

**Dementia Awareness Week conference.
Mon 5 June 2006. Glasgow**

James

Good morning. My name is James McKillop and I'm sharing this presentation with Ross Campbell. We are both founder members of the Scottish Dementia Working Group which exists to give people with dementia a voice.

We have been invited to talk about why reducing the risk of dementia is important.

What effect has having dementia had on my life?

The illness had a big impact on my life. The main one was not being able to work to bring in an income to raise my family. The second impact was giving up driving. I didn't do that voluntarily – they took the licence off me. I felt I could have gone on driving longer.

That's a bit negative. On the other hand, I've met an awful lot of lovely people through my illness and the support groups. All these people gave me the power to believe in myself – to believe I could still do things.

Ross

Like James, at first I just sat in a room and looked out the window. Then I met Sheena. Sheena got me out of my shell. She made me join groups.

When I was first diagnosed I lost my driving licence, again not voluntarily – it was taken off me by DVLA. And I lost my firearms certificate which I'd had since I was 17 years old. It's like losing your legs – it just felt as if I wasn't independent any more.

People like Sheena put you back on track. They just don't get mentioned enough. These people are very important. They coax you, they support you, they back you all the way, and they lead you from one group to another group and you go from strength to strength and they get you back into society and some normal vocabulary of life.

James

What effect has my illness had on my family?

The illness had a devastating effect on my family. Up to diagnosis I was exhibiting behavioural problems. My wife and children used to fear me coming home from work. I would argue non-stop with them, thinking they had done things when they hadn't. I became a bit of a tyrant. My wife didn't understand I was ill – I didn't understand it because I didn't know I was ill. It wasn't till I got a diagnosis that they understood I was ill. They could then make adjustments. Life became much happier after diagnosis – and with treatment, of course.

Ross

My story is similar to James. I gave my wife and family a very hard time, again not realising what it was. I was violent – I don't mean physically, but verbally. My daughter and my wife put up with it. Not a word was said. They never retaliated in any manner.

I used to disappear for hours on end. They had the Police out searching for me and everything. There was no explanation given at all. It was finally diagnosed what was wrong with me. Once I went through 3 years of being a guinea pig with medication, once I got my medication stabilised things really started to settle down. Now we're really a family again, which makes life entirely worthwhile.

James

We've been asked if we wish there had been more information about reducing the risk of dementia 20 years ago.

Certainly, because my dementia came from high blood pressure. My understanding was that it affected the heart. I had no idea it could affect the brain. That's what gave me the multi-infarct dementia. If I'd been more aware of the risk factors I could have worked on them to avoid them, because my father had high blood pressure and he died at 54. I just wish there'd been more information to the general public that there were these risk factors and you could take steps to avoid them.

Ross

I got two interpretations of my dementia. One was – I was asked when I was a child had I had a brain operation? Not to my knowledge had I had a brain operation, or a severe blow to the head – not as a child. I had many a severe blow to the head while I was growing up, but not as a child. I checked with my older brother and my older sisters. One doctor put it down to being workalcoholic, or working all hours under the sun – which I did do because I was employed for myself so I had to do it. After working all day I was coming home and working for hours in the house at night trying to draw the estimates and plans for work and materials in advance. I'd be out to work at half seven in the morning and I wouldn't get to bed till 2 and 3 in the following morning.

I don't know what was the truth . I got two different interpretations of it.

James

With hindsight, would I have changed some things about my lifestyle?

Apart from not having met these nice people, yes I would have changed my lifestyle. I would have avoided the things that were causing my blood pressure to remain high. It was very stressful at work, and you couldn't just leave because you had family to support. I would have done something about my job – I'd have moved or got another type of work which wasn't so stressful.

Also I'd have paid more attention to my blood pressure – to do things like taking more exercise to keep it down, and watching what I ate.

Ross

If I'd had hindsight, going back I'd have took a partner on rather than do it all myself. I waited till the latter end when it was too late and I had to take a partner on. If I'd taken a partner on sooner I could have gave myself more of a family life

Physical fitness, yes I was fit because I ran up and down ladders all day and I was humping big heavy stones all day. Maybe eating-wise, I could have looked at that – I was a bit of a gannet. I was fit but I wasn't eating wise, I could have been a lot healthier.

James

Why should people who are well now think about trying to reduce their risk of developing dementia in the future?

Obviously they can listen to people like myself and think right, I don't want to go there. I think it should even start at Primary School. We hear so much about obesity in school children and I think that's where it should start.

It's far too easy to become complacent, thinking it'll never happen to me. Unfortunately when you look around it has happened to people and it does happen to people in their 40s and 50s and early 60s. You've really got to look at your lifestyle and say I've got to take charge of it and alter it.

Ross

Like James I'd go back to the younger generation. I'm a smoker, but I'm talking about kids smoking and drinking. I mean they're drinking now at 12, 14 years of age and they drink rubbish. They want to get rid of that for a start. That's only leading to trouble in the future. That I would like to see changed.

James

We've been asked to comment on whether some lifestyle changes are worth trying even though there's no guarantee they will affect the onset of dementia.

Yes, I think you should make changes. Forget about dementia, its about keeping yourself healthy so you can enjoy life – when you retire and you're able to do things you've wanted to do for a while, you need to be physically fit for that and mentally capable. And you want to be able to watch your grandchildren grow up and enjoy them, so it's worthwhile making changes.

Ross

I agree. One of my doctors once said to me "walk a mile a day, live a day." I'd love to see youngsters changing their habits, because some of them are heading for serious trouble.

James

You've heard the old adage "Use it or lose it." I believe that mental exercises can only be good for you. It passes some of the time of the day, and I believe in my case it's helped me. I was in a self support group some years ago, and there's only two of us that are still active. I feel that's because we'd been interested in stimulating our brain. Again I think it should start early. I didn't take up crosswords until a couple of years ago. I eagerly devour all the puzzles in the papers – I don't always finish them, but I spend up to a couple of hours a day exercising my brain. I feel, looking around at others, that it's helped to stop me deteriorating quite as much as I might have done. But, quite honestly, if I hadn't met Brenda and been encouraged back into the community the way I have been, I'd have been in a home years ago. That's where I was heading for. All these things – the support I get, the brain activities – are keeping me fairly stable.

Ross

I can honestly say if it wasn't for the activities I do, I don't know where I would be. If it wasn't for being drawn out by Sheena, meeting James – which was one of the best things that ever happened to me I wouldn't be here. My brain's very active now.

You've got to keep your brain active at all times. Immaterial of whether it's darts – anything at all. Keep your mind active.

James

Finally, what can we say to someone who has lived a healthy life but still develops dementia?

I would say that there's no guarantees in life. Don't look on the black side of life. You can still have some sort of life – it's not the same life as you had before. It's going to be a new life because of the things that you won't be able to do, but spend time concentrating on things that you can do. That might be relearning old skills or learning new skills. Don't let anyone tell you you can't learn anything new because you can. It might take longer, it might need more repetition. This has been proved by many people I know.

So I'd say: Sorry, it's just bad luck. You did your best, but make the best of what you have left.

Ross

Unfortunately dementia can happen to anyone at any time. Dinnae gie up. Life goes on with dementia. It's not the end of the world. I've never met so many happy people in all my life as what I have with people with dementia. You just live day by day. I'd say "Live healthily, live happily."

Thank you for listening.