**16th June 2006**

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

Dear Sir/Madam,

**Re Senate Gynaecological Cancer in Australia Inquiry**
**Complications following surgery and Radiotherapy for Gynaecological Cancer.**

I was diagnosed with Ovarian Carcinoma Stage 3C in September 1991 at the age of 60 years. I had no previous signs of any problems until August 1991 when I experienced tiredness and a stitch in my right side. This I put down to overdoing things as we tend to do. Towards the end of August I had severe pains in my stomach and a feeling that something had dropped in my pelvic region.
My Doctor after examination sent me for an Ultra Scan and an appointment with a Gynaecologist Specialist.
After examination he said it was too complicated for him to operate as he did not have the expertise for the type of surgery I would require.
He then made an appointment for me at the KEMH Clinic.
Also I had to have a blood and bowel test as the Specialist was of the opinion that the cancer may have adhered to the bowel.
As you can imagine this was quite devastating and leaves you in shock. When it was confirmed at KEMH that it was definitely Ovarian Cancer, arrangements were made for me to enter hospital in two weeks time owing to the shortage of beds.
I was admitted on the 18th Sept. and needed a kidney scan before the operation on the 19th Sept. That night around 8 pm I had a visit from another Surgeon to inform me he was to perform my operation the next day and not the Surgeon I had previously seen. I was not told to what my operation would entail.
I spent two weeks in Hospital and upon my discharge was told by the Surgeon who performed the operation that I had probably two to three months chance of survival. I was told the Cancer had spread throughout my pelvic area and that he had removed as many Lymph nodes as possible as they were cancerous.
At this stage I did not know what lymph nodes were.
This was devastating news to receive whilst recovering from the operation. I was then told that extensive chemotherapy would begin in two weeks. At the time of discharge my main talks with the Physiotherapist had been to discuss how to get out of bed and to what extent I would be able to function at home and to drive.

I began Chemotherapy by having the first treatment in SCGH overnight to ensure

everything went smoothly.
It wasn't a very pleasant experience. Upon being told about the side effects of the Chemo I was informed that Chemo treatment would take place every month depending upon my blood count.
Unfortunately this did not go very well as my body couldn't take the effects of the two drugs. After two months it was decided to cut out one drug because I was not making up my blood count and the period in between was two long. Together with the side effects of Chemo and the operation I was having a fairly stiff time to put it mildly. I would spend about 4 to 5 hours at the hospital when having my treatment.
The next week would be terrible and just when I starting to feel a little better it was time for the next lot. After about 5 months I became very short of breath and so had to have a Blood transfusion. At this stage I wondered what else could go wrong. I finished Chemo at the end of November and after an MRI was told everything seemed to be clear and to take Tomoxifen for the next five years.
Once again things did not work according to plan as I developed a bad case of shingles. The effects lasted for 4 mths and I was told no more drugs.
At last I could begin to lead a normal life again even though it was a case of taking it very slowly.
In July 1993 my husband and I decided to do a camping holiday around part of Australia. He had always wanted to do this, so I thought I would give it a go as the possibility of me being around for long wasn't on the cards even though I had confounded the powers that be. We were away for a month and I had no problems with my health. During this time I had regular check ups at the Clinic after Chemo gradually going from every 2 mths, 3mths and then 4 mths.

In 1996 a close family member left me a small inheritance so that we could have a holiday overseas which had long been a dream. I checked with the Doctor at the Clinic that this would be OK and he said yes.
Unfortunately this was not the case. We were away for 6 weeks and after flying to England and taking an exyended bus tour through Europe I noticed that my right calf was beginning to swell. On my return home I was due for my 6 monthly check , I mentioned the problem that I had had with my leg. Nothing more was done.
After another month my weight was beginning to go up and my right thigh was very hard as well as being swollen. I didn't know what could be the cause as my eating habits and exercise hadn't changed.
I was worried that it might be DVT so made an appointment to see the Surgeon who had done the operation.
He examined my leg and said there was nothing to worry about. On leaving the Clinic I was told by the attending Nurse that I should go and see the Physio as I may possibly have Lymphoedema. This was my first introduction to Lymphoedema.

Lymphoedema requires constant treatment i.e. Manual Lymph drainage massage, Bandaging and Compression stockings. As I am an age pensioner and not in Private Health Cover this became a problem due to the cost of treatment and the availability. Over the last ten years it has cost many thousands of dollars. You might ask why didn't I rejoin a Health Benefit! Firstly there would have been a time gap and secondly Health Funds do not cover many individual treatments. This has long been a problem as treatment takes at least 1 hour. If bandaging is required to help reduce the swelling another 1 hr is needed. Bandaging has to be done every day for up to 1 week or more

depending on how the swelling reacts. In my case bandaging after MLD and compression stockings is the only thing that keeps my Lymphoedema in check.
I am fortunate in one respect that I am classed as an Out Patient of King Edward so they allow me two compression garments a year. This is a huge benefit for me as I have to have custom made compression panty hose owing to my height. Unfortunately the treatment that I need in between I am unable to have at King Edward as the Physician is only available two and a half days a week. Some of that time is spent on the wards, so you can see that there is not enough time for treatment. This not only happens to me but to all other patients attending the Clinic. We are desperate to have Medicare cover Lymphoedema or to give more funding to Public Hospitals to enable them to provide treatment.
I was very upset when told I had Lymphoedema and that it would be incurable.
I did not have a problem with the Surgeon, because he saved my life, but if I had been made aware of being a prime candidate for Lymphoedema I could have taken steps to hopefully prevent it. Over the ten years I have had Cellulitis numerous times and this has caused problems in my calf and leg due to fibrosis. It has required me to be admitted to hospital on a number of occasions for treatment of the infection.
Lymphoedema has a large effect on your life, especially during the hot summer months.
I had always been an outdoor person and played a lot of sport. This has now changed.
Alternative means of exercising had to be found otherwise weight becomes a problem and this is detrimental to Lymphoedema.

As can be seen from my letter Lymphoedema is a chronic condition and needs to be addressed as such.

I joined the LYMPHOEDEMA ASSOC. OF WA at the end of 1996 and have been President for the last 8 years.
I did this so as I could hopefully make a difference to others by promoting awareness, education and answering a helpline.
There is now a greater education of Lymphoedema in Public Hospitals but the Private Hospitals still have a long way to go.

In conclusion I would like to point out that the Government would save enormously in the long run by supplying services and helping Lymphoedema sufferers manage their condition instead of waiting until they become a burden through hospitalisation.