Submission to the Inquiry into gynaecological cancer in Australia

Terms of Reference

Gynaecological cancer in Australia, and in particular the:

a. level of Commonwealth and other funding for research addressing gynaecological cancers;
b. extent, adequacy and funding for screening programs, treatment services, and for wider health support programs for women with gynaecological cancer;
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;
d. extent to which the medical community needs to be educated on the risk factors, symptoms and treatment of gynaecological cancers;
e. extent to which women and the broader community require education of the risk factors, symptoms and treatment of gynaecological cancers; and
f. extent to which experience and expertise in gynaecological cancer is appropriately represented on national heatlh agencies, especially the recently established Cancer Australia.

I should like to address myself to Terms of Reference b., d. and e. with regard to ovarian cancer in particular. I was formally diagnosed with this cancer on the 19th of June 2006 after the removal of a very large cyst that had developed because of my longstanding endometriosis. I have lived with endometriosis since I was 22, but at only one point was any associated cancer risk ever mentioned and that was when I raised the issue with my gynaecologist (not my current one). Because my mother had endometrial cancer at about 55 years of age and I had a belly full of endometrial cysts, I asked at age 45 or 46 whether there was a link and how would I protect myself from this cancer. As my mother had been a gynaecologist, I thought she would have known her symptoms well and had got in early to eradicate it. I do not have the benefit of that training. The gynaecologist I consulted answered that endometrial cancer was not likely to be a problem, but that ovarian cancer was more likely. He did not elaborate or explain my risks or refer me for any scans or tests. I repeated this conversation with my GP but was never referred for any scans or tests until I was almost 50 and having trouble eating sleeping and breathing and presumed it was my gall bladder acting up as I knew I had some gall stones. In a scan of my upper abdomen on 31/5/2006 a cyst prevented a view of my gall bladder. Little did I realise that this would turn out to be an ovarian cancer, I presumed that it was an endometrial cyst, which is what it began life as.

So why bother telling this story to the Senate Inquiry. Firstly, as an educated woman, I knew nothing about the risk factors for ovarian cancer. I regularly have my pap smear and was approaching menopause and my fiftieth birthday and breast screening. I knew that weight loss was often associated with cancer but not weight gain, or an increase in breast size. I am now well aware that the fact that I have never had a child or even been pregnant is in fact a risk factor along with the endometriosis. I finally have a reason apart from a stressful job to explain my tiredness and the bowel problems that I presumed were irritable bowel or stress. I am now aware that starting menstruation at 11 as I did is also a risk factor. These are the sorts of facts that should trigger screening at 40 or earlier for those in the “at risk” group. If I had known all the symptoms and risk factors and had been screened, I would have elected to have a complete pelvic clearance about 3 or 4 years ago. As I knew none of this at the time, I was not able to make an informed decision.

My first submission to the Senate inquiry is a direct request for screening for ovarian cancer to begin.

I am satisfied with the treatment services that I have received to date, although I am aware of the fact that I live in Canberra and not a small country town. I have the benefit of choice of location for my chemotherapy, and have few out of pocket costs.

I am not satisfied that the even doctors are aware enough of the risk factors as my story relates. Nor am I satisfied that public awareness even exists for this cancer, which mostly strikes much older women than myself.

My second submission is that there should be a public awareness campaign.

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