



australian
nursing federation

Submission to the Senate Community Affairs Reference
Committee - Inquiry into Services and Treatment
Options for Persons with Cancer

March 2005

1. Introduction

1.1 The Australian Nursing Federation (ANF) is the national union for nurses in Australia with branches in each state and territory. The ANF is also the largest professional nursing organisation in Australia. The ANF's core business is the industrial and professional representation of nurses and nursing in Australia.

1.2 The ANF's 145,000 members are employed in a wide range of enterprises in urban, rural and remote locations in the public, private and aged care sectors, including hospitals, health services, schools, universities, the armed forces, statutory authorities, local government, offshore territories and industries.

1.3 The ANF participates in the development of policy in nursing, nursing regulation, health, community services, veterans' affairs, education and training, occupational health and safety, industrial relations, immigration and law reform.

1.4 The ANF recognises that:

- cancer has now replaced heart disease as the single greatest cause of death and morbidity in our community;
- people who are *diagnosed with cancer often have to make life changing decisions at short notice in a traumatized state of mind with very little information about the range of options available to them;*¹
- as a result of current science and technology, a bewildering array of evidence based adjuvant and less well established therapies confront people having to make decisions about their treatment and care;²

¹ Cook, Senator the Hon Peter 2005 *Cancer Inquiry* – Statement published with the Senate Community Affairs Reference Committee Terms of reference for the Inquiry into Services and Treatment Options for Persons with Cancer, Australian Government.

² *Ibid.*

- there is significant need to assist people in the transition from active treatment and care when there is scientific evidence of treatments that will lead to cure or at least remission and when often toxic and unpleasant treatment is futile and active palliative care is needed to enable a person to have some quality and dignity in dying; and
- nurses are important care providers to people undergoing active treatment for cancer as well as providing palliative care to people, in the acute care setting of hospitals, in hospices and in peoples' own homes.

1.5 This submission will briefly address most of the terms of reference; covering the major issues of concern for the ANF, nurses and nursing. However the ANF would welcome the opportunity to involve nurses with expertise in this area to give evidence in the public hearings conducted as part of this inquiry.

2. General Comments

2.1 What is striking when reviewing the resources available when preparing a submission such as this is just how much of the high quality information available to the community and health professionals relates to the diagnosis and treatment of breast cancer, and just how limited the information is for other forms of cancer.

2.2 This is undoubtedly due to the extraordinary efforts of a number of generally woman based community, professional and scientific organisations that have been leaders for more than a decade in their work:

- promoting collective interest (and passion) in consumer focussed, evidence based treatment and care;

- funding research into evidence based care and more efficacious and creative treatment modalities, such as a strong emphasis on multidisciplinary care;
- funding other impressive information resources for people being diagnosed and treated with breast cancer;
- lobbying governments and undertaking innovative and effective fundraising initiative to obtain the necessary funding to undertake this work; and
- recognising that cancer is far more than a physical disease of an individual but a psycho-social challenge for the person with the disease and their families and loved ones and creating effective support networks for all affected by this disease and its often testing treatment.

2.3 The ANF recognises that the infrastructure, activity and outputs that are evident in the area of breast cancer over the past decade could provide potential models for successful, collaborative and consumer focussed approaches to addressing other forms of cancer in the community.

2.4 Of particular note is the extraordinary consumer resource, the *Directory of Breast Cancer Treatment and Services in New South Wales* that was launched in August 2002. While there is significant room for further development and reliability of the information the response to the Directory has been very positive by health consumers.

2.5 The aim of the Directory is to make the selection process easy for health consumers and GPs, and to ensure they are referred to the appropriate health professionals and specialist/s for their situation.

- 2.6 The 170 specialists are listed by specialty: breast surgeons, radiation oncologists and medical oncologists, by public and private hospital, and by postcode. The information provided by specialists details many things people need to know when selecting the best specialist/s. It shows: whether they have the appropriate professional affiliations such as belonging to the professional organisations relevant to their specialty; how regularly they perform relevant surgical procedures which go to the currency of their skills, knowledge and practice; and whether they work in multidisciplinary teams or in relative isolation, among other things.
- 2.7 A section describing the breast cancer journey details the options, the multidisciplinary health teams involved and how to access other services - family counselling, palliative care, prostheses, lymphoedema clinics, support groups - the works!³

Recommendations:

1. The Senate Committee review the infrastructure, activity and outputs that are evident in the area of breast cancer over the past decade as a potential model for successful, collaborative and consumer focussed approaches to addressing other forms of cancer in the community.
2. The Committee support the development, ongoing review and updating of consumer directories for all forms of cancer to assist people diagnosed with cancer, and their GP or other primary care health professional, to make informed decisions about their treatment and care. For example, the multidisciplinary team and health service most appropriate to meet their treatment and care needs as well as their social, cultural, geographic and economic needs.

³ Breast Cancer Action Group and NSW Breast Cancer Institute 2002 Directory: Breast Cancer Treatment and Services for New South Wales women. Available: www.e-strategy.net.au/bci/directory/default.asp
Accessed: 27 March 2005.

3. The delivery of services and options for treatment for persons diagnosed with cancer

3.1 The efficacy of a multi-disciplinary approach to cancer treatment

Of paramount importance is the need for an integrated treatment and care plan for people undergoing treatment and care for cancer. There is a growing body of evidence (particularly in the area of breast cancer) that:

...multidisciplinary care has the potential to reduce mortality, improve quality of life and reduce health care costs.⁴

3.2 The ANF is of the view that multidisciplinary care entails a team approach to the provision of care. That is, medical, nursing and allied health care professionals across primary care and clinical specialties such as surgery, medical oncology, radiation oncology, palliative care and including psychological and social support and care.

3.3 That said, there is also no particular model of multidisciplinary care description of ways in which this could be implemented in the National Health and Medical Research Council's (NHMRC) *Clinical practice guidelines for the management of early breast cancer*.⁵ The guidelines recommend that women with breast cancer should have access to the full range of multidisciplinary treatment options, but does not define any.⁶ Identifying and promoting successful models of multidisciplinary care would be a useful addition to the resources available to consumers and health professionals alike.

⁴ Zorbas H, Barraclough B, Rainbird K, Luxford K and Redman S 2003 Multidisciplinary care for women with early breast cancer in the Australian context: what does it mean? *Medical Journal of Australia* 179 (10) 528-531. Available at: www.mja.com.au/public/issues/179_10_171103/zor10160_fm.html Accessed: 27 March 2005.

⁵ National Health & Medical Research Council 2001 *Clinical practice guidelines for the management of early breast cancer*, Commonwealth of Australia.

⁶ Zorbas H *et al* 2003 *op cit*.

Sadly the past emphasis has been primarily upon the medical aspects of treatment and care only, while health consumers describing their cancer experience clearly recognise the contribution of the nursing and allied health care as critical components of their care. The medico-centric emphasis of health care is one of the known disincentives that lead to nurses leaving the nursing workforce.

3.4 The role and desirability of a case manager/case co-ordinator to assist patients and/or their primary care givers

There is considerable evidence that the failure to coordinate screening, treatment and care, while including the person undergoing the care and their chosen family and significant others is a source of great frustration and a area with rich potential for errors and adverse events.

3.5 In oncology, palliative care and in specialist breast cancer services specialist nurses have been increasingly taking on the care coordination and liaison role for people undergoing complex treatment and care across multiple services and specialties.

3.6 This is also an area where the very specialised and expert clinical knowledge, skills and experience of nurse practitioners could make a real difference.

Recommendations:

3. Research should be supported into the identification and promotion of successful models of multidisciplinary teams providing cancer care, relevant to the context of the cancer that is flexible enough to be able to be responsive to an individual's particular circumstances and wishes.
4. That every health consumer has an appropriate and designated member of the multidisciplinary team as a care coordinator.

3.7 Differing models and best practice for addressing psycho/social factors in patient care

As in other areas, the breast cancer initiatives provide pioneering work in this area. The National Breast Cancer Centre (NBCC), in collaboration with the National Cancer Control Initiative, have developed the *Clinical practice guidelines for the psychosocial care of adults with cancer*.⁷ This document is based on previous best practice guidelines that the NBCC developed for the psychosocial care of women with breast cancer.⁸ These Guidelines reflect the significant high level evidence that exists about the most appropriate psychosocial care for cancer patients and have been approved by the NH&MRC. The NBCC has found that the research shows that the implementation of the guidelines has the potential to improve health care outcomes, including a reduction in psychosocial morbidity and emotional distress, improved wellbeing and satisfaction with care. Many of the guideline recommendations require no new service delivery infrastructure or additional resources.

3.8 These Guidelines are appropriate to guide the practice of nurses and other health professionals. Dissemination and implementation of the Guidelines is where effort is required.

Recommendations:

5. The Committee support the national adoption of the *Clinical practice guidelines for the psychosocial care of adults with cancer* and strongly promote their dissemination and implementation.

⁷ National Breast Cancer Centre and National Cancer Control Initiative 2003 *Clinical practice guidelines for the psychosocial care of adults with cancer*, NBCC, NSW.

⁸ National Breast Cancer Centre 2000 *Psychosocial clinical practice guidelines: providing information, support and counselling for women with breast cancer*, NBCC, NSW.

3.9 Differing models and best practice in delivering services and treatment options to regional Australia and Indigenous Australians

There are considerable barriers to access to a full range of integrated care and treatment modalities for indigenous Australians, people in regional Australia, as well as other groups who can be identified by culture, religion, language, disability, age and socio-economic status. It is important that any recommendations from the Inquiry include the needs of indigenous Australians or those who are disadvantaged by way of any of the above disincentives to safe, high quality cancer care are taken into account and informed by the opinions of the leaders or legitimate spokespersons from such groups. Necessarily the particular needs of these groups may require innovative models of treatment and care or recognisable adaptations of more generic or universal models.

3.10 The moral obligations that surround the appalling morbidity and mortality for indigenous Australians warrants particular focus in developing appropriate models of cancer treatment and care. The *National Strategic Framework for Aboriginal and Torres Strait Islander Health*⁹ provides strong guidance for the ensuring cancer services for communities are provided in a culturally sensitive and holistic way with close involvement of the community.

⁹ Standing Committee on Aboriginal and Torres Strait Islander Health 2002 *Aboriginal and Torres Strait Islander Health Workforce National Strategic Framework*, Department of Health and Aging, Canberra, May.

Recommendations:

6. The Committee requires that the scope of any national initiatives ensure that the needs of all Australians are included, and that the voices of the leaders and spokespersons for indigenous Australians and potentially disadvantaged community and other groups are heard and given heed.
7. Where particular circumstances indicate the need, such as with Indigenous Australians, there are culturally sensitive, ethnically acceptable and specific models of care and treatment developed and implemented.
8. Where access to optimal cancer treatment and care would be unavailable to a person diagnosed with cancer because of the personal cost (including the burden of travel and accommodation), adjustments are made so that Centrelink, Medicare and private health insurance, if held, cover the cost of this treatment and care.

3.11 **Current barriers to the implementation of best practice in the above fields**

Except in the area of breast cancer, there is as yet inadequate evidence of true collective commitment for consistency and strong community involvement in developing appropriate models of treatment and care for people diagnosed with cancer. Unless there is this joint passion and effort, it will be a long hard row to hoe. There must be cooperative efforts across professional lines, across service boundaries and across specialty 'turf' claims. The needs and circumstances of the person with the diagnosis of cancer must be the centrepiece of the treatment and care, not the interests of the providers.

4. How less conventional and complementary cancer treatments can be assessed and judged, with particular reference to:

4.1 The extent to which less conventional and complementary treatments are researched, or are supported by research and the efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies

There is much criticism of less conventional and complementary therapies particularly from supporters of conventional western medicine. This criticism may be warranted to some extent because of the lack of scientific evidence that these treatments are safe, efficacious and less burdensome than others.

4.2 However, other considerations arise. It should also be recognised that a number of conventional, widely used treatments in western medicine have not necessarily been fully researched, yet continue to be acceptable and utilised freely. People diagnosed with cancer often become desperate to seek alternative treatments when conventional treatments fail or are not appropriate for their situation. Others have used and trusted less conventional and complementary therapies for other illnesses and injuries and have faith that they can be used for the treatment of cancer.

4.3 So what of consumer choice? It is difficult to argue that provided with information about their lack of scientifically researched evidence, information about risks, effects and alternatives, the decision of a competent person wishing to pursue such treatment could or should be overruled. Ethically and legally in 2005, this decision should be respected.

4.4 What of the availability of the means to conduct the necessary scientific review of these treatments? While NHMRC do offer project grants to support complementary medicine research, they are certainly not supported in the same way that the clinical trials are supported when the research into a device or therapy is underwritten by commercial interests such as pharmaceutical companies.

- 4.5 There is some evidence that the attitudes of the research funding bodies is a deterrent to providers of less conventional and complementary therapies seeking to have the therapy examined scientifically. Also, attitudes to these therapies within acute health services tend to reflect the prevailing cynical views of conventional western medicine which would make the conduct of clinical trials in that environment extraordinarily challenging for health consumers and even the thickest skinned researchers. While attitudes like that prevail it is hard to see how clinical trials can be conducted successfully in the acute care sector.

Recommendations:

9. The Committee strongly support the right of health consumers to have full information about the scientific basis for any therapy they are offered, the alternatives, the risks, the effects and the potential prognosis.
10. That research into less conventional and complementary therapies is actively encouraged and supported, not as exotic phenomena but in the same way that any potentially beneficial therapy undergoing scientific review would be treated.
11. That research is conducted into prevailing attitudes and cultural barriers to therapies not currently recognised by conventional western medicine with a view to exposing any unreasonableness of these positions and the deterrent effect they have in promoting scientific review.

4.6 The legitimate role of government in the field of less conventional cancer treatment

The ANF is strongly of the view that the government has the same role in the field of less conventional cancer treatment as it does in treatment proposed in conventional health settings, including:

- to recognise the rights of the citizens of Australia to have safe, efficacious, minimally burdensome care and treatment for their cancer;
- to recognise the rights of the citizens of Australia to be fully informed about the safety, effects, risks, alternatives and efficaciousness of treatments and care that are available when they are diagnosed with cancer, and to respect the person's decision in relation to the treatment and care that they choose;
- to promote and fund where necessary scientific research to test the hypotheses as to the efficacy of untested treatments and care;
- to ensure that the systems in place to maintain the quality of treatment and care such as the Therapeutic Goods Administration, the NHMRC and other such agencies are adequately funded and have adequate governance frameworks to serve the people of Australia without fear, favour or prejudice; and
- to not support unreasonable prejudice to care and treatment that is not regarded as mainstream in conventional health care settings.

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