

Scottish Dementia Working Group

“What disempowers us – and what can be done”

If we want to understand empowerment, it is sensible to start by asking “What disempowers us?” By identifying the things which take power away from people when they develop dementia we can often do something about them.

The experience of members of the Scottish Dementia Working Group has been that a lot can be done in the earlier stages of dementia to get back some of the power we have lost. The most empowering thing we have found is becoming part of an outward-looking, positive group of people who are all facing the same issues. We have helped each other to get back into society, to be active citizens again, and to make ourselves heard.

There are some obvious things which disempower us. Our brains no longer function as effectively as they used to and this leaves us unable to do things we previously took for granted. For some of us, counting money becomes difficult. For others independent travel is harder. We can't always concentrate as well as before, and we often get tired.

Medication can slow down the onset of Alzheimer's Disease and all our group members who have been prescribed the available medicines have seen a significant benefit from them. We also know from experience that keeping our brain active doing puzzles or other mental activities can help. But, as in life, there are some things we can do nothing about. We can only come to terms with them and accept them as a fact of life.

We were more interested in the things we can do something about – like the way we cope with our condition, how other people respond to us, and the approach of the organisations with responsibility to provide services.

One of the biggest blows after diagnosis is losing a job. Work has been our life for many years. It constitutes a big part of our social contacts. And it has been the main source of our income. Here is what one member said:

Losing the ability to work was very disempowering. I felt that if I had been given help to find work which I could still manage I would have felt less disempowered.

We have all had to get our life back in some way or another. One member described the help he got from a mutual support group and how this helped him to face up to the fact that he had dementia.

I picked myself up through getting help from other people. Now what I do is give back to other people what I can, to try and help them.

It was as if somebody was stealing your future. You're not always sure its happening at the time. Everything was gone. My hope came from being loved by the people that cared. I realised that instead of looking in I should be looking out from myself. So I started to look outwards and I've never looked back since. I just think love and laughter is the cure. That's the road out.

Many of us felt disempowerment most when we lost our driving licence.

I'm always getting told off by my wife because I still sit beside her and "drive". When I see some drivers and the things they do I think "I could drive better than that!"

There's nothing more calculated to make you feel disempowered than people telling you what you've lost.

I felt disempowered because the people that spoke to me about dementia always spoke about my loss – all the negative things. Nobody ever said "there are things that you've lost but there are also things you could gain." They never really took me from the loss of power into the action. It was the Scottish Dementia Working Group and other people with dementia that did that. I had to find the light at the end of the tunnel.

We believe that the way people are told their diagnosis is very important.

The doctor said to my daughter "Have you heard of dementia. That's what he's got" and he pointed to me with his thumb.

My consultant was very nice. It was just that they were giving you all the negative facts. I felt as if after the diagnosis I might as well just go home and give up.

I was told when the results came back that I would have 10 years to live. Then the doctor said “How long do you think you’ve had Alzheimer’s?” I said “I don’t know. I think probably it could be 2 years.” “Oh well” he said, “That’s it down to 8 years.”

As well as empowering ourselves by finding answers and roads out of despair, we should also empower professional workers and explain to them that there is life after dementia.

We’ve got to be forceful because professionals can be very patronising. They do their training and they think they have the answers to the world, but they need our side of the story.

Another thing that disempowers us at the beginning is the attitude of friends and relations.

Some friends take your confidence away. They treat you like a child. Someone said to me “Come along in the car and I’ll take you out and I’ll bring you a sandwich.” I thought “What’s happened to me?” People said they would sit me out in the garden as if I was a toy. The attitude of people towards us takes away our confidence.

You’re very disappointed with the attitude of some of your friends. They jump in and you don’t have the energy to educate each of them. You feel as though you should have a sheet typed up and say to them “Read that, then come back and visit me.”

Confidence can easily be destroyed. People should understand that we do still have the ability to know ourselves.

I felt confident in what I was feeling and saying. But then people would say to me “Are you sure that’s what you’re feeling or is that your dementia?” I never quite knew. I’m sure inside but other people make me unsure. I have to sit quietly to find out who I am.

One member was so upset by the way health professionals spoke down to him in a patronising way that he got his doctor to invite him to speak to the staff at the local health centre.

After that, they saw things from my side of the fence and had a different approach towards people with dementia.

A lot of it is ignorance, not arrogance. To empower ourselves we've got to empower others through education and communication.

I am a person, not an illness. I've told my care workers "I'm not a number, I'm have a name. I'm a person"

For some of us, our diagnosis has meant that instead of being the person others relied on, we have become the dependent one.

I was the main carer for my Dad who had dementia before I was diagnosed. I was the one to fix things in the family. Suddenly I wasn't the one putting everything into place.

It is very important to have adequate support at the time of diagnosis. If there is someone there then who understands the emotion and turmoil you were going through, life can be very different.

There is a lot of talk about the stigma of dementia. We believe there is something which can be done about it.

I initially felt a sense of shame. It was as if I'd let my family down by getting this condition which affected them all. A few years ago, when three of us wrote the booklet "Don't make the journey alone" we gave false names to the press at the launch because of the stigma of dementia.

By hiding our diagnosis we help to create the stigma. The people creating the stigma are ourselves because we are ashamed of the condition.

If we understand that it's an illness, just like any other, not a disease for which we might have some responsibility, there's no need to be ashamed. There should be no stigma, and we should all speak out about it.

There's a lot more we could say about our journey from a sense of total disempowerment to having the confidence to regain some of our power. Our main strength has come from each other, but we need everyone's help to realise the abilities we still have and to live full lives for as long as possible.

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