

Submission to Senate Inquiry into the Government's administration of the Pharmaceutical Benefits Scheme

Introduction

I'm just one of you, a consumer, an ordinary person. I have cancer. Suppose you had cancer too. Think for a moment, how you would feel?

I have enough to worry about with my cancer treatment. Will it work? Is it enough? Will it stop the cancer growing? Don't make me worry about where the money is coming from to pay for it! Don't make me shop around for affordable medicines. I am too sick.

I am calling you to action. Do something. The decision to delay the listing of medicines which have already been through the PBAC process is killing people. It's killing me and maybe you, or your kids, or your grandkids.

Help me and others in my situation, before it is too late!

Background

For many years I have contributed my services to voluntary organisations, especially in the area of health and rural and remote disadvantage. I am currently an active member of four non-government organisations.

On August 10, 2010 after a 15 month battle with a range of nine specialist physicians, I was finally diagnosed. The long hard haul of chemotherapy made me sick, both physically and emotionally – green in colour, vomiting excessively, not eating or sleeping, loss of hair, no concentration, memory loss and even isolation from the outside world.

Radiation, was this really the walk in the park they said it would be after chemo? Sunburn or just plain burns, burnt skin, burnt esophagus, can't eat, can't swallow, reflux from hell. I no longer represented the person I am, or that I should be, let alone the person I was. I am single, single income when I am able to work, and far too young to die. I need help and so do a lot of other people who walk in my shoes.

Purpose of the National Medicines Policy

As a patient I find it necessary to insist that the purpose underlying the National Medicines Policy be upheld: to produce better health outcomes for all Australians through the use of medicine.

In short this means:

- timely access to the medicines that consumers need, at a cost we can all afford;
- medicines which meet appropriate standards of quality, safety and effectiveness;
- quality use of medicines; and
- maintaining a responsible and viable medicines industry.

Why do we have this policy and such a rigorous and robust quality assurance procedure for listing medicines if recommendations are not accepted and approved by our federal government? Why? Where are the frank and fearless discussions with consumers?

Consequences for Patients of Deferral of Medicines

One must question the recent decision by the Federal Cabinet to defer the listing of medicines on the PBS. What is the message that is being sent to consumers? Money is more important than saving lives? Our lives, and the lives of our loved ones. Is this what our government is all about? Well, let me tell you what this decision means for this consumer. **PERSONAL HARDSHIP**. Do you as an individual consumer know what this feels like?

This deferral decision seriously disadvantages consumers with chronic illness or disease. These are the people that can't work and earn an income due to their medical condition – me for nearly 12 months. These are the consumers who experience financial distress while trying to do everything they can to ensure they win the health battle – the new poor, the people who

used to be financially comfortable who are now forced to shop around or go without the essentials to pay for medicines. I used to have a share portfolio for that rainy day, the rains came, and so did the storms and the floods. I used to own my own home, now I have a mortgage.

Let me give you one of my examples – proven blood poisoning from chemotherapy. Chemotherapy not able to be administered due to neutrophils not being high enough. Delayed chemo sessions allowing the cancer to grow aggressively with too much time in between treatments. However, a medicine could help, split more stem cells. It required two injections a fortnight at the cost of \$1972.41 each for a period of five months. Do the math – do you have that sort of money lying around? I didn't. I now require a stem cell harvest. I have been told that if the cancer comes back within the next five years, doctors won't be able to help me. My insurance policy for one so young is ten hours of intensive and strong chemo followed by two injections a day for ten days, then the harvest. This amounts to \$40,000. Increase the mortgage? Another loan?

I can site many more anomalies in our health system, such as the administering of PET scans, a costly but necessary procedure for cancer patients. How do you feel when you are told "I am sorry, your type of cancer is not covered for a PET scan? You will have to pay the \$1800 with no rebate from Medicare." When I picked myself up from the floor and managed to get out the question "Why?" I was more disappointed to hear, "if you had breast cancer it would be covered." So please explain why our federal health system regards some cancers as "more important" than others.

You may think by now that I am fairly bitter and perhaps even twisted, but I assure you I am not. I thank god I am alive every day and my will to live and positive attitude has certainly pulled me through this journey to date. However, I haven't been able to rely on the federal health system to help me through.

PBS Medicine savings

The question of possible short-term budgetary gains for the federal government needs to be raised. Has the government considered the longer term costs to our communities and to consumers if consumers are not able to access the medicines they require to live comfortably at affordable prices? When correct medicines are not administered, other health problems almost certainly occur. The short term budgetary savings, if any will most likely be far outweighed. The issue is timely access to medicines, not just access.

As a Queenslander, this year has seen massive devastation to people and their families, pets, homes, businesses etc. And yes the federal government was represented in the administration of natural disaster relief assistance. This assistance wasn't only in the form of money. It also came packaged in terms of looking after the human psycho/social needs of community members. How about we apply this principle to patients and consumers instead of worrying solely about the government's hip pocket? How about we help suffering consumers to rejoin the workforce, and get back into a life of routine and normalcy, and be less of a drain on society? How about we take action to preserve patient dignity?

Conclusion

The decision to delay the listing of medicines on the PBS is horrendous. Poor form from our federal government. It should be ashamed of its actions. The reality is people die!

We're in this together. Please, I beg you to do your bit. **Consumers call you to action.**