

Submission to Inquiry into Gynaecological Cancer in Australia

16 June 2006

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

community.affairs.sen@aph.gov.au

Dear Sir,

Thankyou for the opportunity to make the following submission to the Inquiry into Gynaecological Cancer in Australia.

Yours sincerely,

(by email)

Tanya SMITH

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1. My Experience with Ovarian Cancer

Three years ago, at age 40, I was diagnosed with ovarian cancer. Up until my diagnosis, I had experienced an increasing tiredness, and an inability to lose weight, despite participating in a fitness program. Over a period of about a year I felt a general 'unwellness'. I saw my doctor a number of times, he ordered blood tests that showed "something was going on" but nothing specific. For some time, I put these vague 'symptoms' down to leading a busy active life, working long hours in a corporate job and turning 40. I reached a point where I knew something just wasn't right so I saw a doctor who ordered an ultrasound. I discussed my concerns with friends who advised me to see a specialist gynaecologist oncologist. When I visited my GP and asked for a referral to the gynaecologist oncologist, he explained that I didn't need an oncologist, as ovarian cysts are very common and I didn't need to worry about it being cancer. However, I insisted, which was one of the best decisions I made.

My surgeon explained that while he was concerned about the results of my CA125 test and ultrasound, he would not be able to confirm if it was cancer until he operated. We hoped for the best, but the news was not good. My partner, family and friends were shocked and devastated to hear it was stage three ovarian cancer. I had undergone a radical hysterectomy, and awoke with the news that I had ovarian cancer. Although I consider myself an educated person, I had never even heard of ovarian cancer. I knew about cervical cancer and the need to have pap smears, I knew about breast cancer and the need to have examinations and mammograms, but did not know cancer of the ovary even existed.

Not long after my operation I was referred to the Royal Hospital for Women Gynaecological Cancer Centre in Sydney for chemotherapy. I was given the opportunity to participate in an international trial through ANZGOG, a research and trials group. It was a tougher road than the standard treatment with three weeks of treatment and one week off every month, and eight cycles instead of six. But I thought this would give me my best chance, and also may help to redefine the standard treatment given to ovarian cancer patients.

The care that I received at the Royal Hospital for Women was excellent. The centre provides a high level of treatment and follow-up, with easy access to all facilities: specialist consultation and blood tests are done on the morning prior to treatment; a very experienced nursing team deliver chemotherapy; pharmacy medications for the week are delivered while receiving treatment; and access to experienced cancer psychological support is onsite. Each time I required a scan I was able to get an appointment quickly on the campus and pick up the results within an hour or two. This is very important to cancer patients who are often ill and need to access medical care with minimum return visits. It is also important for carers who need to take time off work to take patients to medical appointments.

Shortly after I started chemotherapy I became aware that members of my extended family had undergone genetic testing through the Peter MacCallum Cancer Centre in Melbourne. In 2001 it was found that some members of my family carried a gene fault known as BRCA1, which predisposes them to breast and ovarian cancer. Unfortunately, I was not given this information until after I

was diagnosed. My family is not particularly close and it simply did not filter through to everyone. Once I had advised my specialist I was then referred to the Hereditary Cancer Clinic at the Prince of Wales Hospital and subsequently found to have the same gene fault.

I completed eight cycles of chemotherapy over 6 months and returned to work. Ten months later the cancer returned and I was again having to undergo chemotherapy. However this time there was no chance to recover.

Just over a year ago my partner and I moved to Perth, Western Australia, where I continue to have treatment every month. The move has highlighted to me the differences in gynaecological cancer patient services and facilities. There are excellent support services such as the Brownes Cancer Support Centre at Sir Charles Gairdner Hospital, which provides free complementary therapies and information for cancer patients and their carers. This facility should be duplicated in all the cancer centres around Australia. Disappointingly, there is no gynaecological cancer centre in Perth. I am unable to access all my medical requirements in one specialist location such as a gynaecological cancer centre, as I did in Sydney. This makes it more difficult for my partner and I, as I often go to one hospital for tests, and to another hospital for treatment. While scans and other testing, counselling or other services are done at other hospitals.

2. Comments Relating to each Key Issue:

(a) Level of Commonwealth and other funding for research addressing gynaecological cancers;

I know from first hand experience there is very little Commonwealth funding for gynaecological cancers. I was part of a clinical trial which cost over \$640,000. Funding for this trial came from international oncology groups and it did not receive any funds from government. It is unbelievable that with the current rate of mortality for ovarian cancer, one of the highest, that there is little dedicated government funding for much needed clinical trials or research. Clinical trials are at the forefront of improving the standard of care for women with gynaecological cancers – right now - not in five or ten years. This needs to be urgently addressed.

Funding needs to be in three key areas:

1. National clinical trials to identify the best treatments. Giving all Australian women access to new or improved treatments. This could be done though ANZGOG (Australia New Zealand Gynaecological Oncology Group)
2. Developing predictive tests for all gynaecological cancers such as ovarian cancer.
3. Increase public and medical practitioner awareness about the risk factors, symptoms and treatment options.

(b) Extent, adequacy and funding for screening programs, treatment services, and for wider health support programs for women with gynaecological cancer;

I cannot stress how important the care I have received at the Royal Hospital for Women is in my ongoing battle with ovarian cancer. Every woman needs access to this type of specialist centre care.

Specialist gynaecological cancer centres with psychological support should be available in all states. Each cancer treating hospital needs to be linked to a specialist gynaecological cancer centres, and to ANZGOG, to ensure the best treatments and services available are provided.

Psychological support for cancer patients and their partners is critical. At all stages, from initial diagnosis and throughout treatment many patients with gynaecological cancer experience unique problems. It is essential to have the psychological support.

Centres such as the Brownes Centre at the Sir Charles Gairdner Hospital in Perth need to be set up within each gynaecological cancer centre. The Brownes Centre could be used as the model and duplicated in each specialist centre. Much of the initial funding of the Brownes centre was provided by Brownes Dairy of Western Australia and ongoing funding is provided from other groups and private companies.

(c) Capability of existing health and medical services to meet the needs of Indigenous populations and other cultural backgrounds; and those living in remote regions;

Some of the suggestions listed in the points above and below would also benefit to these communities. However, I do recognise these communities have unique issues which need to be addressed. I feel others may be more qualified to respond specifically to this point.

(d) Extent to which the medical community needs to be educated on the risk factors, symptoms and treatment of gynaecological cancers;

Every general practitioner and other medical practitioners need to be educated about gynaecological cancers. As symptoms are often vague, general practitioners should ensure gynaecological cancers are included in their investigations. Clearly there are still many general practitioners for whom gynaecological cancers are not top of mind.

It is also vitally important to have the best qualified surgeon. A gynaecologist oncologist is best qualified to remove as much cancer as possible (optimal debulking) This gives the patient their best chance. General practitioners need to be aware of this when referring patients to specialists. I insisted on being referred to a gynaecologist oncologist and wonder what would have happened had I not had such a skilled surgeon for my operation.

General practitioners also need to discuss with their patients the importance of knowing familial cancer information and its potential relevance to their health. For many reasons families do not communicate, in my case the information about the BRCA1 gene fault was not passed on to me. If I had

been advised two years earlier I could have had risk reducing surgery and potentially avoided ovarian cancer. There needs to be a mechanism whereby medical information that could affect family members is communicated to all family members. The various familial cancer centres around Australia need to take responsibility to ensure this happens, and not rely on family members to communicate such important information. As cancer is a notifiable disease there should be a way to advise a person potentially at risk without compromising the privacy of other family members if required.

(e) Extent to which women and the broader community require education of the risk factors, symptoms and treatment of gynaecological cancers;

There is very little information in the broader community about many of the gynaecological cancers. Prior to my diagnosis I knew nothing about ovarian cancer. This is a critical problem and a major cause of the high mortality rate for some gynaecological cancers. Ovarian cancer, for example, is almost always diagnosed late. Early detection and treatment would help reduce the high mortality rate. Ensuring public awareness is critical. There is even less public awareness about the importance of knowing and understanding familial cancer information, and gene faults such as BRCA1 and BRCA2.

Just as women present for their yearly mammogram or pap smear they need to be educated to be checked for other gynaecological cancers. This needs to become part of their medical routine.

(f) Extent to which experience and expertise in gynaecological cancer is appropriately represented on national health agencies, especially the recently established Cancer Australia.

Firstly, let me make the point that in Australia we are in the enviable position of having some highly experienced and highly qualified medical practitioners in the area of gynaecological cancer. A number of whom are recognised around the world as leaders in their fields. It is not due to the lack of talent and dedication that we experience such high mortality rates in the gynaecological cancer. We certainly need to ensure that solid representation is given to the gynaecological cancer area in all key agencies particularly Cancer Australia.

On this issue my experience with and research into ovarian cancer has highlighted a number of personal concerns in this area. I am aware of a number of organisations conducting research and working to increase awareness of gynaecological cancer. My concern is that when there are organisations competing for scarce funding that may not openly share information or work together. The fight against gynaecological cancer would be far more effective with a collaborative effort; a sense of urgency and teamwork between all the groups. The area of expertise of all groups in this field needs to be identified. For example, which groups are best positioned to conduct clinical trials, which groups are best positioned to develop predictive testing, which groups are best positioned to increase awareness about the disease. Care must be taken to minimise duplication of skills or resources. There is a great deal of work to be done, and it needs to be done urgently. We cannot afford politics to slow or subjugate this important work.