To the members' of the Senate Inquiry into the Government's administration of the Pharmaceutical Benefits Scheme (PBS)

I would like to make a personal submission on the topic. From a family experience I know the difficulties faced by ordinary Australians who do provide care which includes accessing approved medications through a doctors script and then through the local chemist where we have to pay the full cost. This even when the ill family member and the carer were on Centrelink payments. To be on Centrelink benefits means to have gone through the means test.

I researched and spoke to as many people as possible to understand the illness and the best available treatments. I found that the proven best treatments in our case were through pharmaceutical medications that were not subsidised on the PBS. I did not pay for the necessary medication for over 5 years because I was rich. I bought the medications because they worked. They worked in that they gave the patient a quality of life that she would otherwise have been denied.

The alternative was to accept the GP's recommendations of only PBS subsidised drugs, none of which would have helped the patient, and have the patient committed to a locked institution until her death.

At the outset of the illness we owned 3 houses. By the time of the patient's death all the properties had been sold in order to pay our bills over the period of the illness. Not only is it the cost of expensive medications it is the years of lost earnings from work for the person who has to give up paid employment in order to become a full time carer. I now live in a rented house without sufficient capital left to buy any home for myself. However, my family member who was ill for some 10 years received the best medical care and medications because they were needed and they worked.

Had there been a PBS approval to the medications we needed to help the ill family member I would have been able to continue working for some of those years. The illness had progressed before I found the information and the trial of the drug results to know what to ask the doctor to prescribe.

As a result of experiencing the often time failures in the delivery of services of our health system when the family member died in July 2005 I became a volunteer health consumer representative. I am a member of a number of State based and national health consumer NGO's.

As part of that representation for the past 4 years I have been a member of the Sir Charles Gardiner Hospital Human Research Ethics Committee

Another group I have worked with has been the Federal Governments 'Medical Services Advisory Committees' (MSAC)as the health consumer representative. [redacted] The number of MSAC's I have worked on will show up on a search of process to put new materials on to the PBS. My own record while serving was not to always approve every item that came before the committee, just because it worked. I always looked to see what the greater good was for the community. There is only so much money available and if it's used on a product that has some benefit, but which is limited, then another later product may not be able to be funded. My voting record and reasons I always provided will confirm that statement.

I was also instrumental in changing the way the MSAC's reported. Due to my efforts and the cooperation of the Chair the MSAC, all reports now contain a section on the patient's view.

Introducing change to an established system is very difficult. After the change to include the consumer/patient's experience I was invited by the DoHA to sit on other MSAC committees.

Like the majority of other Australians who become real full time carers when it was over, due to the death of the family member, I was financially devastated with little prospect of regaining paid employment. In my case I studies and completed Cert III, IV and Diploma in Community Development. I still could not get work. I am now into my second year of a Business Management degree through Monash University as a mature aged external student.

I urge the Members of this Inquiry to include the approved PBS items. The cost benefit I believe will be in favour of such a decision. My recent experience is that by saving money on the PBS budget only pushes the cost to another Government domain of financial responsibility. These cost shifting are rarely dollar for dollar but are more often for every dollar involved in the cost shift will cost Government an extra five dollars for every one dollar "saved". Not only is this a destructive use of tax revenue it impoverishes the patient's care. Importantly the quality of life the patient is frequently diminished and impoverished by the action. It also adds additional stress on the family for no actual benefit to anyone.

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