

Minutes

Cross Party Group on Dementia

Wednesday 20 November 2013

Dinning Room 1 (First floor), Tŷ Hywel

Topic: The Importance of Timely Diagnosis

Welcome

Eluned Parrott AM welcomed everyone to the meeting and introductions were made around the table.

In attendance: Eluned Parrott AM, Paul Harding (AMSS Eluned Parrott) James Radcliffe (Researcher, Plaid Cymru) Colin Palfrey (AMSS Lindsay Whittle) Amy Kitcher (Alzheimer's Society) Alice Southern (Alzheimer's Society) Linda Hall, Ken Hall, Prof. Anthony Bayer Cardiff and Vales UHB.

Apologies from: Rebecca Evans AM, Llyr Gruffydd AM, Mark Isherwood AM, Darren Millar AM, Julie Morgan AM, Lindsay Whittle AM and Lynne Neagle AM.

Presentation by Linda Hall, a person with Dementia.

Linda was diagnosed in January 2012 with Posterior Cortical Atrophy (PCA) a rare form of Alzheimer's disease

I experienced very slow onset of symptoms and many different symptoms too, like difficulty walking up and down stairs and problems with my vision. It got so bad that I didn't want to go out.

The first set of tests said that it wasn't dementia, but stress. I was prescribed antidepressants, but this made my symptoms even worse. It was a really bad time and I felt like she was going mad. I went back to the doctor's and was referred to the memory clinic at the hospital. I had regular appointments at six monthly intervals. The process took two years; I think this was too long. In the end it was a small thing that led to the correct diagnosis. The specialist noticed me struggling to get some coins out of my purse.

I was really happy to receive a diagnosis and I smiled when they told me. I thought "I can deal with it now". It's hard, but you learn to cope. If I look after myself I can live with it. Laughter helps, but if you need to cry have a cry. Remember that it's not you, it's the illness. Support from family is very important. There are things I can't do anymore, like sewing or knitting. By you adapt. I use a Kindle now and I use an ink stamp to do my Christmas cards instead of doing them by hand. And instead of talking to a cashier at a desk in the bank, I ask for a side room.

A lot of people are ashamed of having Alzheimer's, but I'm still Linda! There's nothing you can do about it. Everyone must learn to cope in their own way.

A lot of people can't laugh about it. I think that women cope better than men because women talk. Men don't want to talk and they bottle their feelings up. I think it's important for them to still do 'men' things, like play darts with other men. That's how they cope. Support groups are important too.

Presentaion by Professor Anthony Bayer

Personal Chair, Institute of Primary Care & Public Health, School of Medicine, Cardiff University. Director, Memory Team, Cardiff and Vale University Health Board.

Changes in the brain take place twenty years before a diagnosis takes place. Early symptoms don't incapacitate an individual and at this stage no intervention is useful. Diagnosis should take place at the right time for that individual; when the symptoms are having an impact on them and their families.

It is important to get the diagnosis right and it is not always an easy diagnosis to make. Sometimes delay is inevitable.

Diagnosis in Scotland is high because the Scottish Parliament made it a priority right at the beginning. Now they are seeing the benefit of more than ten years focus and investment. Wales is about three or four years behind England; and England is behind Scotland. Furthermore, there are differences across Wales. Cardiff has better diagnosis rate than some places in England. But North and West Wales are worse. Cardiff has less resources than five years ago but is receiving 30%-40% more referrals. North and West Wales haven't invested in new services; they simply renamed existing services 'memory clinics'.

Stigma is higher in Welsh speaking communities.

People need to understand that Alzheimer's is not a mental health issue and this label is unhelpful. Alzheimer's is a neurological condition. We don't talk about Parkinson's Disease as being mental health, it's the same thing.

Diagnosis is the start of something and it should not be an end in itself. It should be the mechanism that leads to support. And that there is a need for ongoing help and support too. There is a risk that focus on increasing diagnosis rates will take resources away from support services and we'll end up with more people with a diagnosis of Alzheimer's and less support to offer them.

Questions:

Eluned Parrott:

What mechanisms are there for family members to talk to medical staff?

Anthony Bayer: Previously, confidentiality blocked it. Now, GP's are more aware and relatives are less likely to take no for an answer.

Action points:

Ask oral question about regional variations in diagnosis rates.

Ask oral question about resources for patients after diagnosis.

The meeting was drawn to a close and Eluned Parrott thanks everyone for their attendance.

Date of next meeting

11 February 2014, Conference Room 24, National Assembly for Wales