

**Senator FERRIS** (South Australia)—I too want to speak on the Community Affairs Committee report *Breaking the silence: a national voice for gynaecological cancers*. On this day last year, I had just begun to learn about gynae cancers, in particular ovarian cancer. At this time last year I had just undergone surgery for ovarian cancer and had joined thousands of women in Australia who are on this, until now, largely silent journey. It was a steep learning curve for me and one which was at times quite frightening.

Gynaecological cancers are often not spoken of in the community and those several hundred women who are diagnosed each year are often unable to find the support they need. Some women say that when speaking of gynaecological cancers they have feelings of guilt, shame and embarrassment, and as a result their gynaecological cancer journey is often made alone and in silence—as silent as the early symptoms of some of these cancers, because symptoms of ovarian cancer are often vague. As with many women who gave evidence to our committee, I paid several visits to doctors before an accurate diagnosis was made. That usually occurs only after a CT scan or an ultrasound.

There are some very frightening statistics that were reported to the committee that I want to note today. In 2001, 1,537 women were diagnosed with uterine cancer, 735 women were diagnosed with cervical cancer and 252 women were diagnosed with vulval cancer. One of the most disturbing figures in the report is the statistic for ovarian cancer. In 2001, 1,295 Australian women were diagnosed with ovarian cancer; 846, sadly, died. Unfortunately some of these cancers carry a very poor survival rate—unlike breast cancer, which in Australia is now curable in more than 80 per cent of cases. What a wonderful outcome that is. There is no doubt that this is partly due to the significant financial support which has been given to breast cancer by this government and the previous government. A total of \$34.5 million has been made available by this federal government and in the final two years of the previous government. Sadly, for ovarian cancer only \$800,000 has been made available over the same period, with little or nothing available to the other, equally important, gynaecological cancers. The future statistics tell their own awful story. In the year 2011, 1,645 women will be diagnosed with ovarian cancer, 1,967 women will be diagnosed with cancer of the uterus, and 461 women will be diagnosed with cervical cancer.

The Senate committee's task was to define the need for a national 'voice' for gynaecological cancers to focus the effort and resources throughout Australia, and to examine the adequacy of research funding in both basic research and clinical trials; the adequacy of access to screening, treatment and wider health support services, particularly for Indigenous women and women from other cultural backgrounds; the adequacy of education for the medical community, women and the broader community; and the adequacy of representation of expertise and experience in gynaecological cancers in national health agencies, including the newly established Cancer Australia.

After extensive evidence from highly qualified experts and representatives of the community and support groups, the committee agreed on the urgent need to establish a national voice for gynaecological cancers. This is a key recommendation that impacts on all areas of gynae cancers and the carers of people with those cancers. We concluded that real change requires a national focus and that the gynaecological cancer sector of our community would benefit enormously from having its own structure, its own infrastructure and its own national voice.

We recommend that initial seed funding of \$1 million be found from the Commonwealth government for the establishment of a stand-alone centre for gynaecological cancers in Australia, within Cancer Australia. This recommendation recognises the importance of Cancer Australia and encourages collaboration and a cohesive approach to cancer care.

We concluded unanimously that there is value in bringing people together to strengthen the understanding of gynae cancer issues at the political and policy level and to provide many of the 'answers' that are needed to lessen the impact of these cancers on women and their families.

The committee believes that there should be increased and better coordinated funding to drive new developments in gynaecological oncology and to make more effective use of Australia's talented researchers and investigators, the priority being the development of a screening test for ovarian cancer to enable earlier identification of the disease and successful treatment—hopefully, lowering those awful statistics that we heard about in evidence. Recurrent Commonwealth government funding is essential for maintaining the vitality and the enthusiasm of researchers and for minimising the burden of fundraising for research by community groups and the very willing volunteer organisations.

The provision of high-quality treatment and wider health support programs is a critical element in improving health outcomes for women with gynae cancers. Evidence showed that access to treatment was not equal across the community, with disproportionate numbers of women from rural and remote areas, Indigenous populations and culturally diverse populations generally having very limited access to the services they need. This is unfair. It has to change.

Improvement is urgently needed in the delivery of treatment and wider health support programs, including the very significant input of multidisciplinary care and the multidisciplinary care teams, and access to appropriate psychosocial and psychosexual care and lymphoedema management—a very important side effect of many of these cancers. Allocation of increased funding for treatment and support programs and more targeted national health strategies were also considered to be very important areas of need.

The committee found there was a varying level of awareness amongst the medical community, women and the wider community. More effort was needed to continually improve the delivery of gynaecological oncology education on a formal and continuing basis. General practitioners and nurses were identified as being crucial to the appropriate referral of women to gynaecological oncologists and it was critical for GPs and nurses to be given opportunities to further pursue education in treatment for gynaecological cancers. We believe that a more targeted approach in the delivery of messages is needed, and programs are thought to be a key area in the referral of women to gynaecological oncologists. Information needs to be visible and accessible to women and the broader community, to raise the awareness of gynaecological cancers and to assist women to make informed decisions about their treatment.

A national awareness campaign is urgently needed, with the coordination of existing education efforts and the development of clear and consistent messages to women and the community. How wonderful it would be for women who have been newly diagnosed with a gynaecological cancer to receive from a survivor something like the very informative My Journey Kit for breast cancer, which women who are diagnosed with that disease can read through with their families. That would allow people to know the journey they are about to undertake. This information is currently not available to women. Those women who try to look on a website to find information about these cancers often find themselves going to the United States websites to get information. How much better would it be for it to be handed to them in their hospital bed by a survivor or in their doctor's treatment room. That is another very important recommendation of this committee.

In conclusion, I particularly thank all of those women—all of them—who courageously came to give evidence to our committee, including survivors of the various gynaecological cancers, the medical experts who treat them, the community groups who support them and the families who care for them. The families who love and support these women and the researchers who are seeking improved treatments for them are an enormously important part of this journey that women undertake.

This has been one of the most interesting and, for me, most significant inquiries that I have been a part of in my 10 years in this place. I look forward very much to the establishment of a national voice for gynaecological cancers which will equal the success of the National Breast Cancer Centre, which has so successfully raised the profile on breast cancers in this country. I look forward very much to being a part of that.

In conclusion, I add my thanks to the wonderful staff in the committee secretariat. They have worked very hard on this inquiry.