COUNTRY WOMEN’S ASSOCIATION OF NEW SOUTH WALES

SUBMISSION TO THE INQUIRY INTO GYNAECOLOGICAL CANCER

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Gynaecological Cancer Inquiry
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INQUIRY INTO GYNAECOLOGICAL CANCER

The Country Women's Association of NSW would like to thank the Committee of Community Affairs for the opportunity to have input into this Inquiry.

We would also like to take the opportunity to extend our congratulations to Ms Margaret Heffernan on being awarded the Order of Australia medal in the Queen's birthday honours list for her service to the community.

As members of the Social Issues Committee of the CWA of NSW, we do not pretend to have the medical background or expertise to comment on some of the issues raised. We do, however, believe we have a wide range of experience, both personal and in various aspects of the community, and would like to think that our input from this perspective can be valuable to the Inquiry.

a) Level of Commonwealth and other funding for research addressing gynaecological cancers:

One of the problems when referring to gynaecological cancers is that there are many different types, depending on which part of the body is affected and even within different organs, for example there are several types of epithelial ovarian cancers. Many women are of the mistaken belief that having a Pap Smear regularly is giving them warning against all types of gynaecological cancers progressing without knowledge. This is simply not correct.

At this stage ovarian cancer has no test available and is insidious in that many of the symptoms are minor and can be mistaken for other things. If every woman in Australia who was feeling tired presented to a casualty department and demanded a full body scan as Senator Ferris did, we would have bedlam.

In fact that is exactly the type of complaint we are trying to get out of our casualty departments and into clinics etc – casualty departments are for broken legs and major injuries - is the message we are being given. Our committee members found Senator Ferris' actions extraordinary and tried to relate it to their own circumstances, with comments such as "I would be told to go home and have a rest" or "try that on in my town!" However, Senator Ferris was totally correct in her actions and the diagnosis proved her concern to be fully justified.

It appears that this particular cancer has no middle ground. In stage 1 where the cancer is confined to the ovary (which is very early on) there are about 90% cure rates. However if it is not detected at this stage (the stage with the very minor symptoms that could be confused with any number of general lifestyle issues), it progresses to a stage where the mortality is extremely high.

Whereas Pap Smears can detect abnormal cells which could lead to cervical cancer, there is no test for ovarian cancer. If a woman is lucky enough to have her Pap Smear taken by a very qualified G.P., that G.P.

might observe other abnormalities such as spongy ovaries and make further tests for other problems, such as ovarian cancer.

However, most women ignore the early "non-specific nature of symptoms of ovarian cancer" and when they do finally seek help, it is too late and the cancer has spread to other vital organs, with a very low survival rate.

The Daily Telegraph on 14 April 2005 reported "Blood Test to Catch Ovarian Cancer Early". Researchers were "developing a diagnostic tool known as a multiplex assay that can screen for many markers in one blood sample – improving the accuracy and sensitivity of tests." It stated that "If Ovarian Cancer is detected early, it is curable and has a better than 90% survival rate. It is mostly a disease affecting post-menopausal women, but women as young as 13 have been diagnosed with the killer." There was hope that an ovarian cancer assay would be running by the end of 2005, but it is now mid 2006 and no wonder test has come into production.

Yes, we should increase funding for research knowing it won't be easy as there are several types of epithelial ovarian cancers. Therefore we support an immediate increase in research funding for the development of a screening test for ovarian cancer.

As we know, cervical cancer, diagnosed by Pap Smears, has had a lot of research put into it and only this week (early June 2006) we have heard that "the needle vaccine, Gardasil, has been found to protect women from two viral strains behind the cancer which kills 500 women in Australia each year and 300,000 worldwide" (Daily Telegraph 8 October 2005), is going on to the American market and will soon be available for use in Australia.

"It is not known if a single vaccination will provide a lifetime of protection", but it is reported that it has more advantage if given to young girls between the ages of 9 to 13, before they become sexually active. The Newcastle Herald of 10 June 2006 lists the age range as 9 to 26, adding that "the vaccine also blocks infection by two other strains responsible for 90% of genital wart cases" and "the vaccine may not protect people already infected and may increase their risk of the kind of lesions that can lead to cervical cancer, the U.S. Food & Drug Administration say".

Gardasil restricts two strains of the human papilloma virus (HPV) – known as types 16 and 18 (carried by about 50% of women). However, HPV causes only 70% of cervical cancers so Pap Smears will be needed for a long, long time.

b) Extent, adequacy and funding for treatment services and for wider health support programs for women with gynaecological cancer.

Treatment and health support programs need to cover all forms of cancer. Many country people simply do not get the treatment and support that they need for treating and managing their cancers.

A recent ABC programme highlighted some of the problems faced by country people. In many cases they need to come to the city for treatment. Whilst this may not seem to be a major issue it is in fact is one of the biggest single reasons why people simply don't bother. They need to have someone take over the property (if they are on the land) while they are away in the city having treatment – not easy to find someone to do that. They need to travel in some cases, huge distances, bearing in mind the patient is already feeling tired, distressed and unwell.

In addition, the IPTAAS allowance is meagre at best and the distances to qualify in the first place are very high, and much higher in NSW than other states. They arrive in a city where they don't know their way around. Driving can be a nightmare. One lady on the programme said it was like being in a foreign country, didn't even know how to catch a bus, even finding a taxi driver that could speak English and knew where to go was a problem. Accommodation is horrifically expensive and is usually required long term, and very little assistance is given.

The things people living in the city take for granted are foreign and difficult for people already suffering not only from debilitating illnesses but from major stress and concern. In some cases this is the first occasion these people have been to the city.

One of our members knows of a cancer patient from the Cooma area who chose to die rather than going all the way to Sydney (Westmead) regularly for treatment. She stated it was just too much effort and energy to make the trips and be away from the family. This would not be an isolated case, and in a country of our supposed standard of living it is a disgrace. No wonder one of the doctors on the ABC programme stated that our country medical services are no better than third world (this is not even taking into account the bigger indigenous problem).

Ms Margaret Heffernan comments in CA 18 Hansard that much of the discussion was not truly on gynaecological cancers, but on the "tyranny of distance" when they are diagnosed. This is certainly an issue, but as already stated it is not restricted to women and not necessarily even related to cancer, but is a separate issue of health services for country people.

However, conversely, we cannot have a discussion about gynaecological cancer and not mention the huge problems associated with getting the initial diagnosis, the treatment and then the ongoing post treatment follow up which, for the "lucky" ones who live longer, can be for many years.

Treatment may prolong life but in some cases because of the trauma and problems of travel, being away from home and loved ones, support networks etc., that quality of life is questioned. That is why so many country women (and men) consider it is simply not worth the effort.

c) Increased funding for the needs of women with gynaecological cancers in the indigenous population and other cultural backgrounds.

One of our committee members wondered what is the percentage of eligible women who do the right thing and have regular Pap Smears. Her Women's Health Nurse stated that she spends a great deal of her time reminding and reminding women to come for their Pap Smear.

If women who are classified as "comfortably-off" cannot be bothered to heed warnings on health, how can it be expected that less advantaged (e.g. from minority groups such as Indigenous or Muslim women) should do so?

Gynaecological cancers also have the added problem that some cultural practices do not assist women to look after their health. In some cases women are not allowed to be examined by a male doctor, and even by a woman doctor, in gynaecological matters.

Every woman who has had a pap smear will attest that it is unpleasant. This is no doubt one of the reasons why we so conveniently forget to have them. Increasing funding may not be the answer here – it is education, although developing a non-invasive test may solve the issues of women simply "forgetting" or not getting around to it, and may also help where there are cultural issues.

The petition says (1.12) "Cervical cancer is the leading cause of death from cancers among Aboriginal and Torres Strait Islander women", but we know that many more Aboriginal women die from heart attacks, blood pressure and diabetes than from cancer. Whilst we should not disregard or consider the problem to be unimportant, where there is limited funding (and there always will be), perhaps there is a case for getting the other killer diseases under control first. The only immediate answer seems to be more health clinics and more female GPs in rural/remote areas.

d) Increased research funding to increase awareness and prevention of all gynaecological cancers to the same level of cervical cancer.

Increasing public awareness of gynaecological cancers is very difficult. It is still a taboo subject to some degree. Breast cancer now seems to be acceptable to admit to and discuss openly – due in some part to high profile patients, such as Kylie Minogue and Olivia Newton-John (although in some cultures the word cancer is totally taboo regardless of the type).

Most women with gynaecological cancers, however, will admit to "cancer" but not reveal which part of their body is affected. Perhaps with the advent of the vaccine for cervical cancer, education for the reason for the vaccine will be given in school Personal Development classes and hopefully not forgotten.

Again, possibly in country/remote areas and in indigenous settlements, days such as suggested by the Gynaecological Awareness Information Network, "Vulva/or other things Gynae Awareness Days" could work.

However there may well be resistance from male partners seeing something sinister in the women being taught such things. Even without cultural issues, many male partners in country areas are still very conservative.

In many cases older country men would know where all the gynaecological parts on their sheep, cattle and horses are but would baulk at discussing similar organs in their women, and probably not even know where they are in the human body! Sadly, however, it is not just the men as many girls and women also have no idea and therefore do not know how to recognise any symptoms.

Some school sex education programs teach a wide range of sexual possibilities and activities, and this may be the forum for better awareness of the various parts of a female’s body and how different diseases can affect them. If the information was taught in mixed classes it may be that the males (over time) would not be so embarrassed about the subject. Posters and publicity could be used in medical centres and other health-related premises, but they would hardly be the bill-board type.

Certainly, cervical cancer has received funding (Australia wide $31.6m for 2005-06), with the funding providing incentive payments to encourage GPs to regularly screen at risk women 20 to 69 years of age, those in rural/remote areas and indigenous women. If only one-third or one-half of the targeted groups were to take advantage of and are helped by this scheme, the funding is well spent, but until a like system for detection of ovarian cancer (pap smears for Cervical Cancer) is discovered, women will not be able to be alerted to a possible ovarian cancer threat. Accordingly, there will have to be an increase into such research.

e) Increase education of gynaecological cancer symptoms with GPs and primary care workers to ensure timely diagnosis and treatment.

With no means of testing (i.e. pap smears) the G.P. is the first to detect any abnormalities. Hopefully the GP will refer that patient to a specialist. It may take 3 to 4 weeks to receive an appointment with the Doctor (because the patient would not say her case was an urgent one – with only vague symptoms), then possibly 1 to 3 months to see a gynaecologist. This is time which can ill-afford to be lost.

One member comments that she has never forgotten what her GP told her in 1959. “I am a General Practitioner, I know a little bit about a lot of things. All a patient can hope for is that the GP, if not completely happy with his own diagnosis, will refer to a specialist.”
Posters and step-by-step checks are all very well. We can train and retrain (or make the suggestion anyway). But the question is when are doctors going to find the time and replacement doctors for this extra tuition.

The question of compulsory training for GPs to retain their license had a mixed reaction from our committee. Some would not advocate legislating for doctors’ annual professional development; however this is common in many other professions and occupations. One member felt that while she did not in principle approve of doctors being forced to under take continuing professional development, it did have the side effect of busy doctors being able to justify to their patients and to themselves that it was necessary, because it was legislation. Otherwise they simply don't find the time. Sometimes we need to be forced for our own good.

f) Recognise the need for, and fund accordingly, psychosocial and psychosexual care for patients and families affected by gynaecological cancers.

We believe that where psychosocial and psychosexual care is necessary it should be available but we would rather see funds directed to supplying information and support for patients and families. When one has the information and the options this may alleviate the need for counselling. Counselling really should be about helping people make their own decisions. If they have the information available to them, then this makes it much easier to rely on your own decision rather than what someone else has recommended. Possibly, with less religious faith now, less community and family support, the need for counselling is greater to assist with closure.

It was interesting to learn that 50% of women who are treated for gynaecological cancer are in private hospitals so don't often see social workers/psychologists, whereas the other 50% in public hospitals receive that luxury. This would appear to be total discrimination.

One of our retired committee members had a major operation in a private hospital under private medical insurance. She certainly could not afford the medical insurance, but her children had put themselves under financial pressure to pay the premiums for her. When it came time for her to leave hospital she was advised she wasn't entitled to any home help etc., (which she would have received after being in a public hospital) because she was wealthy as she had private medical insurance!

As stated in our introduction, we agree in principle with the petition on gynaecological health issues. We do not have the academic expertise to make comments on some of the matters but hope our comments on our own and related experiences have been of some assistance.

Every issue these days is one of finance. Every group has to fight for funding and while we admit that there can certainly be no "bottomless pit" of money for every disease, issue and problem, many in our community find it difficult to understand how governments can find the capacity to suddenly fund millions of dollars to help foreign countries in their times of need, but not be able to offer one of our research facilities extra funding. Perhaps it is time to rethink our priorities.

Social Issues Committee
Country Women's Association of NSW
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