## **COMMITTEES**

## Community Affairs Committee Report Speech

**Senator ALLISON** (Victoria—Leader of the Australian Democrats)—It is a great pleasure for me to join this debate on the Community Affairs Committee report *Breaking the silence: a national voice for gynaecological cancers*. Most of us have been touched by cancer, whether it is our own experience or that of our partner, our father, our mother, our child or a friend. It is a very life-altering experience for anyone who has suffered from it and for those who are around them.

At the outset, I want to pay tribute to all of the women who shared their experiences with the committee during the course of this inquiry. I know it was not easy for many of them. Their stories were very moving; I hope that they feel that the report reflects their hopes for a better approach to gynaecological cancer in the future.

I also want to recognise the efforts of two people in particular. It is unfair to single out two people, but I will do that because they were the instigators and the reason that we had this inquiry. They were Margaret Heffernan and Kath Mazzella, whose work directly led to the inquiry through a petition. What was presented to this place was a petition with some thousand signatures of women. For a long time I have felt that we do not pay enough attention to petitions. For this reason—and I thank the Senate for this—we were able to refer those petitions to the Community Affairs Committee, which then chose to conduct a roundtable discussion to see whether this had substance and should be followed further. Then, as we all know, by joint referral across parties, a referral was made to the Community Affairs Committee for a full inquiry. That was a heartening process, because it involved each party in this place but it also involved the community. That is the great strength of the Senate—that people can speak directly to us. In this case I think there has been a fantastic outcome as a result. I also want to thank the committee secretariat, who once again have done a fabulous job in bringing together all of the evidence and submissions that contributed to this report.

Fortunately, in the past few decades we have made a lot of progress in the area of cancer. We now know more about the causes of some types of cancers. There are more treatment options, and today people with many forms of cancer, including previously fatal forms, can and should expect a cure. But our progress in the area of cancer has not been even, as this report demonstrates.

This week we heard good news on the breast cancer front. We heard that, although the incidence of breast cancer is rising, women diagnosed with the disease have a better chance of survival now than ever before. Major advances in early detection and treatment mean that 86 per cent of women diagnosed with breast cancer today can expect to be alive in five years time. But that is not the case for all cancers. Each year, thousands of women will get some form of gynaecological cancer, whether it is cancer of the ovary, fallopian tube, uterus, cervix, vagina or vulva, and many of these women will, sadly, die.

In 2004, 1,530 women died as a result of gynaecological cancers. If we do not change the way we deal with these cancers, women will continue to die unnecessarily. This group of cancers is more common than lung cancer or melanoma but far less visible. Gynaecological cancer remains stigmatised and there is a silence, uncomfortableness and unwillingness to talk about these conditions that

impedes efforts to end the death and suffering caused by these cancers. Natalie Jenkins, chairperson of the Gynaecological Awareness Information Network, told the committee:

GAIN continues to be surprised and dismayed at the lack of knowledge and awareness of gynae conditions among the general populace. We believe this is the result of the social taboo surrounding the subject.

Women do not know what symptoms to look for, and nor do their doctors in many cases. They do not know that gynaecological cancers are some of the hardest cancers to detect, because many of the symptoms are similar to other conditions and so they get overlooked or attributed to other problems or middle age.

They do not know that cancers of the uterus, the ovaries, the vulva and vagina are on the increase and that we do not have effective screening processes, except for cervical cancer, and even that is worryingly underused. They do not know that some gynaecological cancers are amongst the most deadly types of cancers. Ovarian cancer kills about 60 per cent of those diagnosed within five years—three times the death rate for breast cancer.

Education and communication have to be the first steps in bringing these diseases to the forefront of our minds and in promoting earlier detection, thereby increasing survival rates. Gynaecological cancers affect all women. All women, irrespective of their age, need to be aware of these diseases and need to be advised and guided with care and consideration in their early detection. Healthcare professionals must be informed and as active as possible in spreading information about the need for self-examination and vigilance about the symptoms. If women and their doctors know the risk factors and early signs, they will make use of a specialist to rule out cancer or detect it in the early stages. It is my hope that the report of this inquiry will lead to changes that mean that every patient will find out their diagnosis as quickly as possible and that information will be easily available to women to enable them to become as educated as possible about their condition.

However, information is not enough—we also need to have good services. We hear that, while many women with gynaecological cancers did receive treatment and access to services, many missed out because those services were deficient, uncoordinated, underfunded or simply not available. Gynaecological cancer cannot be treated appropriately if care is not delivered in a comprehensive and coordinated manner. That means that doctors, specialists and other healthcare professionals must work together to meet the patients' specific needs. Women have a far greater chance of survival, for instance, if they are treated by gynaecological oncologists and by treating specialists in public hospitals. One of the key messages in our inquiry was that multidisciplinary care is best practice and provides better treatment, better outcomes, more satisfaction and much less distress.

This is not just about treating the affected organ. We must also do more to manage and help women, their families and caregivers during and after treatment. We must help them live with their disease and to cope with life after cancer. That can be very difficult for many women and their families. Women need to have a range of practical and financial supports and some women will need to make very difficult end-of-life decisions. We must cultivate a more humane response to the totality of women's experiences. We need, for instance, to address some of the results of cancer treatment, like lymphoedema, which at least one of the members of the committee is affected by. We need masseurs who specialise in this area and

physiotherapists who are available. By 'available' to women I also mean affordable. We need more research, too. Gynaecological cancers, like many other diseases, will finally be overcome through research. Research can bring that day much closer. We need additional means, improved organisation and better coordination.

Most of all, we need a powerful voice to improve the profile of gynaecological cancers. Science, medicine and education can do much, but they will only do so by joining forces. This is why the committee has recommended a centre for gynaecological cancers as being essential to achieve that. A centre such as this can be a linchpin and provide the impetus to solve the problems and questions in the area of gynaecological cancers in much the same way as has been done with breast cancer. We need to work together to make sure we use the resources available to maximise advantage for patients.

Finally, I would like to thank my fellow committee members for their involvement in this inquiry. It was an empowering inquiry, if I can put it that way. It was a pleasure to work with so many committed women. I recognise and acknowledge here the personal insights that came from women on this committee who have had more than a brush with cancers. I felt rather daunted by the experience that surrounded me in this committee inquiry. I also learned a great deal about my own body, as much as about cancer. So I thank the Senate for giving the committee the opportunity to conduct such an important inquiry.