Dear committee,

I am writing in response to your public invitation for submissions for your Inquiry into Sleep Health Awareness in Australia. I would like you to consider any information that I provide that could disclose my identity to be withheld from public record.

I am a 50 year old woman living by myself in Government housing in South Australia. I retired from my former APS 5 position with DHS Centrelink in 2017 due to my medical condition, and am currently in receipt of an Invalidity Pension which is paid by PSS which was my Superannuation Fund.

I was finally diagnosed in September 2017 with Narcolepsy, after having lived with this condition for most of my life. My earliest memory of having symptoms of this sleep disorder goes back to when I was in my early teens. My symptoms gradually worsened over the years, with me managing most of the time to continue working and raising a family by making changes to my day to day life whenever possible, all the while not knowing why I was struggling to lead an ordinary life.

It wasn’t until mid 2013 that the associated fatigue finally affected me to the point that I was no longer able to even wake up on a regular basis to go to work. This occurred after having had a demyelinating attack on my brain that my Neurologist has diagnosed as a (CIS) one off attack of MS (Multiple Sclerosis.)

Prior to 2013, I had for roughly 2 years leading up to that been gradually showing other symptoms that I was trying to get answers for with the assistance of my GP. All symptoms were being looked in to, and I was sent to various specialists for further investigation with none of them being able to provide me with a diagnosis. My work was beginning to suffer from the tiredness, and slowly increasing short term memory loss, until I got to the point of no longer being able to attend in 2013.

I spent between 2013 and 2017 attempting several returns to work, as recommended by the specialists that my work sent me to see during this time. The frustration experienced by not being well, yet not being able to provide an answer to why I was like this was horrible. I am fortunate that I had a very good GP who believed me, and had been my GP since 1998, and had witnessed the changes over the years. If I didn’t have that support I would have been forced to resign from my position well before I finally did leave, and then would have had to apply for a payment that I once administered. I would have had to apply for Newstart as I didn’t have an official diagnosis, and would have suffered as a result of not being able to meet the participation requirements to be eligible to receive payment.

It was my neurologist that initially referred me to the respiratory clinic to see the “Sleep specialist”, after I mentioned that my Psychiatrist (diagnosed with depression in 1998), had given me a private script for Modafinil to try to see if it would help my fatigue. I had experienced some improvement with 1 tablet per day, but due to the expense of the medication was unable to increase my dose to see if it improved more. This medication is only discounted for those who have been given a Narcolepsy diagnosis as well as then meeting ridiculous strict requirements set by the government even when diagnosed.

The Sleep specialist referred me to a public hospital for a sleep study to be followed by a MLST the next day. I had previously been for a sleep study at the start of 2013, as my GP sent me to see if I had Sleep apnea. That test result showed that I did not have apnea, and no other possible sleep disorder was investigated. I had also been sent to a Physician by my GP to see if I suffered from Chronic Fatigue, that Specialist looked at the sleep study results as well as running his own tests, and advised that he did not think that I had CFS, no other suggestion was given as to what I had wrong then either.
The ongoing issue seeing all of the different specialists through work, as well as those that my GP sent me to is due to hardly any medical professionals, including the so called Sleep Specialists know enough if anything about other types of sleep disorders, especially Narcolepsy. It is estimated that only 25% of people with narcolepsy have been diagnosed and are receiving treatment, and that only 22% of sleep specialists can identify all 5 symptoms of narcolepsy! Is it any wonder that it takes so long to get a diagnosis, if at all?! This has to change, I could still be in my job, that I was very good at, and loved doing had I been diagnosed years earlier, and been able to receive treatment to help me prior to the irreversible damage that almost a lifetime of sleep deprivation has done to my brain!

I requested that my GP refer me to a sleep specialist in the RAH after getting my diagnosis, as the one that I had initially seen did not have very much knowledge about my condition, and her only answer to me being tired was to prescribe more dex to try to help, which I will add does not help me to wake up or stay awake during the day, and the high amounts are gradually having a negative impact on other areas of my health. My teeth are becoming weak and rotting, and the stimulants are placing excess strain on my heart, which will lead to further complications as well as decrease my lifespan. Despite the effects of the limited treatment that we are allowed to access in this country, and the risk to our health by taking them, we are not seen as a priority. Due to being a minority we are not worth the expenditure required for alternatives to be available. My life is not important enough for our government to consider introducing affordable medications. I am not able to be granted a Disability Pension as the condition is not recognised or listed as a condition under the current DHS medical conditions, nor under the conditions used by NDIS, so I am not able to get any assistance there either. This current system is disgusting and needs to be fixed.

Access to, support and treatment available for individuals experiencing inadequate sleep and sleep disorders:

Support:

Financial Support for anyone with severe Narcolepsy that has reached the point of having to reduce their workload, or cease working altogether is difficult to obtain. They are not able to look for work or participate in a programme designed to return them to the workforce due to their excessive sleepiness, so are unable to manage the requirements for Newstart eligibility. The most suitable payment is Disability Support Pension which currently does not have the condition, or any other sleep disorder listed as a medical condition to begin with. This means that they have to try to relate their impairments to the current Impairment tables, then be assessed under those tables by an assessor who in most cases hasn't even heard of narcolepsy, never mind have any concept of how debilitating the condition can be. Applying for DSP is a long drawn out procedure, that requires a lot of supporting documentation, and the majority of applications from conditions that are recognised are rejected in the first instance. The success of being granted from the initial claim with a condition such as this would have to fall under 3%, this is my estimate based on my knowledge of the system and the procedures as a former employee. Despite being a former employee, and knowing what is required to have a chance of being granted, I have not applied. I simply do not have the energy to fight this battle yet, but I do have to do this soon, as I desperately need a health care card, and my Invalidity Pension is just over the allowable limit to apply for a low income health care card, so my only other option is a pension concession that comes with being granted DSP.

Services Support: The introduction of NDIS has made even those with severe and terminal conditions applications difficult, and many approved are no longer able to access the services that were once available to them prior to the introduction. When I made inquiries about getting assistance at home as I often miss meals due to sleeping, and my housework is no longer a priority due to lack of energy etc I was informed that my condition is not a recognised disability, and the person I spoke to had never even heard of narcolepsy! I have not pursued assistance after this, and knowing about the issues with the current system, and I suffer as a result of not doing so, but I am not prepared to exhaust myself only to be denied.

Treatment:

Medical professionals: GP's, sleep specialists, neurologists, psychiatrists, and physicians need to have a greater awareness of the conditions, and be able to see the signs and refer to have a diagnosis. The medical staff also need to be kept up to date with treatment options, early intervention, as well as be able to prescribe medications to assist those with a sleep disorder. It took many years for my diagnosis, and it certainly wasn't due to a lack of trying, it was a lack of information and knowledge that caused the delay.

Resources: my current sleep specialist is great, I am lucky to have now found someone who has knowledge, and who keeps this updated. He did have access to his own sleep lab where he could run sleep studies to enable patients to be diagnosed correctly, Unfortunately due to the recent relocation of the RAH, he no longer has this lab. The new hospital did not factor this in when making these decisions, and do not intend to have this clinic on the new premises. This has now cost SA a sleep lab, and has placed further strain on the only other public lab which is at the QEH, blowing out the waiting list beyond the current timelines to beyond a year to have a chance of being diagnosed, that is if you even get a diagnosis the first time you attend, I did not get one my first time.I have since been back twice due to needing to have a MSLT the day after the overnight stay. Both times due to lack of staffing, and nobody checking the total hours that I slept through the night before doing the MSLT, I was woken 5 minutes, then 2 minutes too early to fit the requirements to access Modafinil at a cheaper government subsidised price. My specialist would like to run this again, but no longer has a lab to do it in, this needs to be addressed. The private sleep clinics are not an option for me as I do not have health cover, and they charge a lot with no guarantee that I won’t be woken up too soon once again.
Medication: The strict criteria attached to being allowed to access medication is ridiculous, expecting someone with narcolepsy to sleep a straight 6 hours when this is a known problem with sufferers, only limits our chance of being allowed to have it! Despite being classed as having severe narcolepsy with mild cataplexy, I failed the required sleep time and have to pay $150 per prescription privately, and this means I can not afford to increase my dose as I struggle to pay for my tablets as it is, this must be looked in to! The only other option is dex, as for some reason we are able to have this medication, despite it placing our health at risk. Narcolepsy sufferers are allowed dangerous medication, but have to meet ridiculous requirements to be allowed to take medication that has less if any affect on their health! How is this even allowed to happen, how is this government process even legal? There are other medications, and treatments available overseas that we can not even access here at all, it is time for someone to stick up for the minority and push to have these medications made available here, and at an affordable price!

Thank you for taking the time to read my submission, I am happy to be contacted if you see fit to discuss anything that I have written further.

Yours faithfully
Narcolepsy sufferer