Supp. Submission No. 008.1
(Dementia)
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PARLIAMENTARY INQUIRY: DANIJELA TELECONFERENCE 1.40 PM, FRIDAY 27/7/2012

INTRODUCTORY STATEMENT:

I am very grateful that you gave me this opportunity to present my testimony in a teleconference, because I am passionate about improving dementia research and care and I was not able to travel to Launceston.
My submission , you may recall, is about the importance of early diagnosis of dementia in general but also with emphasis on clients of CALD background, because this is where my knowledge and experience are from. I will share some personal findings in the hope of enlightening you on some issues.

Our government needs to accept that dementia is here to stay, it is more dangerous that any other illness because we don't know what causes it, we don't know how to prevent it or how to treat it, so the human and financial cost to us all is enormous. I will cover three Key points:

1-Early diagnosis is a human right

2-The urgent need for improved education of doctors and other medical and care professionals

3-The need to raise awareness on all matters relating to dementia and the need for improved knowledge translation of already established findings

The main positive experiences I have had are in all my dealings with people who have dementia, and their carers, and from a number of networks like Alzheimer's dementia consumers research network, MRC, staff in nursing homes ,my employers. I find people in general are understanding and compassionate about dementia sufferers and their loved ones. My main negative experiences are often due to lack of education and money ; ie

> Lack of knowledge and understanding from GP's, psychologists, nurses and other staff; The stigma, the ignorance, the fear of dementia, and mostly the lack of funds to do more research, and offer better person centred care to both the PWD (person with dementia)and the carer. Personally, and in the name of those I will talk to you about , I would like to see that the necessary funds are allocated to improve this situation, and that at the same time, through education, we start opening our hearts , as well as our pockets. Illness of any kind requires medication as well as love.
> I would like to see better research knowledge translated onto practice, better training of GPs to deliver the diagnosis and to recognise the symptoms, and to acknowledge just how much an early diagnosis can improve the quality of life of the person with dementia and their families and prevent great deal of unnecessary suffering for all involved, and great financial savings.
> Research is showing the importance of early diagnosis. Once the process that destroys brain cells has begun, the disease is irreversible. But if researchers can find a way to catch it early and slow it down, they think they can prevent much of the worst damage.
> William Thies, chief medical and scientific officer at the Alzheimer's Association, in the States, says he expects antibodies already in trials to someday help prevent Alzheimer's by stopping the formation of harmful protein deposits. I would like additional campaigns run by Communities of culturally and linguistically diverse people, in

partnership with Alzheimer's Australia.1 in 9 people who suffer from dementia in South Australia and West Australia are from Non English background,1 in 29 in Tasmania, they deserve equal care in every possible respect.

1st, I want to stress my strong belief THAT EARLY DIAGNOSIS OF DEMENTIA IS A HUMAN RIGHT, any doctor not feeling competent to do it must refer the person to another doctor. Ideally, all GP's should be properly trained in preliminary diagnosis. 10 years ago, my mother and our family lost precious years in sadness and frustration, because we knew nothing of dementia. I took my mother to three different doctors, all caring and good, but all they "saw" was a woman of eccentric behaviour and depression who was very "difficult" and so they told me to place her into a home which of course I refused.. When my mother was telling me that she got lost on the beach and could not come home for dinner, and father and I waited till 9pm on New Year's eve, we did not believe her, were so upset with her. When she would call me many mornings "come quickly" and the bathroom was flooded or smoke detector was going because of a burnt toast, when she accused me of stealing her money, I suffered so much and was angry with her, thinking she is doing it on purpose. **How scared and lonely she must have felt, not being believed.** Yet no doctor thought of referring us to other specialists.
I have had more than one client of CALD background who is in my opinion not safe to live alone at home due to dementia, yet they have not been formally diagnosed and their sons/daughters respect parents desire to stay alone at home. They may be on Extended care packages, but not always, and often they are eating food that is no longer fresh, some have open wounds on their legs, are incontinent etc. A lady of 75 no longer visits her sister in a nursing home, because she fears she may "catch" dementia from her; 3 adult sons and a daughter no longer talk to their mother, who lives alone at home, because she accused them of stealing money from her. She has dementia, lives behind closed curtains...these examples all illustrate lack of education.

In our society today, I think the stigma has diminish a little but in some communities it is still believed that whatever happens to the parents is part of "old age senility" and must be tolerated, and that is all, therefore very few are actually diagnosed and then assisted in a proper way. But the correct diagnosis would not only enable the person to get THE RIGH MEDICATION, to slow down the disease but would also GIVE THEM TIME TO MAKE SOME DECISIONS,AND AVOID HURT AND MISSUNDERSTANDINGS KNOWING THAT THE PERSON'S BEHAVIOUR IS THE RESULT OF THE ILLNESS, AND FOR THE PERSON TO BE REASSURED AND COMFORTED.
I remember my mother asking so many times during about 4 years:" Am I going mad??"

2-Second key point of my Submission is the urgent need to educate doctors to accept responsibility to
1-deliver tests for early diagnosis professionally and efficiently
2-deliver results of these tests as well as a package of information for the person with dementia and family. If I may point to an article in
The Telegraph, UK last Feb 2012: QUOTE

The study revealed a number of disturbing attitudes held by doctors and nurses when dealing with vulnerable patients.

One consultant admitted to using a “veterinary approach” towards those needing treatment while another said dementia patients were “hugely sapping of our scarce resources”.

It was even reported that some medical staff believed dementia sufferers do not feel pain in the same way as those without the condition.

The startling disclosures were made to John Gladman and his colleagues at Nottingham University who carried out interviews with 60 doctors, nurses and other staff at the Queen’s Medical Centre and Nottingham City Hospital (which started in 2008.)

Prof Gladman, who specialises in care of the elderly, said most of the staff had not been trained to look after dementia sufferers and often “make it up as they go along”.

He said: “Some people (doctors and nurses) said they had never had any training at all. People said they knew the causes of dementia – they could tell you microscopic changes that happen to patients – but they didn’t know what to do. They sort of make it up as they go along.”

UNQUOTE

And my experience confirms this; having cared for my mother during her for 10 years struggle with dementia, I saw all the stages. Having worked with people who have dementia, I saw a variety of Alzheimer’s conditions. When I myself had a number of problems with short term memory, lack of concentration, lack of balance, no co- ordination, and I underwent general psychological tests to determine if I had dementia, the doctors said “NO dementia diagnosed; , WHAT IS HAPPENING IS DUE TO STRESS, NO NEED TO WORRY.

When I said I was not satisfied with this, and would like to have more tests, I was told I would need to pay over $800 for a Neuro-psychological testing. When I asked if we can at least monitor me every year, I was told no, it is too expensive, I can come back in 3 years. In the last 7 months, I have suffered from 3 suspected Transient Global amnesia attacks (twice hospitalized) as well as dizziness; and yet, I am still waiting for an appointment with a Neurologist through Royal Hobart.

I believe any test that would determine if I have dementia or not should be on Medicare because in the long run the savings of a correct and early diagnoses to the health care budget are very high.

To illustrate the need for further training of doctors, I will add my doctor (clinical psychologist)comments:: quote” Why would you want to know if you have dementia any way! You would only worry.” unquote

I replied:

“No, I would not worry; firstly I would be satisfied to finally have a diagnosis to the poor performance of my brain, second- I would be able to make some plans for my life; sign documents, make provisions; thirdly I would maybe be able to take medication that slows down the progress of dementia.”

The doctor then told me she did not know such medication exists. So I know from experience that doctors, nurses, support workers, all need more education and training on how to diagnose and how to treat dementia, some studies should be compulsory, and others optional to those who select to work in the field. And I would also like to stress that no matter how much we are in the technical world of computers and tablets and I pods, for people of CALD background the old fashioned way of personally attending seminars, courses, hearing testimonials , discussing, sharing information etc is often still the preferred way to go

3rd Key point in my testimony is the necessity to raise awareness of dementia. You would be surprised how often I come across people, taxi drivers, teachers, sales people, who still know nothing about dementia. I believe we need to use people who have knowledge and experience of dementia to give talks, write books, make documentaries . And in addition, we must improve knowledge translation of research findings into practice. I believe that in the last 3-5 years we have had a number of great research projects with significant findings, yet the recommendations of these findings have not been adopted.

I would like to refer to an article *in Neuropsychologia*. July 2009 quote:

Can using pictures assist memory recall in people with Alzheimer's disease? It's possible it may, according to researchers from Boston University School of Medicine, who found that pictures allowed those with mild cognitive impairment, a serious form of memory loss that sometimes precedes Alzheimer's, to better recognize and identify a subject as compared to using just words.

The reason using pictures may help, the researchers found, was that those with memory defects retained a general sense of familiarity with various subjects, even though they couldn't find the words to recall or recognize them. The findings appeared in the current issue of the medical journal *Neuropsychologia*. " Unquote-

MY MOTHER, FOR EXAMPLE, recognized SNOW on the mountain, one day when we were driving towards Mt Wellington, and happily exclaimed in her language:SNEG GLEJ SNEG!" (Snow, look, snow).

Five minutes later I pointed to the mountain and said to her: Look mum how the sun is shining on the snow now" she looked at me confused: "Snow, what is that?" And later I asked her if she wanted a banana, and again she did not know what that was; when I gave her one into her hand, she smiled with delight:" I love bananas" she said.

YET, DESPITE KNOWING HOW PICTURES AND REAL OBJECTS CAN HELP, THERE IS NOT ENOUGH EMPHASIS ON USING THEM IN NURSING HOMES OR IN FACT AT HOME; especially with CALD clients, pictures and sounds, bilingual posters etc.,are so helpful. Mum was given mashed vegetables; she asked why she is given baby food; she did not recognize it as a vegetable; or if there was sliced veggies, they were usually covered in gravy; picture of a clear color and object helps person identify it. At home, with clear red carrots, white cauliflower etc., she ate with pleasure.

I believe pictures should also be used in the tests for EARLY DIAGNOSIS , WITH THE PRESENCE OF A QUALIFIED INTERPRETER.

Mum and I had an appointment with so called "dementia specialist" about two years ago, to assess progression of the illness. She was already in residential care however spending most days with me at home. The doctor asked me to translate for mum: Questions were like:

"Do you know what day it is, what month, where you are, who is this woman with you, what is your name, are you married, how many children you have, and so on; (my mother migrated to Tasmania in her seventies, and relied on me totally, never had any English, and never needed to know about days and months). She did not have answers to other questions but she did tell him she knew who I was-her mother who took such good care of her.

UPON HER REPLIES, THE DOCTOR TOLD ME HER DEMENTIA IS "STABLE"…but I could see all the other signs and I knew it has progressed. **The doctor was following a prescribed list of questions, in my opinion, useless. Just as I believe Mini Mental State examinations are totally inappropriate for some people. I met 4 Tasmanians in the last few years that were wrongly diagnosed as not having dementia because they passed the Mini Mental with flying colors!**

IT IS VERY IMPORTANT TO TAILOR THE TESTS TO EACH INDIVIDUAL 'S NEEDS.

And to go back to the article I mentioned earlier: quote

"Pictures have a clear memorial advantage over words, but the debate as to why - is far from settled," Dr. added. If that's the case, it may be possible to develop techniques to enhance memory in patients with Alzheimer's, the researchers proposed". unquote

I believe that to use pictures in all the tests to diagnose possible illness, or to check its progress, would be very beneficial.

As for raising awareness, in general and more so in CALD communities, I believe we need people who have dementia at an early stage, and carers who have practical experience, to go to gatherings in Day Centers, Churches, clubs, and talk about dementia, share knowledge and experience. There should be procedures in place for each state bodies of Alzheimer's Australia, Carers Australia, MRC, Multicultural Councils, **to work together,** to know exactly who are GP's trained in dementia as well as cultural diversity, how many non English speaking clients with dementia there are in nursing home, what bi cultural assistance they need, and the same for those still at home, as well as how many bi cultural workers with dementia training there are, where to find them; these registers would enable better access to assistance

I have, in the last 3 years attended many conferences, forums, workshops on dementia, in Tasmania, and on the mainland. When I give presentations, people often have tears in their eyes; I show a DVD of my mum, I read poetry and prose about what dementia did to her, to me, to our family. And mostly, I try to educate that dementia is not all doom and gloom. In the last 4 years before she died, my mother no longer remembered her 2 wars she lived through, her unhappy marriage, her addiction, her ill health, her displacement from her homeland, her far away brother and sister…Our last 4 years were often filled with laughter and joy, she felt loved, young, beautiful; she often fell in love with a kind softly spoken resident in her retirement home; she was cheeky, all inhibitions were lost, she felt loved and to the end of my life, I will remember her happy face, sparkling eyes, as soon as she saw me walk through the door, “MY DANIJELA”, she called out in delight. IT IS CRUCIAL TO RAISE AWARENESS ABOUT THIS SIDE OF DEMENTIA TOO, and how much family can help, and how much more the government must do to ENABLE THIS TO OCCUR IN A SAFE AND FINANCIALLY ACCEPTABLE WAY. Our government needs to accept that WE , AND MANY OTHERS, HAVE LOST PRECIOUS YEARS DUE TO A MIS DIAGNOSIS OR LATE DIAGNOSIS OF DEMENTIA. Our very sad suffering of 4 years could have been prevented. The human and financial cost to us all is enormous. I sincerely hope that this parliamentary enquiry will be able to make the necessary recommendations to eliminate dangers of late or wrong diagnosis of dementia and I thank you for listening.

CARPE DIEM-SEIZE THE MOMENT: THE TIME TO ACT IS NOW

One of my poems about dementia:

Mother dear,
despite your dementia
you were wiser than me:
You knew how to savour
the breadcrumbs of your life,
refusing to succumb to
dementia cruelty.
Thank you
for allowing me to live **for** you,
while sharp antenna of dementia induced sensitivity
enabled you to dance and forget and laugh.
It is our mind alone that chains us
or sets us free. Yours, consumed by dementia,
opened a door to spontaneous, inhibitions free joys,
moments of flirting, being in love again,
so excited at the wonders of life.
“Life is beautiful, if you know HOW to live it”
you told me with a wink in your eyes.
You radiated light mother
I merely reflected it.