

Mrs. K. Cowley

23rd February 2015

Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600

Dear Sir/Madam,

Availability of New, Innovative and Specialist Cancer Drugs in Australia.

Australian cancer patients need, expect and deserve timely access to the latest cancer drugs under a system that is fair, equitable and in a sustainable way. From my perspective, Australia seems to be behind overseas counterparts in adopting medical technologies.

I am a cancer survivor, I am not privy to the machinations of government policy but from where I sit and what I have seen and read from cancer medication advocates such as Cancer Drugs Alliance and Breast Cancer Network Australia (whom I am a Consumer Representative), I believe fundamental reform on the way cancer drugs are currently funded is needed which could take time, therefore interim solution must be found now so people can get access to drugs when needed. People with cancer don't have time to wait for drugs to come onto the PBS.

I have been living with HER2-positive cancer for 8 years and firmly believe that Herceptin has been my silver bullet. I am now on an improved targeted treatment Kadcylla which has given me a new lease on life. Not having to contend with the affects of conventional chemotherapy because this drug only targets the cancer, I have minimal side affects which do not impact on my daily life. I have been treated with Kadcylla since May 2014. It's vital that my information and others are captured and passed onto decision makers to confirm and improve on data provided from pharmaceutical company Clinical Trials. This is where breast cancer clinical registry is so important.

I got access to Kadcylla through the pharmaceutical company's compassionate program. I paid \$15,000. I am now on a disability pension and my husband has just turned 60 and working 6 days a week to make ends meet. It's too much for him. Going forward we are unable to fund another drug. Even though I am a skilled professional, I am trying to get part-time work to make ends meet but being in my late 50s with cancer, difficult to find work.

The irony is that Kadcylla has made me well enough to feel I can work again. I live in hope, as it goes against my grain to be a pensioner which has been my last option as our savings are depleted due to my loss of income and 8 years of out of pocket medical costs.

Living with cancer affects a person physically, emotionally, and mentally. It can interfere with everyday activities. For many years I felt I was on a tightrope having many different regimes of drugs to manage my disease with many side effects. Kadcylla has been a revelation, since May 2014, I feel that I have some control in my life as my disease is stable and I have less side effects. Administration of the drug is also less invasive, with only one infusion taking less than an hour whereas other medications took several hours.

In the future I see new medical technologies allowing people to have a relative normal life, with treatment being a part of everyday life giving quality that enables cancer survivors to remain part of mainstream society.

I am living proof that treatment can be used to control the cancer, help relieve symptoms, and allow you to live longer. It's normal to feel sad when you find out that the cancer cannot be cured but there's a good chance you can live a long time with cancer with a drug such as Kadcyra. My medical team is buying me as much quality time as possible. I'm good with that, and I take each day as it comes.

I count my blessings that I am still here enjoying life with my family and friends.

Yours faithfully,

Karen Cowley
Breast Cancer Network Australia Consumer Representative
Cancer Survivor for 8 years