

Are younger people with dementia and their carers being informed and supported appropriately at the time of diagnosis?

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Younger onset dementia refers to any dementia in a person with an onset of symptoms prior to the age of 65. Over the past 4 years The Ella Centre, which is a provider of aged and disability community care services in the Inner West region of Sydney, has provided services and support to 27 people with a primary diagnosis of younger onset dementia.

At the time of assessment the view was often expressed, by both the client and their carer, that although the time of diagnosis was obviously a very negative experience, it was worsened because they were provided with only limited information and support at the time of diagnosis from the medical professional they were consulting with and that referrals to other support services, for both the person with dementia and the carer, were decidedly lacking.

Let me set the scene with a scenario I have heard several times in the past few years:

For the past 1 -2 years your husband (aged in his 50's) has been slowly changing. With some determined persuading from you, they eventually agree to see their local GP, who listens to the story and begins treatment for stress.

Despite medication there is no improvement and in fact things worsen – the mood swings, forgetfulness and issues with communication. After buying a new puppy (so you have someone to love you) and a year of constant arguments, you eventually insist further investigation is required, so the GP sends your spouse to a specialist, who orders a range of test and scans that incorporate every letter of the alphabet CT, PET, MRI, SPECT etc.

By now you are convinced your spouse has a brain tumour and won't see next Christmas. Finally, after the specialist has examined all these test results, the time arrives when you accompany your spouse to receive the diagnosis – “Dementia” is the pronouncement. The specialist comments that you are young to have this illness, rattles off some technical jargon, says he will send your GP a letter and waves you farewell.

Is that it? What does that mean? Frontal what? Lewy who? What does this mean for your future retirement plans? Does this disease progress and will the symptoms get

worse? What help is available for your spouse? Where do you, in your new role as a carer, go now for information and support?

Case studies show a similar story – one where carers are left to find their own way through the maze after their spouse receives a diagnosis of younger onset dementia. There is little information provided about the disease and how it will progress and little input, at the initial stage of diagnosis, from the medical professional as to how they can access the information and support they desperately need, for both the person with the diagnosis and for themselves as a carer.

It is only by pure chance that they may eventually stumble on someone who can head them in the right direction.

Let me share some case studies with you that highlight this.

Case Study 1

S. first noticed changes in B. in 2006, when he was aged 55. B. was a builder, with his own company and S. was the Office Manager for the company. According to S. she had noticed confusion in time and place and obvious short term memory loss. For 3 years his symptoms were put down to stress and that "his wife was mad".

In early 2009 B. was seen by a Geriatrician who, armed with results from an MRI, PET Scan and a CT Scan, conducted a mini mental and eventually made a diagnosis of dementia. According to S., B. showed "no real emotion one way or the other" to the diagnosis, whilst she was "Happy to actually have a diagnosis"!

The doctor provided only verbal information and the long term situation was not discussed. There was no information provided regarding any type of services to support either B. or S. In fact, S. reported that later on she found the number for the Carer Respite Centre "by accident" and they gave her information on available services.

Case study 2:

In 2009 G., a community nurse, noticed both confusion and personality changes in her husband P, who was a forklift driver. He withdrew from social activities he had previously enjoyed, becoming jealous and angry if G. continued to participate in social events they had previously enjoyed together..

In July 2010, following a SPECT Scan, MRI, Mini mental and 6 hours of psychological testing, P. and G. saw a neurologist, who diagnosed dementia. They were given limited verbal information about dementia and no written information. There was no information provided about the course the disease would take and how it would progress, as well as no referrals to health services or community support services.

P. refused to accept the diagnosis and G. said when she came away from the appointment she was left feeling "depressed ++". To date, G. has still not accessed any services, as P. refuses to believe there is anything wrong with him, despite the diagnosis and a further visit with the neurologist. G. has been forced to access information without P.'s knowledge.

This anecdotal evidence led The Ella Centre, in early 2011, to investigate further whether the experiences of people with younger onset dementia, at the time of diagnosis, were as unsatisfactory as it appeared. Issue 45 of the Pfizer Health Report titled 'Dementia is everybody's business', published in 2011, stated that "63% of people are afraid of getting Alzheimer's or another form of dementia - a fear that is second only to the fear of having cancer (66%)".

Given this, the delivery of a diagnosis of dementia would be expected to be made by a knowledgeable health care professional, who was able to deliver the diagnosis in an empathetic and supportive manner, whilst ensuring that appropriate information (verbal information that was supplemented by written materials) was provided to meet the needs of both the person with dementia and their carer, as well as providing opportunities for questioning.

Evidence from other sources demonstrates that the nature of the dementia diagnosis delivery has been an issue that others have felt a need to investigate and comment on. On 20 October 2006 Alzheimer's Europe released a paper detailing their position on the disclosure of the diagnosis of dementia to people with dementia. This paper was based on a carers survey, carried out by Alzheimer Europe, involving over 1,000 carers of people with Alzheimer's disease.

Their position paper concluded with the statement that "Alzheimer's Europe emphasises the need to provide people with dementia and carers with information about the disease, treatment and services at the time of diagnosis, and to ensure that every person receiving a diagnosis of dementia is given the contact details of the national and local Alzheimer associations"

In Alzheimer's Australia Paper 10, published in March 2007, titled 'Early Diagnosis of Dementia', Alzheimer's Australia stated their view that, amongst other points, they believed everyone has the right to :

- *"Sensitive communication of a diagnosis with appropriate explanation of symptoms and prognosis,*
- *Sufficient information to make choices about the future".*

In 2008 the Alzheimer's Association in America drafted a statement called '*principles for a dignified diagnosis*' following the report *Voices of Alzheimer's Disease: A Summary Report on the Nationwide Town Hall Meetings for People with Early Stage Dementia*.

In this the Alzheimer's Association identified diagnostic challenges and dissatisfying interactions with the medical community as two major challenges articulated by people living with the disease.

These principles are their insights on how to make that experience better and include points such as:-

- ***"Deliver the news in plain but sensitive language.***

This may be one of the most important things I ever hear. Please use language that I can understand and is sensitive to how this may make me feel.

- ***Give me tools for living with this disease.***

Please don't give me my diagnosis and then leave me alone to confront it. I need to know what will happen to me, and I need to know not only about medical treatment options but also what support is available through the Alzheimer's Association and other resources in my community".

In September 2010 Dr Jill Phillips (University of Newcastle) Professor Dimity Pond (University of Newcastle) Dr Allan Shell (University of New South Wales), in their publication **Quality Dementia Care Standards: No time like the present: the importance of a timely dementia diagnosis** stated that:

" *While circumstances differ from person to person, everyone has the right to:*

••A thorough and prompt assessment by medical professionals

••Sensitive communication of a diagnosis with appropriate explanation of symptoms and prognosis

••Sufficient information to make choices about the future

After reviewing information from papers, reports and research as to what constitutes an acceptable diagnosis delivery, it was decided to look into whether, at the time of diagnosis, younger people with dementia and their carers, living in Sydney, had received their diagnosis in a manner that was consistent with the following essential elements for a dignified delivery of a diagnosis:

1. Sensitive delivery of the diagnosis
2. Clear verbal information on the nature of the illness and the expected progression of the disease

3. Written information that could be taken away and read later to provide further understanding
4. Referrals to health services / agencies for ongoing management of the disease
5. Information on community support services that could assist the person with dementia
6. Information on community support services that could support the carer

A survey was designed that would record the experiences of both the person with dementia and the carer at the time of diagnosis, to discover what was happening when people were receiving this diagnosis of younger onset dementia. For many, reaching this point of diagnosis had taken an extended period of time and this appointment with their health professional was to be a turning point in their lives.

Our survey aimed to determine whether this diagnosis was delivered in a sensitive manner, with adequate verbal and written information for both the person with dementia and their carer, so that their distress at the diagnosis wasn't increased by insensitivity, a lack of information and feelings of isolation due to an apparent lack of support options available.

23 surveys were sent to people with younger onset dementia and their carers who were known to me through my work at The Ella Centre or through the Younger Onset Dementia Association. Of these, 17 were returned, providing a return rate of 74%.

The average age of the respondents who had been diagnosed with younger onset dementia was 57. The average timeframe to achieve their diagnosis, from the onset of symptoms, had been 1.5 years.

The statistical responses were as follows:

REQUIREMENTS of a QUALITY DIAGNOSIS	YES	NO
Sensitivity	71%	29%
Clear verbal information	76%	24%
Written information	35%	65%
Information on the progression of the disease	47%	53%
Health referrals	53%	47%
Community support service information	40%	60%

Of the 17 people, 2 had received their diagnosis from a psychiatrist, 4 from a geriatrician and 11 from a neurologist. Of these 17 health professionals delivering this life changing diagnosis, only the 2 psychiatrists and 2 of the neurologists provided a comprehensive verbal diagnosis that was backed up by written information about the disease that could be taken and read later.

REQUIREMENTS of a QUALITY DIAGNOSIS	GERIATRICIAN	PSYCHIATRIST	NEUROLOGIST
Sensitivity	100%	100%	80%
Clear verbal information	100%	100%	72%
Written information	25%	100%	27%
Information on the progression of the disease	25%	100%	50%
Health referrals	25%	50%	60%
Community support service information	50%	0%	20%
Carer support service information	25%	0%	9%

Although mindful that a degree of recall bias would occur and that recall may be affected by the time elapsed from the diagnosis to the time of the survey, the memories for the carers were still so pronounced that it would seem there is a high level of validity to the findings. Given this, I feel it appropriate to also note some of the written responses provided by the carers to some of the questions.

REQUIREMENTS of a QUALITY DIAGNOSIS	COMMENTS WE SHOULDN'T HEAR
Sensitivity	*a more appropriate bedside manner no compassion *doctor was cold, blunt and insensitive
Clear verbal information	*very confused *distinct lack of information *confirmation only - sought information myself
Written information	*given technical reports to read *no - due to my job may have assumed (pharmacist)
Information on the progression of the disease	*long term NOT discussed *told she had 5 years to live *letting us know more about the progression - that it is terminal *told could not guess progression as all different
Health referrals	*friend working in health

Community support service information	*package on services for the elderly *by accident *making phone calls
Carer support service information	*no - made own calls *none - had to research *made tons of phone calls

Even though the number of survey respondents represents a very small snapshot of people living with younger onset dementia, I feel it is still possible to draw a number of conclusions from these results, which highlight areas for improvement.

1. The provision of *written material*, as follow up reading and with numbers to call for support and further information at a later date, is limited.
2. There is a distinct lack of information provided on the *manner* in which the disease may *progress*.
3. *Referrals* to other *health services* needs to be improved.
4. Information regarding *community support services*, for both the person with the *diagnosis* and the *carer*, is largely ignored by health professionals when delivering the diagnosis.
5. Overall, *neurologists* faired poorly when compared with geriatricians and psychologists.

I leave you with the words of Harvey Williams Cushing, M.D. (April 8, 1869 - October 7, 1939), who was an American neurosurgeon and a pioneer of brain surgery who stated that:

"A physician is obligated to consider more than a diseased organ, more even than the whole man - he must view the man in his world"

