

“Dementia Active: Changing how we see dementia”

Glasgow Royal Concert Hall

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Making a difference by getting involved

Ted Cleland, Scottish Dementia Working Group

Philip

Ted, can you say why you think it is important that people with dementia are involved in campaigning and getting their voices heard?

Ted

If we're not campaigning and getting our voices heard nobody is going to be. Dementia is mainly a condition affecting older people, and older people are perhaps rather scared of taking initiatives to get their voices heard.

I think this business of having groups where people can talk to other people with the same problem is a vital part of the positive aspects of trying to keep yourself operating.

When this happens people in society in general become more aware of dementia.

Philip

Why is it important for you to be involved?

Ted

I've been involved with the Scottish Dementia Working Group for about a year. Since I left the Navy about 14 years ago I've been involved in the voluntary sector a lot and I've realised that the voluntary sector is extremely important in creating an awareness of what the problems of dementia are.

I believe it's very important that people with dementia get involved in the development of the work.

Philip

Do you enjoy being involved?

Ted

Oh, very much so. Yes. I like projects. I like developing new projects, and there's a lot of that going on.

There are links with my previous work. I ran the Family Mediation Service in Edinburgh for 12 years, from starting it up through fundraising, and I enjoyed that very much so this is a follow on, and it's extremely good work.

So I enjoy being involved because I can use my skills and experience.

The meetings and the company and the empathy which people with the problem have with each other are other reasons why I enjoy being involved.

I didn't know any of the people in the working group when I first joined but I feel I know them now - very much so. There's a very grave danger if you have dementia of becoming isolated because you forget things and you get scared of involving yourself with other people too much and I think that should be fought.

Philip

Shall we run through some of the things you've been involved in?

Ted

I go to all the meetings, which I enjoy very much and try and contribute to.

I think the dementia café in Edinburgh is extremely good. I must confess that initially, being used to a more structured system I was quite surprised that there was no agenda. People just talk. As I went to more meetings, I became aware that that's actually what it's about.

The Scottish Dementia Working Group has to be more structured because it's dealing with policy all the time.

A week ago I went to a meeting with Quality Improvement Scotland about developing guidance for what they are calling Integrated Care Pathways. The

idea is to compare the planned care with the services actually given and to work with the services locally to measure practice against national standards.

I took part in a focus group on the Blue Badge parking scheme.

I've been proactive in trying to ensure that medication for Alzheimer's disease is prescribed when a doctor believes it will help. My test score has remained constant. In theory it should have gone down a bit. I attribute that to the medication.

Philip

I know that you stood up at the first UK Convention of People with Dementia in Newcastle and spoke about the Scottish group.

Ted

Yes, I enjoyed that. It was a big audience and an appreciative one. Most of the audience had a diagnosis of dementia, and I thought it was a great opportunity to publicise what we're trying to do.

Philip

Were you involved in the action the Working Group took about an advertisement for one of the medications picturing a man with dementia?

Ted

Yes, I was. As I remember it they had got it all wrong in the advertisement. A picture of a poor old man looking a bit dopey. Absolutely disgraceful. Someone from the drug company came and met us and we had a good discussion. They promised they would consult us when they are planning their next advertising campaign.

Philip

What was the best thing you've done so far?

Ted

That's difficult. Before I became involved with dementia the best thing was setting up from scratch and running a family mediation service to help separating parents come to agreement about arrangements for their children without battling through the legal system. That was very rewarding work, particularly working with groups of children.

Philip

What you are doing now is similar. You have experience of dementia and you're one of the people who can speak up.

Ted

There's a great danger of becoming isolated. Loss of memory means fear of getting yourself involved. That's the thing people with dementia ought to be working to overcome.

Philip

What (or who) has helped you to become involved?

Ted

Certainly an awareness of the importance of the voluntary sector. I know the amount of work people are doing there. The work we do is very important to the general public.

When I first got involved I felt at home. At meetings there's an agenda you've got to get through and I like that. I like a bit of structure. At the same time members of the group feel free to come up with whatever issues they want to.

Philip

Has being involved made a difference to you personally?

Ted

Oh yes. No doubt about it. It actually helps to restore the confidence that you've lost as a result of the diagnosis. It's 18 months since I was diagnosed and I feel no worse. Being a member of the group must help to keep the brain going.

Meeting the people in the group has made a difference too. We all share the same problem.

Philip

What have you or the group done that could make a difference for other people with dementia?

Ted

Well, lobbying about the medication. And also getting other people in the early stages, just after their diagnosis, aware of the fact that the group is there and gives them the chance to come along if they want to. Having a group to go to at that point is enormously helpful.

Philip

What do you hope to do next?

Ted

I think PR, and public awareness that dementia is not something that automatically writes people off is important. I'm sure many people think "Oh, he's got dementia, poor old fellow." That's just not the case. People with dementia are not write-offs.

An early diagnosis comes as a bit of a shock, then you find that it's not nearly as bad as you thought and you just work towards keeping communications going.

Philip

Do you think we can build on the UK Convention which brought together people with dementia from England, Scotland and Wales?

Ted

I'm sure we can. To me that was one of the most edifying days I've had since diagnosis. I want to keep getting the message across that a diagnosis of dementia does not write a person off from constructive activity.

We're living with dementia, not dying from dementia.

Philip

Is there any last word you'd like to add?

Ted

Yes. I'd like to record that the Scottish Dementia Working Group has given me more information and more psychological help than anything else and has also shown me that I'm not alone. Those are very important factors in keeping people involved in the community.

