

## Doreen's Kyoto Talk

### Input about the Scottish Dementia Working Group

My name is Doreen and I have dementia of the frontal lobe. I was invited here today to say a few words about the Scottish Dementia Working Group and Alzheimer Scotland from when I first became involved until the present day. So please allow me to take you all on a journey, and for me it was a journey into the unknown.

(Pause and look up !)

After being diagnosed with dementia I thought my life was finished. I couldn't believe someone my age could have this. I was only 47, there must have been some mistake, but in the end, somewhere in my mind I knew it was true. I sat at home staring at four walls, numb with shock, unaware of anything happening round me, not thinking or caring how my family were feeling. You see, through lifes ups and downs, I had always bounced back - but here I was faced with a battle I knew I was not going to win so I sat at home and I'm ashamed to say I just gave up the fight, or so I thought.

(Pause and look up)

A few weeks or so passed and one day there was a knock at my door and I was introduced to a lovely lady who said she was from Alzheimer Scotland. Her name is Eileen and she is the counsellor with the service for younger people with dementia. I learned later on that I had been referred to her by my consultant.

(Pause and look up)

Within a short period of time I felt so at ease talking to Eileen that all my fears and worries came tumbling out. We spoke in

depth, on a regular basis, and through time she helped me and my family come to terms with dementia. Eileen became my guiding light in a very dark tunnel. On one of her visits to my home, Eileen asked if I would join a small group of people with the same memory problems as myself. To be honest, I was scared, a bit of a coward but anyway Eileen was very persuasive and eventually I agreed.

(Pause and look up !)

After my first meeting I felt so much better. The people in this group were just like me. All of them had the same fears, feelings and problems as myself. New friendships were formed, we care and support each other. We may be at different stages in our lives but we are all together in so many other ways and so we are all very close. I started to live again, counting the days on my calendar waiting for my next meeting. The group helped me gain some of the confidence I had lost. It gave me a voice that people listened to. It gave me a lifeline I desperately needed. According to my family, who I'm lucky to have, I'm a different person since starting my group.

(Pause and look up)

And so this takes us to the next step of our journey, again for me a step into the unknown. I was asked to join a small group of people who were getting together to start a working group solely for and run by people with dementia. Well, with the confidence I had from my small support group I didn't need persuading. I said "Yes" immediately. Right there and then, with the support of Alzheimer Scotland and workers from other dementia agencies, we became the Scottish Dementia Working Group. I'm very proud to say it's one of the first of its kind - although if we do our work properly it won't be the last.

(Pause and look up)

We now have around 25 people with dementia from across Scotland on our mailing list. We meet as a national group every second month and local groups meet outwith this. Between 10 and 15 people with dementia usually manage to get to the meetings. As a group working together, we want to tackle all the issues we have about dementia, and the list is a long one. We want to change the way that people think and view dementia. People such as employers, the police, people across the board in caring professions, schools and in many other settings.

- We want to tell people that although we have memory problems we are not stupid.
- We can make some decisions for ourselves.
- We like to be spoken to, and not over our heads about the things that concern us.
- We are not useless

We want to teach (and yes, that's right, I did say TEACH) people that we are able to make choices in things that concern our day to day lives, and who better to teach everyone concerned than the people who know best, ourselves.

(Pause and look up !)

The Scottish Dementia Working Group has identified three main areas that we want to campaign about. These are the areas of:

- early diagnosis and post diagnosis support services
- respite care
- access to medication

For many people in our group, it took literally years to get a diagnosis of dementia. People were bombarded with anti-depressants and told they were depressed. What a waste of money ! Why not spend more money on scans ? And once you are diagnosed

(Pause and look up)

Many people with dementia need respite care. People don't know what they are entitled to. They are scared of being put in a home with older people who are further on in the illness. They don't want to be put in a hospital and left without stimulation or activities. Hospitals are for the sick. Many of us are not sick so why put us there ? Respite care should be suitable for your age and stage of illness. I told you the list was a long one. Although respite care in Scotland is getting better, we aim to push it all the way with the people who hold the purse strings. For equal and better conditions. We have worked and payed our dues and we are entitled to some quality of life.

(Pause and look up)

Another issue for us is access to medication for dementia. Some people are getting the medication they need but it can be patchy. We would like to see the drug memantine available on prescription in Scotland - it might not help everyone with dementia but if it can help some people, especially later on in the illness, where there are fewer options available, it must be worth the cost.

(Pause and look up)

We will continue to campaign for better services in all the places where it needs to be bettered. I live in Glasgow, in the urban part of Scotland where we are fortunate to have a good

range of services. People in the Highlands and the more rural areas of the country are not so lucky. If we can change and improve anything then our legacy will be a better life for the people who come after us.

The Scottish Dementia Working Group started formally in April 2003 so we have been going for 2 and a half years now. I think we have achieved a great deal with help from our friends in Alzheimer Scotland and other agencies and a lot of hard work from ourselves. A few of our proudest achievements so far have been:

- Roadshows to other parts of Scotland to encourage people that groups of people with dementia can and do work
- Training sessions on working with the media to get our message across.
- Speaking to the Health Minister at the Scottish parliament on World Alzheimer Day last month about the issues I have spoken about here.
- Taking part in training videos for health and care workers about working with people with dementia
- Producing information about our group and leaflets for people newly diagnosed with dementia.
- I think our greatest achievement is that we have been awarded £87,000 from a charity called "Comic Relief" . This money is being match funded by Alzheimer Scotland so we now have enough money to pay for a national worker to work for us for the next 3 years.

(Pause and look up !)

So what are our plans for the future ? Again, with support from Alzheimer Scotland and other agencies, we hope to get other groups of people with dementia up and running. The more groups there are, the louder our voice will be. If we in

Scotland can achieve all this, and more, then surely it can be done in other places too ?

(Pause and look up !)

As part of this talk I was asked to come up with some advice for Alzheimers organisations who want to start working with groups of people with dementia in a realistic way. The tips I would have are:

- Firstly, be aware that this kind of work does not happen overnight. From my own experience, I needed to come to a small, self support group to begin with. This allowed me to build up my confidence and to share my thoughts with people I got to know well and trusted. Without the good experience of the smaller group I would NEVER have gone to a larger group.

(Pause and look up !)

- This kind of work is also not cheap. People with dementia are likely to need the assistance of support workers to actually GET to meetings and to take part in the business of the meetings. We have been generously supported by Alzheimer Scotland and other local dementia services. We could not manage without this.
- We have found that our meetings need to combine business with a social aspect so that everyone can get something out of them. We have also found that we need to build in regular breaks so that people have time to talk informally and do not have to concentrate for too long at a time. We start the meetings at 11.00 a.m. with tea and coffee together so that people are not rushed first thing in the morning. We also share a sandwich lunch together.

- We have a planning meeting before every full meeting so that we can make sure we have a mix of activities. If we have a guest speaker we ask them not to speak for longer than 10-15 minutes and to put up key phrases or memory prompts on flip charts or slides. We also always try to break into small discussion groups so that people who do not like speaking out in a large meeting get the chance to have their say.
- To make sure that our meetings really are run by people with dementia FOR people with dementia, only people with dementia are allowed to be full group members and to vote. We always listen to what our supporters have to say but they do not have any voting rights

(Pause and look up)

Well friends, that is my journey so far. I hope I haven't been too boring for you. All that's left to say on behalf of the Scottish Dementia Working Group is that we are very grateful to everyone in the Alzheimer organisations. Without you my journey would not have been possible. You have given us your time, your patience, your support but more importantly you have given us hope for the future, if not for ourselves then for the people who come after us.

I'm happy to try and answer any questions you might have. Please remember though that I have dementia and I'm stressed enough already, just standing here ! If I can't remember things and can't answer any questions today, I've a friend here from Alzheimer Scotland who may be able to help me. Otherwise I 'm sure the organisers of the workshop can note any questions down and we'll get an answer to you somehow.

Thank you and God bless !