

25 April 2005

The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
Canberra ACT 2600

***Submission to the
Inquiry into services and treatment options for persons with cancer***

The specific area on which I wish to comment is the “*current barriers to the implementation of best practice in the above fields*”. In essence, the barrier in question is one of cost, whereby the cost of early diagnosis may have the effect of delaying diagnosis and thereby restricting the treatment options for those later diagnosed with cancer.

I take my examples from the early diagnosis of breast cancer, in which field there is a very well established clinical pathway for early diagnosis and a track record of excellent contributions from the work of BreastScreen Australia in its various State-based incarnations. In that earlier diagnosis makes a significant clinical difference in the treatment of quite a wide variety of cancers, there appear to be profound lessons to be learned from this set of examples that are applicable far more broadly than the specific area of breast cancer.

When a person has been well, and never diagnosed with breast cancer, a free screening mammogram is available from BreastScreen Australia. Few would argue with the significant contribution made by this program to reducing the numbers of undetected breast cancers, and indeed, many would advocate that a similar program should be a high priority for development in other areas where reliable diagnostic tools and benefits from early diagnosis are clear.

However, as explained in Annex A, this service is not available to women who have had breast cancer. A case example of the problem is provided at Annex B - matching factual examples have also been offered by individuals in suburban Melbourne, regional Victoria, metropolitan Perth, suburban Brisbane and various parts of NSW. I think this serves largely to highlight the uneven provision of services that arises from a haphazard policy and incomplete coordination between providers of clinical services. Some sufferers of breast cancer are adequately served in terms of early detection of future problems, but a great many appear to slip through the rather patchy net.

The overall problem is summarised in the article enclosed entitled “Mammograms - costing an arm and a breast”, written by Carmel Green, a first year journalism student at the University of Technology Sydney. She independently confirmed the information provided to me, and her approach and research were also verified by her lecturer for the relevant subject.

Overall, there are many cancers in which early diagnosis should be a priority, and this should be delivered on a model based on the service provided to well women by BreastScreen Australia. Having been ill with cancer should not preclude this model of service being accessed, or those who have been ill and suffered financial hardship will face an invidious double jeopardy.



Carolyn M. Evans

Annex A - Who gets a free Mammogram?

- BreastScreen Australia - which operates as BreastScreen NSW, BreastScreen WA, etc - has responsibility for delivery of free mammograms to women aged 50 - 69. On a doctor's recommendation, they will provide a mammogram for a woman aged 40 - 49 or over 70. They make it very clear on their web site that women aged 50 - 69 are their "primary objective".
- However, they will not do a mammogram if the woman has previously had breast cancer. Their charter and purpose does not include this group, so the service is not provided.
- Women who have had breast cancer generally require both a mammogram and an ultrasound as the basic diagnostic tools to screen them for new breast cancers. Formerly, women who had already had breast cancer were referred to the privately-operated imaging labs that are common now - the sort that do xrays etc in local medical centres and shopping precincts. These were bulk-billed - therefore, the woman had no out of pocket cost.
- However, this practice receded and is not available in many areas. The problem appears to originate in the Medicare schedule amount for this service - all service providers appear to charge above the schedule fee. So whilst a partial claim might later be paid by Medicare, these women must now pay out for the procedure and be satisfied with a partial refund - on top of the many financial hardships that come with a serious health problem.
- This is obviously a huge burden for many women on low incomes or none at all - and is a pressing social issue for women who do not have direct access to money and may be unable to ask for money for this purpose.
- Women at serious risk are being placed at greater risk because of an inept policy. The Federal Government's own information confirms the higher risk - the BreastScreen NSW web site says, in a section about who is at risk of breast cancer:

"If a woman has been diagnosed with breast cancer previously, there is a greater risk of the disease reoccurring or developing in the other breast.... Women who have had benign (non-cancerous) breast problems are also at an increased risk but to a lesser extent It is very important for these women to have regular check ups with their doctor or specialist."

Thus, women at higher risk are denied access to either a free or a bulk billed basic diagnostic or "screening" service.

- A couple of the largest hospitals in Sydney (but certainly not all of them) will take a doctor's referral and do a free mammogram for any woman, and there is evidence that suggests that this may be done on a special request at some regional hospitals. Private information suggests that some of the imaging places will do "charity cases" at the request of a doctor. But this puts women with a genuine need in a parlous position, relying on the chance of locating and accessing grace and favour assistance for basic health services.
- Recent public debate suggests that many of the relevant clinicians are unaware of this problem, and so assume that the problem does not exist. It seems unlikely that their patients would choose to discuss their financial position with the clinician, and so their lack of exposure to this issue is both unsurprising and uninformative - just because they are not aware of the problem hardly disproves its existence!
- Perhaps the solution is as simple as adjusting the Medicare schedule fee for this service as it may be inadequate, and the problem could be solved by increasing it to a level that would return the majority of this work to bulk billing. There seems only a marginal likelihood of over-servicing in this area given the nature of the service, and this is readily controlled through the usual requirements for a doctor's referral.

***Annex B - First Hand Case Study -
Anonymous woman living in south west Sydney:***

“I was diagnosed with breast cancer in November 2003 and like others I was quite surprised to learn that I no longer had access Breast Screen for follow up mammograms.

As a consequence when I had my first follow up mammogram, in December 2004, it was a private operator.

They informed me (at the time of booking the mammogram) that I had to pay the \$314.00 up front. As a younger breast cancer patient (under 50), I also have to have an ultrasound which was included in the cost.

However, of the \$314.00, I got a grand total of \$164.60 back from Medicare.

Whilst being out of pocket \$149.00 does not seem like a lot of money, it is when you have had 12 months of costly medical treatment, 6 months off work, 6 months part time work - and I'm one of the luckier ones.

What really takes the cake, however, is that my 3 sisters - who have not had breast cancer - have access to a free mammogram each year, simply because my cancer puts them into the high risk category! Where's the logic in this?”

Mammograms: costing an arm and a breast.

By CARMEL GREEN

Victims of breast cancer do not receive free mammograms after surgery.

Due to changes in the Medicare schedule and the lack of availability of bulk billing for mammograms, women with a history of breast cancer cannot receive access to free mammograms.

“Yes this is the case” said Germana Morassi, Sydney’s Breast Screen promotional officer “of course we need more funding, everybody wishes we could have more funds from the government, however I do not think it is a big issue as you can always go through the private and public system”.

“For women who have had breast cancer before, this immediately increases the risk of reoccurrence”

However, as another additional cost on top of surgery, medicines, a prosthesis and wig, going through the private or public system may not be an option for some people. The cost of a mammogram alone can be a burden.

Lottie Brand, a single mother of three children is undergoing her last dose of chemotherapy this week. Lottie is appalled by the news. “It is hard enough having to keep up with the costs of the surgery and hospital fees, it

feels like I am being punished for something I have no control over, but you have to have mammograms because you know that there is a high chance of the cancer coming back”.

“It feels like I am being punished for something that I have no control over”

According to Elma Villaneueva, an epidemiologist from the National Breast Cancer Centre; “Statistics show that there is a 1-2% chance per annum of breast cancer reoccurring. If a woman has had breast cancer before, this immediately increases the risk of reoccurrence by 2-5 times the population rate.”

It is ironic that whilst most medical breast institutions label mammograms essential for any women over 50, there is a lack of funding in the particular area of health.

A petition is currently being circulated to raise awareness about the issue. “Most people don’t know that this is the case and when they find out, they are horrified” said Joanne Morris, Mayor of Hurstville. “Women who have had breast cancer are more vulnerable than the rest of the population because they are usually more at risk from a health perspective (within five years there is a very high incidence of cancer recurring in the other breast) and less able to pay because of the financial implications of having had the disease before. It is ridiculous and unfair”

“Most people don’t know that this is the case and when they find out they are horrified”

Joanne Morris, along with other women from the Sydney South

region, are apart of “Tank” an all women’s group who are “Not afraid to have an opinion” and addresses the many social justice issues that concern them. Carolyn Evans, an active member of Tank said “I found the news about mammograms very disturbing! Literally my reaction was “that can’t be right”.

When asked what the aim of the petition was, Carolyn Evans said “The aim of our petition is to change this policy so that there are no out of pocket costs for basic diagnostic tools such as mammograms & ultrasounds. We are fighting for the matter to be raised in both the state and federal parliaments - the federal government should look again at the policy to provide a workable solution. That solution must ensure that any person in medical need of basic diagnosis for breast cancer - man, woman or child; whether or not they have had breast cancer in the past - can have that diagnosis without incurring out of pocket costs.”

“The Government needs to provide a new policy to ensure that any person in need of basic diagnosis can have one without incurring out of pocket costs”.

This issue has outraged many, with hundreds signing the petition. Whilst the issue still needs wide spread attention, ‘Tank’ ensures that “if nothing changes we will definitely ramp up the campaign”.