

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

Recommendations regarding research priorities

It came up a lot in the Hansard Report, and I agree that it is absolutely essential that an early detection test be found for ovarian cancer. Too many lives are lost and too much misery is being caused at the moment by this cancer for which we do not know the cause and which cannot be detected at an early stage. An early detection test would lead to a much higher cure rate. It needs to be borne in mind though that most specialists and GPs consider ovarian cancer to be a very aggressive cancer, and that from the time of onset to when the cancer is already too advanced to treat effectively would only be a matter of about 6 months. This means that if an early detection test did exist, women would need to be tested pretty often – at least every 6 months; it would not just be a matter of having it done every 2 years when you had your smear test.

Whilst I do not underestimate the importance of research to find an early detection test, I feel that it is **equally important** to conduct research aimed at helping the people who already have ovarian cancer, particularly since it will probably take a while to establish the early detection test anyway (and in the meantime many more lives are lost and a lot more misery caused). So please don't write us off. We should be looking for better methods of treatment for the people who fell victim before there was a reliable test.

The only thing at present that can help ovarian cancer patients is chemotherapy and this has numerous side effects. Losing your hair and having to wear a wig is a horrible and humiliating experience. Other side effects are equally bad. Some people hate the whole experience so much that when they have a recurrence, they are not prepared to go through with it again. A few more drop out at the time of the second recurrence – they have had enough! Maybe they could have lived longer by having treatment, but they consider that the **quality of life** is just too bad. Finally, there are a number of patients who do not respond to chemotherapy at all. What is being done for them?

Should we therefore not be looking at alternative methods of treatment that were effective but had fewer side effects? I am aware that there is research being conducted at present targeting some of the receptors of cancer cells. These are receptors that are believed to be involved in cancer cell motility and metastasis. We also know that cancer cells overexpress genes for certain proteins which may or may not be expressed by the genes of normal cells. These proteins which may have a role in cancer progression could also be the target of cancer therapy and so could the genes that code for them. I believe these areas of research should have higher priority for funding.

Finally, does anyone really understand why if chemotherapy kills cancer cells, the cancer keeps coming back? What is different about the cells that were obviously not destroyed? Why did they escape the effects of the chemotherapy? Were these cells different from the others from the beginning and what was different about them, or did they develop some protection during the attack? If so, what was the mechanism of action? Is there something that could be done to break this cycle of remission/relapse in ovarian cancer patients? These are all areas which should be explored if we are ever to find an answer to this mystery and they **are** important.

I do not believe that there is any ovarian cancer laboratory research happening in South Australia. I looked pretty hard for this, as I would have been interested in supporting it financially if there had been. I am not sure about the other gynaecological cancers, but have not heard of any research, and suspect that the position is not much better, particularly for the less common ones. I do know however that there is heaps of research for breast and prostate cancer.

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

Medical Care

There is no doubt in my mind that the best specialist for an ovarian cancer patient (and probably for other gynaecological cancer patients as well) is a gynaecological oncologist. For a start it's a "one stop shop". You go there for your physical examinations and also for the blood tests and the oncology treatment. It was also brought to my attention (but not until a year after I was diagnosed) that outcomes for patients who see a gynaecological oncologist are about 25% better than for those who don't. I did not have a gynaecological oncologist at first, but when my gynaecologist retired (a year after I was diagnosed), I asked to be referred to one.

Some of my friends do not see a gynaecological oncologist. They go to an ordinary gynaecologist for their physical check-ups and to an oncologist for their chemotherapy. I consider the care that I get from my gynaecological oncologist to be vastly superior to what they get as my doctor is so experienced with this type of cancer. An ordinary gynaecologist would probably not see many cases of ovarian cancer and is unlikely to ever have operated on such a case. I am sure that a general oncologist would not see many ovarian cancer patients either as they would deal more with people with breast or lung cancer, so they wouldn't develop quite the same expertise as my specialist.

One of the problems (at least in South Australia) and the reason I suspect GPs don't refer patients to gynaecological oncologists is that we have a severe shortage of such specialists. My doctor is the only experienced gynaecological oncologist that I know of. I am aware of about 3 (or possibly 4) others, but these only qualified in the last

couple of years and one of these does not administer chemotherapy (the lady that I know who goes to him has to go to a general oncologist for this). I think we need to spend a bit more money to get a few more of these specialists trained up.

Support Services

I note the comments in the Hansard Report about private patients not having access to social and support services and I agree with this. When I had my first recurrence, I made enquiries about getting a counsellor as I was feeling very distressed. I was told by the leader of our support group that there was an excellent counsellor at the Royal Adelaide Hospital. I pursued this further, and found that it would cost me \$200 per hour to see this person privately, but I might get a bit of it back from my Health Insurance. If I was a public patient, I would no doubt have had free access to this service. Not being able to afford this, I had to cope without. Eventually, an acquaintance referred me to another service which apparently was more affordable. The only catch this time was that the person I was allocated to was very inexperienced. I got the impression that I was the first patient who had ever come to her and that I had been given to her to “practice on”. I only attended for one session as I got absolutely nothing out of it. It was only just recently that the South Australian Cancer Council started offering counselling services to cancer patients, but the number of sessions is limited. I have been to one such session, and I am very happy with the service I am getting now. It’s a start, but there’s a long way to go before we have anywhere near the same services as public patients.

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

I think there should be some training for GPs so that they are better able to recognise the symptoms of ovarian cancer. I did not get anywhere when I presented to him with symptoms. I also did not get anywhere when I went to see my gynaecologist, as he also misinterpreted my symptoms. I had to see a third specialist before I was finally diagnosed.

The difficulty with GPs is that they rarely see cases of ovarian cancer. They also have a heavy workload, and the symptoms they are presented with could just as easily be something else. Furthermore, every woman I have spoken to who has had ovarian cancer presented with different symptoms; no two women experienced it in the same way.

I liked the idea that was discussed in Hansard about a step by step checklist. This I think, would make it easier for doctors. I think GPs also need to be more aware of the CA125 test, as this is easy to do and may lead to the correct diagnosis (but not always of course). This is not an easy issue; it is very difficult for GPs always to get it right without the benefit of a conclusive test.

I think there should also be more collaboration between specialists in different areas. An example of this is when a patient presents with gastrointestinal symptoms, but the test results are negative. The gastroenterologist should realise that there is probably **something** wrong with her and should consider whether or not she should be referred to a gynaecological oncologist. Some training here may be beneficial.

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

I think this is a bit of a waste of time at the moment, at least in relation to ovarian cancer. I once was asked to attend an “awareness day” at a shopping centre and to hand out pamphlets about ovarian cancer. It’s an experience I would not be interested in repeating. The majority of people just walked past and did not want to know about it. Let’s face it, who wants to know about an illness that only a few people get, that can’t be cured, and you can’t do anything to prevent or detect it early anyway?

If we get an early detection test however, it would be a totally different ball game. We should really go for it then with the public awareness campaign, as women could then do something to lessen the awful consequences of this disease.

The people I would however like to target in an awareness campaign are women who contracted breast cancer at an early age and survived after treatment, particularly if there were other cases of either breast or ovarian cancer in their families (but even if there weren’t). It is quite possible that these people could have a genetic mutation in the BRCA1 or BRCA2 gene and may be susceptible to ovarian cancer later on in life. They may well be able to benefit from the first class genetic counselling service that is available in our capital cities at the moment and perhaps take steps to avoid “the silent killer”. Perhaps the awareness campaign could take place through one of the breast cancer awareness groups.