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(Dementia)
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MISDIAGNOSIS AND LATE DIAGNOSIS OF DEMENTIA TAKE AWAY PRECIOUS MOMENTS TO PEOPLE WITH DEMENTIA AND THEIR FAMILIES.

My name is Danijela and I thank you for the opportunity to make this submission to the House Committee on Health and Aging Inquiry into Dementia Diagnosis and Intervention.

My mother Marija had dementia and I was her carer.

My mother died 4 months ago. I miss her terribly. I am writing this submission to point out how important it is FOR DEMENTIA TO BE DIAGNOSED AS EARLY AS POSSIBLE for ALL concerned.

Our dementia journey is over 11 years. The first 4-5, were the hardest and most damaging to my mother and all the family, because WE WERE ALL UNAWARE THAT SHE WAS ILL AND THE DOCTORS CONTINUED TO TREAT HER FOR SEVERE DEPRESSION AND ADDICTION. (My mother suffered from both these conditions all her life).

Doctors must be aware that a person of culturally and linguistically diverse (CALD) background who have limited to no English must be tested in all possible ways to establish whether changes in behaviour are due to existing illnesses, old age, or in fact the symptoms indicate dementia. Unfortunately, mum suffered from extreme mood swings, was quite self centred, stubborn, wanted always to be the boss and believed that what was ours was also hers as we were her family. Additional behavioural changes were forgetfulness, hiding money and jewellery then not finding it so she accused family of stealing from her; burning food, going for a walk then telling us she got lost, lots of crying, leaving tap on and flooding the bathroom etc. Her medication consisted of anti-depressants and tranquillisers as well as painkillers and cigarettes. (We removed alcohol from her life).

I knew nothing about dementia; we lived in a small country town in Tasmania. We regularly used three local doctors who were all very caring and kind to us, however all three doctors basically advised me to place mum in a nursing home because she was “becoming too difficult”. My parents depended totally on me for everything. My mother was often frightened of her own behaviour, and we, the family were often angry with her BECAUSE WE DID NOT KNOW THAT HER STRANGE BEHAVIOUR WAS AS A RESULT OF HER HAVING DEMENTIA…When my father died mum and I lived alone and it was very hard to keep her safe and happy and we were often angry with each other.

In 2005, I needed to go into hospital and required respite for mum. I placed her in a culturally appropriate nursing home in Melbourne, where staff spoke her language and many residents were from the same country of birth. I hoped that mum would be safe and happy there. AFTER 3 DAYS I WAS TOLD THAT MY MOTHER’S HORRIBLE BEHAVIOUR WAS TOO

DISRUPTIVE &UNACCEPTABLE, AND STAFF AND CLIENTS COULD NOT TOLERATE HER. At that point the manager of the facility asked if “mum had been assessed for dementia?”

So after so many years my mother was finally diagnosed by doctors in Melbourne as having alcohol related dementia. Creutzfeldt-Jakob disease.

I was told at the time that any kind of medication TO SLOW DOWN THE PROGRESSION OF THE DISEASE WAS NOT POSSIBLE FOR MOTHER – DUE TO BAD SIDE EFFECTS. But no one told me that as mum was no longer drinking, her dementia may improve or stabilise and I believe it did, in some ways.

With the diagnosis, I was able to accept all of my mother’s behaviours, I loved her, helped her and reassured her. Often she asked: “am I going mad? What is wrong with me?” I replied with reassurance and compassion, letting her know that we will always be together and I will always be there for her. As a result I LEARN”T ALL I COULD ABOUT DEMENTIA.

The last 5-6 years of our dementia journey have been fantastic, filled with laughter, excitement, joy, and so much unconditional love. She was my light, my purpose; I was her window to the joys of life. Of course, for both of us, to accept the progression of illness was very hard; it was very difficult when she could no longer recognise her other daughter; when she could no longer go the toilet on her own; when she stopped enjoying her food or when she no longer cared about her grey hair and wrinkles.

MY DEEPEST REGRET IS THAT WE LOST SO MUCH TIME DURING THE FIRST YEARS OF HER ILLNESS. TIME WASTED BY REPETITIVE MIS-DIAGNOSIS BY ALL HER DOCTORS. I AM SAD ABOUT ALL OUR UNNECESSARY FEAR, STRUGLE, ANGER, MY POOR MOTHER MUST HAVE FELT SO MISUNDERSTOOD AND ABONDONED AT TIMES, WHEN WE DID NOT BELIEVE HER.

IN ADDITION, I HAVE LOST PRECIOUS YEARS WHEN I COULD HAVE BEEN STUDYING ABOUT DEMENTIA AND ACTIVELLY ASSISTING MY MOTHER, INSTEAD OF BECOMING EMOTIONALLY AND MENTALLY ILL IN MY CARING ROLE.

EARLY DIAGNOSIS OF DEMENTIA IS A HUMAN RIGHT AND MORE RESEARCH IS NEEDED **NOW**, ESPECIALLY SO AS TO ENABLE PEOPLE OF CALD BACKGROUND TO BE DIAGNOSED IN A TIMELY MANNER, WITH APPROPRIATE TESTS, INTERPRETERS and BI CULTURAL AND BILINGUAL CLINICIANS.

MY MOTHER NEVER KNEW SHE HAD DEMENTIA, AND SHE WOULD NOT HAVE UNDERSTOOD MUCH ABOUT THE ILLNESS. I HELPED HER ACCEPT ALL THE GRADUAL CHANGES IN HER LIFE AND SHE HAD TRUSTED ME COMPLETELY.

THREE YEARS AGO I UNDERWENT SOME TESTS MYSELF, DUE TO POOR MEMORY, LACK OF CONCENTRATION, POOR ORIENTATION, DEPRESSION, POOR CO ORDINATION. I WAS WORRIED I TOO HAD DEMENTIA. THE DOCTOR SAID TO ME:” But why do you want to know IF IT IS DEMENTIA? You will just panic and worry…? NO, I WOULD NOT PANIC, I WOULD **ACT**. Doctors should not determine what we should or should not know, if an individual asks for the TRUTH they should be given it.

In my work in aged care, I see so many cases of people of CALD background living alone at home, no longer safe or well, many with dementia not diagnosed due to language, stigma issues and cultural misbelieves that it is “just old age”. I see their family members or partners angry and impatient with them, and very hurt too, not knowing that the change in the behaviour may be caused by dementia.

DEMENTIA takes away a person’s independence and dignity we owe it to society to facilitate early diagnosis so that people can take control of their lives and make decisions before it is too late. It is so important to <u>IMPROVE ACCESS TO EARLY DIAGNOSIS OF DEMENTIA FOR **ALL** PEOPLE.</u>

KEY POINTS
1-Continue the research to improve testing/diagnosis of dementia particularly for people of CALD Background
2-Educate doctors to accept the responsibility to deliver the results to people with dementia and their family
3-Raise awareness of dementia, the more we know about the disease the better we can deal with it, manage it and support people with dementia their families and carers.

Danijela