair, SDWG)*

We hope that our stories will serve as encouragement for other people receiving the diagnosis of dementia.

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Ruby

About this project

This paper forms part of a series of *Perspectives* commissioned to support the five-year research programme, A Better Life. This programme investigates what will improve quality of life for some of the most marginalised, and least heard, people in the UK – older people with high support needs.

A microsite based on these *Perspectives* will launch in January 2012. It will provide a unique digital platform to showcase the voices of older people with high support needs and features photos of people who contributed their perspectives and a poem by Sir Andrew Motion. To find out more visit www.jrf.org.uk/work/workarea/better-life

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