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mal (Dementia)

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To Members of The Standing Committee on Health and Ageing,

RE: *Dementia: Early diagnosis and Intervention.*

At the outset may I commend the Minister and the Committee for addressing this issue of major economic and social importance to the health of Australians. I have read the terms of reference of the committee and would like to make a comment which may, on the surface, appears to be unrelated, but which I hope I will be able to demonstrate is at the heart of early *and accurate* diagnosis of dementia.

I am an academic researcher who has been studying the clinicopathological correlates of dementia and other neurodegenerative diseases for over two decades. In the early 1990s my colleagues and I established a brain donor program which allowed people with dementia, and their families, to donate brain tissue for scientific research. My experience over that time has shown me that post-mortem examination of the brain to establish the underlying diagnosis is essential to further research and clinical practise in dementia. I therefore ask the Committee that consideration be given to exploring ways to facilitate neuropathological examination of the brain in patents with dementia.

The clinical diagnosis of dementia is often inaccurate, a feature which I believe the majority of clinicians would acknowledge. The development of new investigations or diagnostic protocols relies on being able to (ultimately) show that the diagnosis was correct. There are a number of different pathologies that can cause dementia and many have overlapping clinical features (e.g. memory loss) so without this final "answer" much effort could be expended with little benefit to patients or their families. In addition, it is not uncommon for more than one pathology to exist in the brain of elderly people making the accurate identification of the cause of dementia difficult.

Furthermore, one of the goals of early diagnosis of any disease is the timely initiation of appropriate treatment. While at present no disease-modifying therapies are available, several are under development, many of which are aimed at disrupting specific protein aggregates or pathways. The usefulness of these discoveries will be compromised if patients with the



specific underlying pathology cannot be accurately identified early enough in the disease process for the treatment to be effective. This means that establishing the underlying cause of the dementia in each patient is as important as developing better clinical tools.

Programs such as the one I am involved in are useful in helping to establish the underlying pathology of dementia and furthering knowledge in the area. Unfortunately, only a small number of patients, involved in ongoing research studies, can be accommodated in these programs. Other potential sources of pathological confirmation of disease are hospital-based or forensic autopsies. Over the past decades changing practice has seen the number of hospital autopsies decline steeply. Furthermore, the majority of dementia patients die at home or in residential care facilities so are not considered for autopsy. Forensic autopsies are often confined to determining immediate cause of death and chronic diseases are not investigated. Consequently there are few avenues for neuropathological examination and confirmation of diagnosis.

In my role as Director of the NSW Tissue Resource Centre I am often approached by the families of patients with dementia wanting to know the underlying cause of the dementia in their family member. Unfortunately this type of confirmation is outside the scope of my facility and, sadly, I have to refuse the request. Many of these families are interested to know the reason for the dementia and the implications such a diagnosis may have for them or their children.

In summary, I believe there is a gap in medical services available to people with dementia which is impeding progress in developing better diagnostic tools. This in turn is preventing progress in the areas of development of new treatments and planning of care needs for people with dementia.

I would be happy to elaborate further on any of the points raised, should the committee require.

Thank you for your consideration of this matter.

Yours sincerely,

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