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(Dementia)
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Submission to House Committee On Health and Ageing

Inquiry into Dementia: Early Early Diagnosis and Intervention

My name is Leo and I want to thank you for the opportunity to make this submission to the House Committee on Health and Ageing inquiry into Dementia Diagnosis and Intervention. I have Dementia. I have no doubt that you have received very many submissions outlining the difficulties and heart breaks in obtaining an early and accurate diagnosis; I am one of the lucky few as it was only 6 months from the time I first saw my doctor about my memory problems until I received a confirmed diagnosis. I offer my case to you so that you may better understand why my case was so different to so many others and the benefits of receiving a quick diagnosis.

In September 2008, shortly before my 60th birthday I saw my GP for depression. I was feeling quite depressed and among other things began to forget appointments and meetings that I had attended. My Doctor started me on anti-depressants; however, I did not get better and in fact became even more depressed and forgetful.

In October my doctor decided to take me off of the anti-depressant and said that once I had “cleared my body of the antidepressant we would look into some other things”. While I was going through that process, I became disoriented while walking around in downtown Launceston. I was quite familiar with this location and became dismayed when I couldn’t find my way to the place I was going and then could not find my way back to where I had parked my car. I knew the name of the street where my car was located but could not find it. When I eventually, with help from other people, found my car, I couldn’t remember how to drive home. I sat in my car for several minutes while I slowly figured out where I was and how to drive home.

When I got home I called my wife and we scheduled an appointment with my Doctor. When I told him what had happened, he immediately scheduled me for a C-T brain scan, referred me to a Neuro-psychologist, and referred me to the Launceston Memory clinic.

My C-T scan revealed some small changes in the hippocampus region of my brain; this is the region of the brain that is often first affected by Alzheimer’s Disease.

The Neuro-psychologist administered a whole series of tests over a 6 week period. At the conclusion of those tests, she gave me a preliminary diagnosis of Dementia-possible Alzheimer’s.

After 4 months I still had not been given an appointment at the Launceston Memory clinic and took steps to get an appointment. When I got my appointment, it was very quick and hurried. Basically following a physical exam, I was sent off to get blood work done and told I would have another appointment in 3 to 4 months.

Not being content to wait, I was able to obtain an appointment with a Psych-Geriatrician in Hobart through the assistance of my Neuro-Psychologist and Advocacy Tasmania. At that 2 hour appointment, the doctor listened to me, read the report from my Neuro-psychologist, discussed my C-T scan with me, and administered more memory tests. At the conclusion, she gave me a confirmed diagnosis of Dementia probable Alzheimer's and started me on medication (Aricept) that day. I then cancelled my follow up appointment at the Launceston Memory clinic.

Thus it was only 6 months from when I first saw my Doctor until I received my diagnosis. This is quite different from the experience of most people with Dementia who seek medical assessment and go years before getting their diagnosis. I believe there are 3 reasons for my early diagnosis and treatment.

First, I had an excellent GP; he recognised the symptoms and took immediate action. His actions stand in stark contrast to many doctors who either mis-diagnose or fail to tell the person that they have dementia.

Second, I knew something was seriously wrong with me and I was not going to stop until I found out what it was. If I had not seen the Neuro-psychologist and waited patiently for an appointment at the Launceston memory Clinic (as most people do) I would have wasted several months or longer in getting a diagnosis. Currently the time to obtain an appointment at the Clinic is over 9 months.

Third, I had the money to pay for the Neuro-psychological testing ($800) which is not covered my Medicare or private cover. The Neuro-psychological testing is very extensive and detailed; it gave me lots of information about how my dementia was affecting my memory. Anything the Committee can do to get this testing covered by Medicare would go a long way toward improving the time of diagnosing dementia.

The benefits of my early diagnosis are many. They include the following:

I was able to start medication very early in the process. The medication is most effective when started early. Under the direction of my Psych-Geriatrician, I still take Aricept and this allows me to stay independent for as long as possible.

My wife and I were able to get counselling help while I was still quite cognitive. We saw the counsellor for 1 year after my diagnosis.

My wife and I were able to complete an "Enduring Power of Attorney" and a "Living will" in a timely manner and plan for other changes while I was fully able to comprehend what was going to happen to me.

> My wife and I were able to take advantage of other Support agencies including Alzheimer’s Australia.
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> As hard as it may seem to believe, receiving my diagnosis was a relief to me. My biggest fear was that doctors were going to tell me that nothing was wrong with me when I knew something was seriously wrong; I would have thought I was going crazy. By getting the diagnosis, as bad it is, at least I know what I’m dealing with.

Please feel free to contact me if you have any questions or desire any additional information.