The Parliament of the Commonwealth of Australia

House of Representatives

Standing Committee on Community Affairs

REPORT ON THE MANAGEMENT AND TREATMENT OF BREAST CANCER IN AUSTRALIA

February 1995

Australian Government Publishing Service
Canberra

ISBN 0 644 42896 1

THIS REPORT IS DEDICATED TO

THE WOMEN OF AUSTRALIA

Produced by the Australian Government Publishing Service

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BACKGROUND TO THE INQUIRY

In November 1993 the then Minister for Health, Senator the Hon Graham Richardson referred an Inquiry into the Management and Treatment of Breast Cancer to the House of Representatives Standing Committee on Community Affairs. A sub-Committee with the following membership was formed to conduct the Inquiry:

Hon Wendy Fatin, MP	Brand, WA (Chair)
Ms Maggie Deahm, MP	Macquarie, NSW
Mr Harry Quick, MP	Franklin, TAS
Mrs Silvia Smith, MP	Bass, TAS
Ms Trish Worth, MP	Adelaide, SA

Prior to the commencement of the Inquiry, discussions were held with the Senate Standing Committee on Community Affairs. The Senate Committee had already commenced an Inquiry into breast cancer screening but was not addressing the question of overall management and treatment post diagnosis.

It was considered appropriate and essential to extend the Senate's consideration of the issue by examining the next stage of management and treatment in this Inquiry.

The terms of reference required the House of Representatives' Committee to inquire into and report to the Parliament on the management and treatment of breast cancer in Australia, with specific reference to:

- patient access to treatment facilities;
- adequacy of current treatment regimes;
- the role of general practitioners in the management and treatment of breast cancer;
- the role of the Department of Human Services and Health in the management of breast cancer;
- the role of cancer registries;

- international treatment and management experience; and
- the development of a national treatment strategy, including the development of agreed protocols for the management of breast cancer.

The Inquiry was advertised in the major metropolitan newspapers on Saturday, 11 December 1993.

A total of 192 submissions and 62 exhibits were received. Public hearings were held in Darwin, Brisbane, Sydney, Adelaide, Canberra, Melbourne, Dubbo and Perth resulting in 1 318 pages of transcript evidence and 1 077 pages of written submissions. Those contacted by the Inquiry included patients, specialist groups working within the hospital system, the various specialist Colleges, Cancer Councils, nursing groups, cancer support groups, and a variety of interested individuals.

COMMITTEE MEMBERSHIP

37th Parliament

Members

Mr Allan Morris, MP (Chairman)
Hon Don Dobie, MP (Deputy Chairman)
Mr Rod Atkinson, MP (to 23 February 1994)
Ms Maggie Deahm, MP
Mr Richard Evans, MP (from 23 February 1994)
Hon Wendy Fatin, MP
Mr Chris Haviland, MP
Mr Neville Newell, MP
Mr Harry Quick, MP
Mr Philip Ruddock, MP
Mr Bruce Scott, MP
Mrs Silvia Smith, MP
Ms Trish Worth, MP

Secretariat

Mr Bjarne Nordin (Secretary)
Mrs Cheryl Samuels (Inquiry Secretary to 19 August 1994)
Ms Julie Wade (Inquiry Secretary from 9 September 1994)
Ms Jodie Williams

SUMMARY OF RECOMMENDATIONS

CHAPTER THREE - DOCTORS AND PARAMEDICS

1 The Committee recommends, as a matter of urgency, that *members of the medical profession who deal with breast cancer, liaise* under the auspices of their respective Colleges, with a view to developing more accredited groupings of multidisciplinary teams which are based on what is now generally considered to be a "best practice" model. This model incorporates a team approach by multiple medical and paramedical disciplines. Through their combined understanding of current knowledge and practice about the best use of the options available in individual circumstances, all members of the team liaise and co-operate together and with the patient to diagnose, treat and manage the condition of breast cancer to the highest possible standard of care. **(para 3.2)**

2 The Committee recommends that Commonwealth and State/Territory governments and hospital administrators plan for and fund, as a priority, multidisciplinary teams to treat women with breast cancer. **(para 3.3)**

i Undergraduate Education

3 The Committee recommends that medical schools, as a matter of urgency, examine their curricula with a view to initiating courses which will enable their undergraduates to access information about the diagnosis, management and treatment of cancer with particular reference to breast cancer. Attention must be given to educating undergraduates about the emotional and psycho-social context within which patients must deal with their malignant disease. **(para 3.8)**

ii Postgraduate Education

4 The Committee recommends that medical Colleges liaise with a view to co-operating to provide their Fellows and Members with cross-professional education and information on breast cancer, its diagnosis and treatment, keeping in mind that such sharing is in the best

interests of the patient and is not a matter of "ownership" but a matter of "best practice". This sharing should involve areas such as diagnosis, co-operating with mammography programs, hospital management such as multidisciplinary teamwork, hospital based data collection, and research. **(para 3.12)**

iii General Practice

5 The Committee recommends that greater and urgent attention be given by the Royal Australian College of General Practitioners to address the lack of exposure by general practitioners to training about the management and treatment of cancer, and in particular of breast cancer. That training should include: the need to encourage both self examination of breasts and regular examination by the general practitioner; the need to encourage appropriate patients to undergo mammography screening; the role of multidisciplinary teams in the diagnosis, management and treatment of breast cancer and appropriate referral to such teams; and, aspects on the benefits to the patient and their family of counselling and support groups. **(para 3.14)**

6 The Committee recommends that the Royal Australian College of General Practitioners include as a compulsory core topic, training about the management and treatment of breast cancer. **(para 3.15)**

7 The Committee recommends that the Royal Australian College of Medical Administrators address the issue of hospital discharge practices and how better communication links can be provided between the hospital, the patient's general practitioner and community based care groups. **(para 3.16)**

8 The Committee recommends that, for the purposes of discharge planning in public hospitals, general practitioners be eligible for a Medicare rebate. **(para 3.17)**

iv Surgery

9 The Committee recommends that The Royal Australasian College of Surgeons give high priority to considering the role of the general surgeon in the management and treatment of breast cancer, with a view

to the early implementation of a scheme which will allow for a compulsory form of accreditation and audit process for surgeons performing breast cancer operations. **(para 3.20)**

10 The Committee recommends that the National Health and Medical Research Council working party which is developing clinical practice guidelines on the treatment of diagnosed breast cancer give due attention to the optimal period of time required for proper patient and medical considerations to be made between diagnosis and surgery. **(para 3.24)**

v Pathology

11 The Committee recommends that pathologists working on the diagnosis of breast cancer be specially trained and have sufficient experience in the area in which they are working. **(para 3.27)**

12 The Committee recommends that a pathologist be a member of all multidisciplinary teams. **(para 3.28)**

vi Radiotherapy

13 The Committee recommends that general practitioner education and reskilling sessions in Departments of Radiation Oncology be provided by the Colleges as a matter of urgency. **(para 3.30)**

14 The Committee recommends that greater exposure of medical undergraduates to Radiation Oncology Departments be provided by the medical schools as a matter of urgency. **(para 3.31)**

15 The Committee recommends that the Australian Technology Advisory Committee address immediately the distribution of radiotherapy units and the required number of radiation oncologists and technical staff. **(para 3.33)**

16 The Committee recommends that the National Health and Medical Research Council working party which is developing clinical practice guidelines on the treatment of diagnosed breast cancer, pay particular attention to determining when radiotherapy for breast cancer should be

administered. **(para 3.35)**

vii Medical Oncology

17 The Committee recommends that the National Health and Medical Research Council working party which is developing clinical practice guidelines for the treatment of diagnosed breast cancer, address the best use of chemotherapy and other adjuvant therapies, taking into account quality of life issues as well as medical imperatives. **(para 3.37)**

viii Counselling

18 The Committee recommends that when a multidisciplinary team is set up, counselling services be an integral part of that team. **(para 3.39)**

ix Physiotherapy

19 The Committee recommends that the essential need of some breast cancer patients for physiotherapy for post-operative conditions be recognised by those treating the patient, and that steps be taken at the Commonwealth and State/Territory government levels to ensure that public breast cancer patients can easily access physiotherapy. **(para 3.41)**

x Data Collection

20 The Committee recommends that the Australian Health Ministers' Advisory Council address, as a matter of urgency, the setting up of a comprehensive national data base on breast cancer. This should be collected and monitored by the National Breast Cancer Centre. **(para 3.45)**

xi Research

21 The Committee recommends that the Commonwealth Government provide more funding for the National Health and Medical Research Council to conduct bio-medical research and clinical trials. **(para 3.48)**

22 The Committee recommends that the National Health and Medical Research Council initiate action to:

(1) address the current lack of emphasis in clinical trials on a variety of treatment methods for breast cancer and how a greater variety of clinical trials might be funded;

(2) provide funding to allow participation in internationally conducted clinical trials for breast cancer consistent with Commonwealth Government current research and development policies; and

(3) provide funding towards longitudinal research into the period of survival. **(para 3.49)**

CHAPTER FOUR: PATIENTS

i Women as Patients

23 The Committee recommends that service providers examine the conditions under which services are provided and how they might be altered to better address issues such as privacy and ease of access. **(para 4.2)**

ii Participation in Clinical Trials

24 The Committee recommends that the Colleges and the Commonwealth and State/Territory governments address the lack of guaranteed "best practice" care outside clinical trials. **(para 4.9)**

25 The Committee strongly recommends that the Commonwealth and State/Territory Ministers for Health address the problem of casemix

disincentives for participation by women in clinical trials by ensuring that practitioners are given adequate time and funds. **(para 4.11)**

iii Psycho-social Needs

26 The Committee recommends that the National Health and Medical Research Council provide adequate funding for research to investigate the extent and severity of psycho-social morbidity and how it can be addressed. **(para 4.13)**

iv Decision Making

27 The Committee recommends that the appropriate Colleges address the need for medical practitioners to be aware of the requirement to actively involve their patients in the decision making process about the management and treatment of their disease. **(para 4.15)**

28 The Committee recommends that the appropriate Colleges address the need for medical practitioners to be aware that a woman should be given adequate time and counselling in order to make an informed decision about her choice of treatment. **(para 4.16)**

v Information

29 The Committee recommends that women be provided by practitioners with written information about breast cancer to which they and their families can refer repeatedly. The information should be written to meet the differing needs of individuals by encompassing approaches which range from the purely supportive to the medically sophisticated. Information should be presented in a manner which will not make assumptions about which level of information the recipient will require. **(para 4.18)**

30 The Committee recommends that the National Breast Cancer Centre as a matter of priority, and as part of its educational role, co-ordinate the production and distribution of information on breast cancer in the major community languages. **(para 4.19)**

vi Rural and Remote Area Patients

31 The Committee recommends that the Commonwealth and State/Territory governments, along with practitioners and professional bodies and all other service providers, give urgent priority to addressing the problems faced by women from rural and remote areas in accessing multidisciplinary teams, adjuvant therapy, clinical trials, counselling, support groups, and information. **(para 4.27)**

32 The Committee recommends that the Commonwealth Government, in conjunction with State/Territory governments, standardise and broaden the travel assistance schemes. In the event that this cannot be achieved the Commonwealth should assume full responsibility. **(para 4.28)**

33 The Committee recommends that the Commonwealth and State/Territory governments address the issue of the provision of child care while a woman from a rural or remote area is absent from her home while receiving treatment. **(para 4.29)**

vii Aboriginal and Torres Strait Islander Women

34 The Committee recommends that the Commonwealth and State/Territory governments address the issue of acquiring more information on the incidence of breast cancer in rural and urban Aboriginal and Torres Strait Islander women, and their experience of the management and treatment of that disease. The means of addressing any revealed problems should then be implemented by the Commonwealth and State/Territory governments. **(para 4.31)**

viii Women from a Non-English Speaking Background

35 The Committee recommends that the Commonwealth and State/Territory governments through the Australian Health Ministers' Advisory Council address the issue of how a woman from a non-English speaking background can be assured of easy access to appropriate interpreter services and suitably written information during the course of her diagnosis and treatment for breast cancer. **(para 4.35)**

36 The Committee recommends that the appropriate Colleges address the need for practitioners to be aware of the requirement to provide interpreter services for non-English speaking background patients. **(para 4.36)**

ix Waiting Times for Surgery

37 The Committee recommends that the Australian Health Ministers' Advisory Council examine the reasons for any inappropriate delays between the diagnosis and treatment of breast cancer. **(para 4.38)**

x Lymphoedema

38 The Committee recommends that the Minister for Human Services and Health investigate the issue of how women with lymphoedema can receive financial or other assistance in accessing compression bandages and garments and what role the Commonwealth Rehabilitation Services might play in the provision of treatment programs. **(para 4.40)**

xi Mammary Prostheses

39 The Committee recommends that the Minister for Human Services and Health, as a matter of urgency, amend the Medicare rebate schedule to include the provision of mammary prostheses. **(para 4.44)**

xii Palliative Care

40 The Committee recommends that the Commonwealth and State/Territory governments review the adequacy of funding arrangements for community based palliative care services. **(para 4.48)**

41 The Committee recommends that the Australian Health Ministers' Advisory Council investigate the supply of, and access to, hospice care in Australia with a view to increasing specific purpose facilities. An assessment of the forms they should take in rural and urban communities should also be conducted. **(para 4.50)**

xiii Family, Friends and Support Groups

42 The Committee recommends that the counselling services provided within a multidisciplinary team, provide those services to the patient's family and support person if desired. **(para 4.53)**

43 The Committee recommends that the appropriate Colleges bring to the attention of their members the need for patients to be made aware of the value and availability of support groups and counselling services. **(para 4.54)**

PRELIMINARY OBSERVATIONS

Breast cancer is the most common cause of death from cancer in Australian women, with the risk of a woman developing the disease estimated in the range of 1 in 11[1] to 1 in 16[2]. The worldwide incidence of breast cancer in males is approximately 100 times lower than in females[3].

In the past, the most common way a woman found she had breast cancer was by the discovery of a lump either through self-examination, examination by a doctor, or by chance. With the advent of the breast screening service in Australia, increasing numbers of women are being diagnosed with lesions at a level of development which, it is believed, if appropriately treated, can result in a reduction of morbidity and mortality.

While some medical practitioners have stated that Australian women are being provided with the best management and treatment possible for breast cancer, the evidence gathered by this Inquiry would not support such an assertion.

Although there is a paucity of empirical information about past and current practice, two recent Australian studies indicate that operations for breast cancer are being undertaken by surgeons, not all of whom have a large body of experience in that area, and that the overall management of women with breast cancer is not multidisciplinary.

In 1990, a study in Victoria showed that 41% of breast cancer surgery was undertaken by general surgeons who were performing a mean average of 8.7 operations a year[4]. A total of 764 operations were performed by 176 surgeons in the six-month survey period. In that

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[1] Professor Peter G. Gill, Director, Breast and Surgical Oncology Clinic, Royal Adelaide Hospital, South Australia: Transcript of evidence, p 524.

[2] *Cancer Control in Australia - An Overview*, Australian Cancer Society, March 1994, p 29.

[3] Thomas, D., *Male Breast Cancer*, Epidemiologic Reviews, Vol 15 No 1 1993, p 221.

[4] Professor Alan Rodger, William Buckland Radiotherapy Centre, Victoria: Volumes of submissions, p 1011; Mr John P. Collins, Chairman, Breast Study Committee, Anti-Cancer Council of Victoria: Volumes of submissions, p 195-196.

period, case loads ranged from one operation (56 surgeons) to 70 operations by one surgeon. Surgeons treating over 20 patients annually operated on 36% of the patients surveyed in 1990, compared with 22% in 1986. The proportion of patients treated by surgeons who operated on 10 or fewer women annually decreased from 56% to 41% between 1986 and 1990[5].

In Western Australia in 1989, 701 new breast cancers were diagnosed in 692 women. Those 692 women were treated by 105 different surgeons of whom 25 saw 10 or more cases in that year, but 43 of whom managed only one case[6].

It is obvious that such individual small case loads could not result in the use of the most up-to-date information and state of the art techniques. The high rate of mastectomy still being performed in Australia in lieu of lumpectomy would appear to be an indication of a failure to access the most recent information on specific treatments and their medical and psycho-social outcomes.

There are indications also, that for many women, the management and treatment process is fragmented and unco-ordinated, with little guarantee that it is being provided from a basis of current information and balanced assessment. While there is evidence to show that there is an increasing percentage of conservative[7] surgery taking place, continued improvements in management and treatment will be difficult to achieve in a situation where innovations depend "upon the acquisition of substantial new skills or upon the referral of patients to others who have the requisite skills"[8].

A considerable volume of evidence has been gathered by the Committee which shows that women who have not had access to specialist,

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[5] Hill, David J. et al, *Changes in the detection, investigation and management of primary, operable breast cancer in Victoria*, The Medical Journal of Australia, Vol 161 18 July 1994, p 121.

[6] Dr Michael Byrne et al, The Cancer Foundation of Western Australia: Volumes of submissions, p 908.

[7] "Breast conserving treatment ... consists of various wide local excision, lumpectomy or quadrant re-section ..." (Professor Peter G. Gill, Director, Breast and Surgical Oncology Clinic, Royal Adelaide Hospital, South Australia: Transcript of evidence, p 531).

[8] Hill, David J. et al, *Op cit*, p 122.

multidisciplinary care have been disadvantaged in terms of receiving "best practice" management and treatment for their breast cancer. Those at greatest disadvantage in accessing such multidisciplinary care are some women from rural and remote areas, Aboriginal and Torres Strait Islander women, and women from non-English speaking backgrounds.

Evidence presented to the Inquiry leads to the conclusion that the determining factor in the best management and treatment of breast cancer today is to have a sufficient number of accredited, specialist multidisciplinary teams established around Australia that women in country and urban areas can easily access.

Such teams must provide a continuum of treatment which begins with diagnosis, incorporates currently informed treatment decisions, and provides access to counselling services. By providing this broad range of services the teams will take into account, not only the medical and surgical needs of their patients, but their emotional and psycho-social needs as well.

In addition, it is considered essential that this continuum of treatment incorporate the active participation of the woman in her management and treatment plan.

The Committee considers it essential that there should be no financial disincentives to the establishment of multidisciplinary teams.

In the area of breast cancer, the challenge for the medical profession, as well as Commonwealth and State/Territory governments in Australia, is seen to be one in which all groups will co-operate in addressing the issue of providing patients with accredited, co-ordinated, management and treatment regimes based on the concept of "best practice".

It is important to emphasise that this management and treatment model is not seen as operating in isolation, rather as operating within a larger management model which encompasses community based services. Clear lines of communication need to be established between the multidisciplinary team, the patient's general practitioner, and when appropriate, palliative and hospice care services.

It is considered essential that all these services be delivered within an environment which is designed to be as physically and emotionally comfortable as possible.

Attention must also be paid to the provision of improved care services within the community, for example, nursing services which provide community based post-operative and palliative care.

Palliative care services have been shown to be working at some disadvantage, caused by a lack of appropriate funding and by a lack of continuity between curative and palliative care.

A lack of data has also been shown to severely disadvantage any attempt to evaluate management and treatment outcomes. Despite advances in management and treatment methods, most studies to date show that survival rates from breast cancer have improved little over the years[9]. There is, however, some recent statistical evidence which shows that early diagnosis leads to increased survival rates. For example, for cancers diagnosed in New South Wales in 1987-91 the 5-year relative survival (to 1992) was 77% compared with 70% for 1972-76 cases. Survival following the diagnosis of localised tumours in 1987-91 was 90% compared with 70% for regional spread and 18% for metastatic disease[10].

There is a severe paucity of long term data at the State/Territory and national levels which makes any hard and fast statements about management and treatment outcomes difficult to substantiate, resulting in the medical profession and others being forced to resort to anecdotal evidence which may or may not be indicative of particular or general circumstances.

Cancer registries should, therefore, be established to monitor breast cancer care and its outcomes. Government support for adequate staffing at an appropriate level should be a high priority for these registries. Only when an adequate data base has been established can properly informed assessments be made of treatment modes and their short, medium and long term outcomes.

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9. Dr Neil R. Wetzig, Consultant Surgeon, Queensland, Volumes of submissions, p 272.

10. NSW Cancer Council, *Breast Cancer in New South Wales 1972-1991*, September 1994, p 5.

It is also apparent that there has been a lack of consensus about what constitutes "best practice" medical treatment for breast cancer. It is pleasing to note that work has begun on achieving that consensus. For example:

(1) Australia's first National Breast Cancer Consensus Conference was held on 15-17 June 1994. The Consensus Report of this Conference has now been published and outlines what the Conference participants considered to be "best practice" treatment options.

(2) Emeritus Professor Thomas S. Reeve, Chairman of the National Health and Medical Research Council working party which is developing clinical practice guidelines on the treatment of diagnosed breast cancer has reported that: "It is expected that the first stage, that is the development, final agreement and promulgation of the guidelines, will not be completed until November 1994. The other necessary tasks: implementation, monitoring and evaluation, and regular updating in light of [the] latest research would take the Working Party past this 2 year [funded] period and ... it is expected that an extension of funding will be sought."[11]

It is agreed that, while prescription of treatment in such a diverse and complex area is not desirable, any steps taken towards describing what would be considered to be "best practice" treatment can only be an improvement for the patient.

However, while these current activities have focussed on "treatment", it is again stressed that the "management" of breast cancer must include a broader view. It is essential that the concept of "best practice management" incorporates both the active participation of the woman in the decision making process about her treatment, and strong links with general practitioners, counsellors, and community based support services.

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[11] Emeritus Professor Thomas S. Reeve, Chairman, University of Sydney, Department of Surgery, Working Party on the Treatment of Diagnosed Breast Cancer: Volumes of submissions, p 135.

The Australian woman who is faced with dealing with breast cancer, regardless of where she lives and whatever her social and economic background, should have the very best treatment and support available which will allow her and her family and friends to feel secure in the belief that everything that could be done, has been done. In some cases this may mean having treatment that gives the best chance of survival, while in other cases the issue of quality of life will determine the appropriate course of action. In every case, however, the management and treatment of a woman's breast cancer must be capable of being recognised as constituting current "best practice" for her particular circumstances.

Throughout the following report, all references to patients will be in the female gender to reflect 99% of all cases of breast cancer.

ADDENDUM

During the course of the Inquiry, it became clear that the terms of reference needed to be broadened. In particular, the limited role of the Department of Human Services and Health in the management of breast cancer became evident and the Committee determined that it was necessary to pay attention to how the Commonwealth and State/Territory governments fulfilled their various obligations.

Although evidence was given to the Committee on the various aspects of international management and treatment experience, these aspects could only be viewed within the context of what was currently taking place within Australia. The Inquiry concentrated more on the extent to which international "best practice" experience was being used as a model within Australia.

The Committee is of the opinion that, when its recommendations have been implemented, those recommendations, in conjunction with the other activities that are now taking place, will result in a more cohesive approach to the management and treatment of breast cancer in Australia. While all these activities have not been designated as such, they are all components of a national strategy.

It was suggested to the Committee that a national task force which was composed of a small group of people should be convened to implement and conduct a national strategy which would incorporate prevention, early detection, treatment, research, education, and centres of excellence.

It is suggested that a review of progress in this area take place at the end of 1996 with a view to examining the need to implement a more formal structure for a national strategy on breast cancer.

Although the issue of prevention was not addressed directly in the terms of reference for this Inquiry, it would be remiss if the need for further investigation into the primary prevention of breast cancer was not mentioned.

The Committee heard evidence about a variety of theories on the causes and prevention of breast cancer, but none of these are conclusive.

It is urged that attention be given to a broad range of research into the possible causes of breast cancer so that primary prevention strategies can be developed. Only prevention can avoid the need for treatment and its associated suffering.

PART 1: THE CURRENT SITUATION

CHAPTER ONE - DOCTORS AND PARAMEDICS

> ***"The management of women with breast cancer has changed dramatically over the past 20 years. The number of treatment options available for various stages of the disease has increased with a better understanding of tumour biology and an increased awareness of the aims and limits of each therapeutic type or modality. .... The most important principle which has been developed is the use of multi-modality therapy." (Dr Raymond D. Snyder, Chairman, Medical Oncology Group of Australia Inc., New South Wales: Volumes of submissions, p 300).***

i Undergraduate Education

1.1 Despite the fact that cancer is a major cause of morbidity and mortality in Australia, and that breast cancer is the most common cause of death from cancer in Australian women[12], the undergraduate curriculum has failed to address the need for graduates to have acquired a good knowledge of oncology practice in general and of breast cancer in particular:

> "...research suggests that Australian medical undergraduates are not always adequately trained in the care of women with breast cancer". (Dr Christine Bennett et al, Royal Hospital for Women, New South Wales: Volumes of submissions, p 669).

1.2 Because of that lack of exposure to oncology and its treatment, few undergraduates have a knowledge of the use of radiotherapy. For example, in the University of New South Wales, undergraduates "... receive only 24 hours of structured teaching in cancer throughout their six years of education." (Professor John H. Kearsley, Fellow, Royal Australasian College of Radiologists, New South Wales: Transcript of evidence, p 324).

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[12] Australian Cancer Society, *National Cancer Prevention Policy 1993*, p i.

ii Postgraduate Education

1.3 A general observation resulting from the Inquiry is that the various Colleges for medical practitioners appear often to stand in isolation from each other with very little interaction and sharing of information being undertaken. For example, most College conferences of surgeons or practitioners are held with only each College's members present. It was suggested to the Committee that there is, therefore, a dearth of commonly shared information about what is currently considered to be "best practice" in relation to the management and treatment of breast cancer.

1.4 There may be a variety of reasons for this lack of interaction which results in doctors of all types not accessing information, for example: undergraduate curricula; the structure of the Colleges; the relatively few multidisciplinary teams which exist where "best practice" occurs; the geographical distance from many information sources; and the viewed "ownership" of breast cancer by surgeons to the exclusion of other specialities. The Committee was told on a number of occasions, that this results in less than satisfactory management of the patient.

1.5 Perhaps the most significant factor is the lack of intercollegiate communication: "When the College of Surgeons meet, the breast subcommittee meets. However, there are not medical oncologists, radiation oncologists or nurses. It defines the surgical group somewhat, but it does not actually promote the multidisciplinary scenario, which we think is the way things are happening." (Professor Martin H.N. Tattersall, New South Wales: Transcript of evidence, p 385).

iii General Practice

1.6 The role of the general practitioner in the ongoing management of the breast cancer patient should be one in which the general practitioner would play a critical part in providing support for the patient and her family and being closely linked with the multidisciplinary team which co-ordinates her management and treatment. Current experience is that:

> "...women frequently consult their GPs immediately on receiving a diagnosis of breast cancer [as a result of the mammography screening program]. GPs are therefore frequently the first to

> discuss management and treatment options with women." (Ms Onella Stagoll, Director, BreastScreen, Victorian Breast Screening Co-ordination Unit: Volumes of submissions, p 349).

1.7 However, there is evidence to suggest that the failure of undergraduate medical courses to adequately address the management and treatment of breast cancer is not rectified by ongoing general practitioner education. This has resulted in many general practitioners having significant deficiencies in their knowledge of best and current practice about breast cancer:

> "Breast cancer management is not covered well in the undergraduate medical curriculum and for most general practitioners significant deficiencies exist in their knowledge of oncology practice. ....
>
> Similarly, knowledge of appropriate diagnostic investigations is often limited. In one study, delay in diagnosis of breast cancer because of false negative mammography was attributed to reliance by the general practitioner on a single investigation ...". (Professor John H. Kearsley et al, the Radiation Oncology Standing Committee, Royal Australasian College of Radiologists, New South Wales: Volumes of submissions, p 250).

1.8 The Royal Australian College of General Practitioners does not require general practitioners to continue their postgraduate education based on a core group of specified topics. The general practitioner is not, therefore, exposed to topics which do not meet their immediate personal interests but which are, nevertheless, essential to meeting the needs of their patient population:

> "I am trying to persuade the college of GPs at the moment to have certain types of continuing education. We now have vocational registration. .... And there is a requirement for training for general practice, which we support. You must train to be a GP. I have to do continuing education. I have always done it. Most of us have. I can do all my continuing education in something I am already good at or something I like. There should be core topics. I should have to do a core topic in mental health. I should have to do a core topic in paediatrics or in cancer, for example. There are some fundamental things which you would expect all GPs to be required to have continuing education on." (Dr

> Brendan J. Nelson, Federal President, Australian Medical Association, Australian Capital Territory: Transcript of evidence, p 688).

1.9 This lack of knowledge about the management and treatment of breast cancer can result in poor outcomes for the patient:

> "...I was assured very emphatically by my G.P. and radiographer [sic] that the growing lump was nothing. In the end at my own insistence I went to a specialist who removed my breast a few days later. ...it was found the cancer was in the lymph glands." (Name and Address Withheld: Volumes of submissions, p 119-122).

1.10 The consequences of this lack of knowledge include:

(1) A failure to refer a woman with suspected breast cancer to a specialist multidisciplinary team so that further diagnosis can take place within a setting which uses the combined resources of radiologists, radiation oncologists, pathologists, surgeons, and medical oncologists. (It is noted that some practitioners in private practice have informal networks with other specialists which, in effect, provide the services of a multidisciplinary team but not all in one location.)

The introduction of the mammography screening program in Australia allows for the detection of breast lesions at an earlier stage than was possible in the past. The small size of these lesions, allied with the lack of undergraduate and graduate exposure to the disease, would appear to have resulted in few general practitioners being adequately informed about the now recognised complexity of the disease and the current options available in the management and treatment of impalpable lesions. For example:

> "Many women referred for open biopsy require hook wire localisation of the lesion, as many lesions are impalpable. This procedure requires a high degree of skill as the position of the wire guides the surgeon and in many instances ensures that the margins of the lesion are cleared to acceptable standards thus ensuring that no additional surgery is required. Open

> biopsy is outside the provision of service in our program and the most persistent complaint we receive is from women who have undergone the localisation procedure. The importance of the procedure is not understood by many medical practitioners. As an example in a recent inservice to GPs in the local area on the issue of breast screening and assessment it was found that none of them knew what the procedure was or what it entailed." (Ms Beth Trevan, Director, North Coast Breast Screening Program Inc., New South Wales: Volumes of submissions, p 317).

(2) Failure to refer the patient to an adequately experienced and trained surgeon.

> "The management of breast cancer in Australia shows great variation depending in large part on the person to whom the woman with breast cancer is first referred. .... General practitioners are commonly not well informed about the special interests of surgeons practising in their area, and it is common for them to refer to their 'usual surgeon' whether or not he,she has a particular interest in the management of breast diseases." (Professor Martin H.N. Tattersall, Professor of Cancer Medicine, University of Sydney, Department of Cancer Medicine: Volumes of submissions, p 116).

(3) Concern that the most expert practitioners are not always having patients referred to them by general practitioners for techniques which require a high level of expertise, for example, fine needle aspiration:

> "In the past few years, I have been referred ... a few patients who have had fine needle aspirates performed by their well meaning GP and the patient is left with either distorted clinical findings caused by haematoma formation or cytology reports which are difficult to interpret, thus a biopsy which may not have been necessary becomes essential to exclude cancer in an already anxious woman." (Dr Neil R. Wetzig, Consultant Surgeon, Queensland: Volumes of submissions, p 272).

1.11 General practitioners are not performing breast examinations on a routine basis: "I notice that some of the reading I had done suggested that GPs were not examining women's breasts and that they were simply being sent for a screening mammogram ....". (Dr Brendan J. Nelson, Federal President, Australian Medical Association, Australian Capital Territory: Transcript of evidence, p 689).

1.12 It is essential that the general practitioner have a full understanding of the methods of early detection of breast cancer and be in a position to encourage their female patients in self examination, regular breast examinations by the general practitioner, and to encourage attendance at mammography screenings.

1.13 Because it is the general practitioner who is most often the first point of referral for a woman concerned about the possibility of breast cancer, it is essential that the general practitioner be fully aware of the most suitable referral for that woman and to have a good understanding of the processes which she will undergo. Important also is the ability of the general practitioner to understand the emotional stresses undergone by the woman and by her friends and family.

1.14 The well-informed general practitioner is also able to play a central role in the post-operative care and follow-up of patients and in the area of palliative care.

1.15 The general practitioner's role is often influenced by the post-operative and discharge practices of hospitals:

(1) "...sometimes it is six or eight months after somebody comes out of hospital before you get the summary..." (Dr Mary Surveyor, Medical Director, Osborne Division of General Practice, Western Australia: Transcript of evidence, p 1302).

(2) "We have got a liaison nurse in each of the major hospitals. So when somebody requires hospice care that person will be seen in hospital and we arrange their transfer to our service. That transfer happens very quickly. We have got a very good information system where the information is simply put onto the computer. That is read out at the base. That person gets a visit that day and a GP is informed immediately that person is home." (Mrs Marie Watts, Manager, Hospice Care Service, Silver Chain Nursing Association, Western Australia: Transcript of evidence,

p 1194).

1.16 The two extremes quoted above illustrate the diverse range of discharge and post-operative follow-up planning for the patient and the difficulties or otherwise these can create for the general practitioner in providing post-operative care for their patient.

1.17 While it is not possible to state whether delays like the six or eight months described is endemic or not, there is a clear need for action by all hospitals to improve their discharge practices and information links with the general practitioner and other community based care groups. (As this Committee has already highlighted in its July 1994 report on the Home and Community Care Program, "Home But Not Alone", there is no specific medical rebate for general practitioners attending patients in hospital.)

1.18 It also appears that many general practitioners are failing to provide post-operative care which encompasses counselling for both the patient and their family.

iv Surgery

1.19 As in the past, most women today who have been diagnosed with breast cancer go to a surgeon. That surgeon performs an operation which, according to evidence given, is not technically difficult. However, it is now acknowledged that the surgical element in the treatment of breast cancer is only one element in the total management and treatment of that condition:

> "The management of women with breast cancer has changed dramatically over the past 20 years. The number of treatment options available for various stages of the disease has increased with a better understanding of tumour biology and an increased awareness of the aims and limits of each therapeutic type or modality. .... The most important principle which has been developed is the use of multi-modality therapy." (Dr Raymond D. Snyder, Chairman, Medical Oncology Group of Australia Inc., New South Wales: Volumes of submissions, p 300).

1.20 It is now accepted that survival rates associated with breast conserving techniques are similar to those obtained with mastectomies[13].

1.21 Yet, evidence shows that in Australia mastectomies are still being performed at a level generally perceived as inappropriate:

> "One of my registrars who came to me last year who was doing a training stint for a year at one of these [teaching] hospitals said that he had worked there for a year and had never seen anyone have a lumpectomy; all he had seen was mastectomies... He had never seen any specialised screening work." (Professor Peter G. Gill, Royal Adelaide Hospital, Breast and Surgical Oncology Clinic: Transcript of evidence, p 517).

1.22 However, over the last few years a perceptible change has occurred in some parts of Australia with more breast conservation now being undertaken. For example, a study undertaken by the Anti-Cancer Council of Victoria showed that there has been a steady increase in the number of patients having breast preservation:

> "In 1990, 42% of patients had conservative surgery compared with only 22% in 1986." (Mr John P. Collins, Chairman, Breast Study Committee, Anti-Cancer Council of Victoria: Volumes of submissions, p 196).

1.23 Within Australia there are approximately 1 400 general surgeons, all of whom can operate on women with breast cancer. While the Victorian figures above imply an increasing level of expertise and education within the ranks of surgeons in the area of breast surgery, there is still a significant group of general surgeons performing low numbers of breast cancer surgery. In 1990 in Victoria, general surgeons were performing a mean average of 8.7 operations a year and in Western Australia in 1989, 692 women were treated by 105 different surgeons of whom 25 saw 10 or more cases in that year, but 43 of whom managed only one case[14].

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[13] The Lancet, *Editorial*, Vol 341, February 6, 1993, p 344.

[14] Professor Alan Rodger, William Buckland Radiotherapy Centre, Victoria, Volumes of submissions, p 1011; Mr John P. Collins, Chairman, Breast Study Committee, Anti-Cancer Council of Victoria: Volumes of submissions, p 195-196; Dr Michael Byrne et al, The Cancer Foundation of Western Australia: Volumes of submissions, p 908.

1.24 In the Victorian survey, there were 56 surgeons who treated only one breast cancer patient in six months[15], and in Western Australia:

> "The proportion of patients with operable breast cancer who were treated with breast conserving surgery... was 30% overall. Among individual surgeons the proportion of breast conserving operations performed varied from zero to 60%. ...It is clear... that the rate of uptake of new developments varies considerably." (Dr Michael Byrne et al, The Cancer Foundation of Western Australia: Volumes of submissions, p 911).

1.25 In New South Wales in 1989 "442 surgeons performed one to two mastectomies per year .... and in 1992/93 182 surgeons performed less than five mastectomies per year on women holding private insurance ...." (Dr Christine Bennett et al, Royal Hospital for Women, New South Wales: Volumes of submissions, p 671).

1.26 The Victorian study also found that women from non-metropolitan areas in Victoria were at a disadvantage vis-a-vis breast conserving surgery, but this appeared to be more because "they are presenting with later stage disease than because surgeons approach their treatment differently"[16].

1.27 The numbers of general surgeons still performing small numbers of breast cancer operations is a cause for concern. While mastectomy is not technically difficult surgery, there is an increasing need for an expertly informed understanding of the complexity of the disease and its complicated treatment.

1.28 The use of multi-modality therapy, which provides a variety of treatment options for various stages of the disease, is now incorporated within the structure of a multidisciplinary team. One example of such a team is described below:

> "The group comprises three surgeons, a medical oncologist,

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[15] Mr John P. Collins, Chairman, Breast Study Committee, Anti-Cancer Council of Victoria: Volumes of submissions, p 196.

[16] Hill, David J. et al, *Changes in the investigation and management of primary operable breast cancer in Victoria*, The Medical Journal of Australia, Vol 161, 18 July 1994, p 122.

> radiation oncologist, four radiologists, three cyto/histopathologists, a lymphologist, a liaison psychiatrist, two specialist nurses and a part-time data manager. All members of the group have a special interest in Diseases of the Breast and are active members of the South Australian Breast Cancer Study Group, an education and advisory body established in 1989." (Dr Stephen Birrell et al, Director, Flinders Surgical Oncology Clinic, South Australia: Volumes of submissions, p 722).

1.29 This process of change involves significantly more than just the type of operation being performed:

> "The type of operation performed by surgeons is clearly amenable to substantial change over a short period of time, which augurs well for the innovation of surgical techniques of proven benefit that require changes in long-held beliefs and professional habits. However, it may be presumed that change in professional practice will be harder to achieve if the innovations depended upon the acquisition of substantial new skills or upon the referral of patients to others who have the requisite skills."[17]

1.30 The Royal Australasian College of Surgeons currently only needs an expression of interest from one of its Fellows to designate them as a "breast surgeon". It is not a current requirement for that "breast surgeon" to undergo further training or to attend any education sessions in their designated area of interest. While the College has introduced an audit process, it is optional and none of its components are specifically directed towards breast surgery. In short, the College's position continues to be that "general surgeons in their training are trained and equipped at the end of their training to deal with breast problems." (Dr Colin M. Furnival, Chairman, Section of Breast Surgery, Royal Australasian College of Surgeons, Victoria: Transcript of evidence, p 184-186).

1.31 It cannot be said, that a patient can be confident that the surgeon who is to operate for breast cancer, is someone with a professionally recognised and standardised contemporary understanding of the management and treatment of her condition.

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[17] Hill, David J. et al, *Changes in the investigation and management of primary operable breast cancer in Victoria*, The Medical Journal of Australia, Vol 161, 18 July 1994, p 122.

1.32 However, there does appear to be an increasing recognition of the need to have some form of compulsory accreditation for surgeons specialising in breast cancer:

> "I believe that breast surgeons who specialise in this area should be identified and I personally have no opposition to some sort of accreditation which would identify these people. That is not presently the position of our college." (Dr Colin M. Furnival, Chairman, Section of Breast Surgery, Royal Australasian College of Surgeons, Victoria: Transcript of evidence, p 186).

1.33 There is no requirement for a general surgeon to be accredited before performing breast surgery. Despite the body of evidence which describes an increasingly complex scenario of multidisciplinary diagnosis, management and treatment of the condition, it is difficult to understand why the College has not addressed this vital issue.

1.34 This reluctance by the College to confirm for the patient population that its members are currently informed on the management and treatment of breast cancer and have undergone some form of compulsory accreditation, must change.

1.35 The multidisciplinary team structure recognises the need to provide the woman with psychiatric or psychological services because of the mental stress which she undergoes. However, outside this structure there is an insufficient recognition of the need to address the psycho-social needs of the woman and the stress she is experiencing. In some instances, the management process actually contributes to that stress.

1.36 It appears that in many cases the initial treatment of breast cancer is conducted in a crisis management mode. The perceived need for extreme haste is, in most cases, unjustified on medical grounds:

> "Three or four days is not going to make any difference to the outcome. ...The biology of the disease is such that one day, one week or two weeks does not make any difference. But if you have a patient who later on says, 'Did I do the right thing? I felt I was rushed into it', she is never going to lose that." (Professor John McCaffrey, Chairman, Medical Advisory Committee, Queensland Cancer Fund: Transcript of evidence, p 219).

1.37 At the other extreme, however, there is evidence to suggest that inordinate delays have occurred in the process of diagnosis:

> "It is our understanding that in some instances the time frame from discovery of the symptoms to diagnosis by open biopsy has been up to 17 weeks." (Ms Beth Trevan, Director, North Coast Breast Screening Program Inc., New South Wales: Volumes of submissions, p 317).

1.38 These extreme delays appear to be the result of the fragmentation of service provision to the patient. Another factor appears to be that public patients are not getting quick access to hospital facilities, although access may be improving with recent changes to hospital funding:

> "...I was told that I would have to have .... a lumpectomy .... this was 12 March and I was booked in for a lumpectomy on 22 April and my baby was due the week after. ... I would have had to wait over a month in the public system .... So I paid for a hospital bed. I went in as an intermediate patient. .... I got in three days later [to the same hospital] or something like that by paying." (Mrs Catherine R. Sheil, Queensland: Transcript of evidence, p 140-141).

v Pathology

1.39 It is now recognised that breast cancer varies in presentation with more than twenty pathological types being listed[18]. This variety, combined with the increasing detection of early lesions, now requires a greater level of expertise in diagnosis and prognosis:

> "In the early days, certainly in the 1960s, they [breast cancers] were certainly never diagnosed until there was a lump and virtually all carcinomas that produce a lump are at the stage of invasion.
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> ...If we look at the breast cancers that would turn up, for example,

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[18] Gallager, H., *Problems in the classification of breast cancer*, Radiology Clinics of North America, Vol 21, 1983. Page, David L. & Anderson, Thomas J., *Diagnostic Histopathology of the Breast*, Churchill Livingstone, Edinburgh, 1987.

> in a screening program, a very large percentage of those will still be at the in situ stage where they have not invaded the tissues and they are incapable of metastasising. So although the true nature has not changed, certainly the nature of the material that is presenting in patients has changed over the years. Now the role of the pathologist is essential in defining exactly which stage the tumour is at, and other factors, which we call prognostic factors, which might indicate what will be the best treatment for that patient..." (Dr Jennet Harvey, Head, Department of Pathology, University of Western Australia: Transcript of evidence, p 1175).

1.40 Because the patient's treatment and prognosis is very much dependent upon the accuracy of the pathologist's diagnosis, it is essential that all women have access to services provided by pathologists who have specialised in breast cancer.

1.41 However, there are indications that this level of expertise is not always being accessed. For example, although pathology specimens from patients in rural Australia can be sent to specialist pathologists for diagnosis:

> "In a rural setting pathology services are often performed by those who are in close proximity (because of time and distance) rather than [because of their] expertise and in some instances this has been detrimental to the outcome for the patient." (Ms Beth Trevan, Director, North Coast Breast Screening Program Inc., New South Wales: Volumes of submissions, p 320).

1.42 Within the multidisciplinary team setting, the pathologist and medical oncologist are in a position to work closely with the surgeon on formulating a management and treatment regime for the patient, based on an expert understanding of the implications of the lesion.

vi <u>Radiotherapy</u>

1.43 Despite the increased numbers of new accelerators and new radiotherapy centres in Australia, it is considered that the number of patients undergoing radiotherapy is too low:

(1) "The percentage of patients undergoing radiotherapy is remarkably low, considering the number of patients who are now being offered conservation treatment. I would say that I think it is of concern because it is certainly not, in my opinion, in keeping with international standards and international guidelines. ...I have a concern that there is an under-referral of patients for radiotherapy, which I do not believe is entirely a geographical problem." (Professor Alan Rodger, Director and Professor of Radiation Oncology, William Buckland Radiotherapy Centre, Alfred Hospital, Victoria: Transcript of evidence, p 826)[19].

(2) "I think South Australia at the moment treats [with radiotherapy] about 35 per cent of all major malignancies. Overseas countries would suggest that 50 to 55 per cent is more appropriate." (Mr Murray B. Schirmer, Chief Radiation Therapist, Radiation Oncology Department, Royal Adelaide Hospital, South Australia: Transcript of evidence, p 609).

1.44 The failure to train medical undergraduates and graduates in oncology and their consequent lack of knowledge about the use of radiotherapy was frequently identified as one of the reasons for the low referral rate:

> "... knowledge of appropriate diagnostic investigations is often limited. ....Diagnostic investigations of breast cancer patients and subsequent management have changed significantly over the past 20-30 years. ***The Royal Australasian College of Radiologists strongly recommends funding for appropriate GP education and reskilling sessions in Departments of Radiation Oncology and greater exposure of medical undergraduates to Radiation Oncology Departments.***" (Professor John H. Kearsley, Chairperson, Working Party, The Royal Australasian College of Radiologists, New South Wales: Volumes of submissions, p 250).

1.45 This low referral rate in Australia has been identified in

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[19] See also: Morgan, G., *The Problems Facing Radiation Oncology in Australia in the 1990's*, Cancer Forum, Vol 17 (1), March 1993, p 3. Professor John H. Kearsley, Chairperson, Working Party, The Royal Australasian College of Radiologists: Volumes of submissions, p 246, 247.

surveys which show that:

> "... approximately 35 to 40 per cent of patients with cancer were referred for radiotherapy at some time during their illness, whereas the international standards in developed countries such as the countries in Europe and North America would suggest that figure should be in excess of 50 per cent. That is all cancers." (Professor Alan Rodger, Director and Professor of Radiation Oncology, William Buckland Radiotherapy Centre, Alfred Hospital, Victoria: Transcript of evidence, p 827-828).

1.46 Because of the lack of training at the medical undergraduate and postgraduate levels, the role of radiotherapy in palliative care is poorly understood: "... radiotherapy is the 'best drug' for bone metastases, resulting in a significant reduction in pain in about 90%, with no further treatment required before death in 60% of patients."[20]

1.47 While this Inquiry is not in a position to enter into the particulars of the debate on the required number of units or the required number of radiation oncologists, it notes that the overview of the October 1989 Report of the Australian Health Ministers' Advisory Council (AHMAC) Working Party on Radiation Oncology and the responses to it, highlighted some of the problems in estimating the resources required:

> "... as the WP's Report itself points out there is a wide range of values which can be adopted for the parameters used to estimate the resources required to adequately treat cancer patients. Different values provide differing estimates and it is necessary to consider carefully those chosen ...". (Dr John Loy, First Assistant Secretary, Commonwealth Department of Human Services and Health: Volumes of submissions, p 806, Attachment 3B Report of the AHMAC Working Party on Radiation Oncology).

1.48 Nevertheless, given the concerns raised during the course of the Inquiry, that debate should be resolved.

1.49 There is general agreement that on economic and technical proficiency grounds, radiotherapy units should be located in densely

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[20] Morgan, G., *The Problems Facing Radiation Oncology in Australia in the 1990's*, Cancer Forum Vol 17 (1) March 1993, p 4.

populated areas. However, the current distribution of radiotherapy units may not be optimal:

(1) "The hyperfragmentation of radiotherapy services in some states such as Victoria and NSW must raise some concerns. While it is socially better for patients needing radiotherapy to find it nearer home, it is only appropriate if such highly expensive centres can ensure an adequate patient number and thereby, expertise.

I see no evidence of true, accountable and totally justifiable distribution of radiotherapy centres in Victoria, and others have suggested the same may be true of NSW." (Professor Alan Rodger, Director of Radiation Oncology, The William Buckland Radiotherapy Centre, Alfred Hospital, Victoria: Volumes of submissions, p 98).

(2) "It has to be accepted that it is not practical to attempt to provide radiation oncology facilities within easy access for all Australians and travel will continue to remain a problem. Nevertheless, additional facilities are required and it is no longer reasonable to justify the centralisation which has occurred, for example, in Queensland where all current facilities (3) are in Brisbane." (Professor Allan O. Langlands, Chairman National Breast Study Committee, Australian Cancer Society: Volumes of submissions, p 379).

1.50 As with so many of the issues involved with the treatment of breast cancer, there is a lack of consensus about the need for, and outcomes of, radiotherapy: a lack of consensus which may be one of the factors in the perceived low referral rates. For example, there are opposing views about the value of radiotherapy for women who have had breast conservation treatment:

(1) "...if a woman does elect to have conservative surgery and this is not followed by post-operative radiotherapy (for whatever reason), she has at least a 40% chance of recurrence within the breast." (Professor John Kearsley et al, The Royal Australasian College of Radiologists, The Radiation Oncology Standing Committee, New South Wales: Volumes of submissions, p 246).

(2) "In the worst series, the local recurrence rates in women who do not have radiotherapy after breast conservation surgery are

> around 30%, and in the best series around 10%. Thus between 70% and 90% of women would not have developed recurrence without radiotherapy, and in theory have had their radiotherapy unnecessarily. ...[the radiotherapy] often results in an oedematous, swollen breast which may last years or be permanent; and the radiotherapy may affect the underlying ribs, with chronic pain from the ribs. ...The difficulty is in identifying those women who do not need radiotherapy." (Associate Professor David Ingram, The University of Western Australia, Department of Surgery: Volumes of submissions, p 927).

1.51 This diversity of views about the value of radiotherapy in particular circumstances exemplifies the wide range of views currently held about the treatment of breast cancer and reinforces the argument for multidisciplinary teams.

1.52 The diversity of views and practices which can grow in isolation can lead to a situation of extraordinary fragmentation:

> "There is clear evidence in the UK from a survey by the Royal College of Radiologists that the radiation treatment regimes prescribed for breast cancer are highly variable in terms of dose, duration and numbers of treatments. Radiation oncologists were shown to follow their original training rather than the literature. In one UK centre of five specialists there were six breast treatment regimes." (Professor Alan Rodger, Director of Radiation Oncology, The William Buckland Radiotherapy Centre, Alfred Hospital, Victoria: Volumes of submissions, p 97).

1.53 A multidisciplinary team would overcome this degree of variability by drawing on a range of disciplines:

> "The treatment of primary breast cancer is no longer the simple surgical option of mastectomy. Breast cancer treatment is a multidisciplinary exercise in which surgeons work closely with their colleagues in radiation and medical oncology, and the selection of treatment is the key to successful results." (Professor John H. Kearsley, Chairperson, Working Party, The Royal Australasian College of Radiologists, New South Wales: Volumes of submissions, p 251).

1.54 Access to radiotherapy is thought to be a factor in the type of surgery performed on non-metropolitan women:

> "... the decision to go south for ... [radiotherapy] for six or eight weeks, does influence quite a few women towards mastectomy as an equivalent safe alternative as far as life saving and safety goes." (Mr Phillip Carson, Specialist Surgeon, Northern Territory Department of Health and Community Services: Transcript of evidence, p 8).

1.55 Whether or not radiotherapy treatment is undertaken by a patient from a non-metropolitan area may also be influenced by the types of accommodation and travel subsidy schemes which are administered at the State/Territory level, the benefits of which are limited and fail to meet the financial needs of the patient:

> ".... for a protracted course of treatment where the patient may require to be absent from home for periods of up to 6 weeks or more, the cost to the patient can in fact be substantial. If accompanied by a partner, a patient attending Westmead Hospital's Casuarina Lodge, would be required to make a payment of close to $1,000." (Professor Allan O. Langlands, Chairman, *National Breast Study Committee, Australian Cancer Society:* Volumes of submissions, p 379).

vii Medical Oncology

1.56 The Committee was told that "[v]irtually all tertiary teaching hospitals have a medical oncology service" and that in those rural and remote areas where a full-time medical oncology service is not available, a visiting program is usually available[21].

1.57 It is considered essential for a medical oncologist to be included in a multidisciplinary team to manage and treat the breast cancer patient[22].

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[21] Dr Raymond D. Snyder, Chairman, Medical Oncology Group of Australia Inc., New South Wales: Volumes of submissions, p 302.

[22] A medical oncologist is a physician who is trained and experienced in the use of chemotherapy drugs and hormones in the treatment of cancer, and in the use of drugs and other techniques for the palliation and control of symptoms associated with cancer and its treatment. Dr Raymond D. Snyder, *Op cit*, p 300.

1.58 The positive benefits of medical oncology are widely recognised and should be regularly considered within a multidisciplinary team context:

(1) "[E]vidence has been published throughout the last few years - and over the last two decades, based on earlier trials - that lives are saved by the additional treatment we call 'adjuvant therapy'. There are three types of adjuvant therapy: removal or suppression of the ovaries, chemotherapy, and hormonal therapies such as tamoxifen. All of those work in particular groups." (Professor Alan S. Coates, Vice-Chairman, Australian-New Zealand Breast Cancer Trials Group, Oncology Clinic, Dubbo Base Hospital, New South Wales: Transcript of evidence, p 1093).

(2) "In early stage disease, it is now widely recognised that the use of adjuvant systemic therapy (chemotherapy and hormone therapy) given after local treatment, such as surgery, will reduce the risk of the breast cancer recurring (and therefore causing death) by between 20 and 30% for longer than ten years after the time of diagnosis.

The appropriate use of hormones and chemotherapy for patients with advanced breast cancer can control their disease and thereby improve their quality of life and often increase their period of survival. This is an important part of the management for the 30-40% of patients who have recurrent or advanced breast cancer." (Dr Raymond D. Snyder, Chairman, Medical Oncology Group of Australia Inc., New South Wales: Volumes of submissions, p 303).

1.59 There is a lack of consensus about what may be the best use of these adjuvant therapies:

> "At present many patients in Australia with node positive breast cancer are receiving chemotherapy when an alternative, less toxic and less expensive treatment with either tamoxifen, or ovarian ablation (by surgery or radiotherapy) can provide the same order of improvement in survival." (Professor John H. Kearsley, Chairperson, Working Party, The Royal Australasian College of Radiologists: Volumes of submissions, p 244, 249).

1.60 Treatment with chemotherapy is widely available because it can be administered on an outpatient basis and requires only a few special resources[23]. But the quality of life issues of this and other adjuvant treatment options need to be addressed[24]:

(1) "When finally diagnosed as suffering from breast cancer the disease was so far advanced that surgery was no longer an option. ...My mother suffered the horrors of chemotherapy and died after months of debilitating sickness." (Ms Maxine Stewart, Queensland: Volumes of submissions, p 56).

(2) "...one sees ...chemotherapy happening with people at a fairly late stage in their disease which is producing appalling quality of life for very dubious gain." (Dr Mary Surveyor, Medical Director, Osborne Division of General Practice, Western Australia: Transcript of evidence, p 1318).

1.61 Addressing these issues within a multidisciplinary team is one way of achieving the maximum benefits for a patient, as their individual needs and circumstances can be discussed within a case management forum:

> "Single solutions do not exist for complex multi-factorial biological situations superimposed on equally complex human physical, psychological social and environmental circumstances."(Dr Peter Jeal et al, Peter MacCallum Cancer Institute, Victoria: Volumes of submissions, p 421).

viii <u>Counselling</u>

1.62 When a woman is being treated for breast cancer, there is a real and continuing need for her to be able to communicate freely and frequently with those treating her. The required level and frequency of communication, unfortunately, is rarely available, leaving some women dissatisfied with the advice they have received and feeling that they have not been given enough time and attention:

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[23] Dr Raymond D. Snyder, Chairman, Medical Oncology Group of Australia Inc., New South Wales: Volumes of submissions, p 302.

[24] Professor John H. Kearsley, Chairperson, Working Party, The Royal Australasian College of Radiologists, New South Wales: Volumes of submissions, p 244.

(1) "Many breast cancer patients complain to us about the cold and clinical way their medical practitioner or specialist informs them of a cancer diagnosis. There often appears to be little account taken of how the diagnosis affects the patient emotionally or how the prospect of surgery may damage the patient's relationship with her partner if she has one. Sometimes marriages break down after breast surgery. Many medical practitioners do not refer their patients to organisations such as ours for support." (Ms Pat Coonan, Cancer Support Group of Victoria: Volumes of submissions, p 71).

(2) "...many women complained that they had been unable to develop rapport with their specialists, who seemed unable to communicate with them at their level. Often these doctors resented questions and even became angry if asked about options." (Name and Address Withheld: Volumes of submissions, p 93).

1.63 The Committee recognises the attempts made by many practitioners to meet the needs of their patients, often at some cost to themselves:

> "I am not sure, in truth, that I could cope with seeing more than the number I see now - emotionally and in terms of time. .... I work mostly 12 hours a day, and some of the more difficult time consuming stuff is spending hours with my breast cancer ladies - firstly, in the decision making process and, secondly, in the support and care straight after the surgery when more questions arise. Then they perhaps go for radiation oncology, and then they are back again with questions they did not ask .... ." (Mr Anthony J. Green, Secretary, Divisional Group of Rural Surgery, Royal Australasian College of Surgeons, Victoria: Transcript of evidence, p 949-950).

1.64 It is unfortunate that in Australia, the need for the integrated participation of the specially trained nurse or some other professionally trained counsellor in the management and treatment of breast cancer, has received only marginal recognition:

> "In Australia there are few facilities offering a comprehensive programme delivered by nurses or indeed any other health professionals. The nurse counsellors attached to breast screening units do not follow the woman through to her treatment and

> beyond." (Ms Anne Fletcher, R.N., Breast Care Consultant, Queensland: Volumes of submissions, p 217).

1.65 Even in the area of community based care, the role of the specially trained nurse is under-utilised with Victoria being the only State to have community based specialist breast cancer nurses[25]. Under the auspices of the Royal District Nursing Service (Victoria), the nurse, after undergoing a training program, provides information to the patient at the hospital and within the community on matters such as prostheses.

1.66 This under-utilisation of the nurse/counsellor on an integrated, pre and post-operative basis is the result of the current fragmentation in which, rather than referral to a team which includes either a specialist nurse or counsellor, referral is made to a broad range of specialists in different physical locations not working as a team. It is also the result of the failure to recognise that women being treated for breast cancer must be offered a continuous support system during the course of their treatment and afterwards.

1.67 A model has been developed in the United Kingdom which integrates specialist nurses within its management and treatment regime. The value of this model is beginning to be recognised within Australia:

> "I think one of the things we could do, and which we are going to do at the Royal Adelaide Hospital because we got funding for it, is something which I saw working very well last year when I visited a few breast units in the United Kingdom. Over there all the breast units have one or more breast care nurses who have psychological training as well as working with the clinic.
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> ...I think you need backup from the time the patient is seen by a doctor in the clinic, for however many appointments there are, to when they come into hospital. That is where these breast care nurse-counsellors provide that backup, often with an outreach situation; they meet the patient in the clinic; they become involved with the family; and they monitor any problems or changes in decision..." (Professor Peter G. Gill, Director, Breast and Surgical

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[25] Ms Susanne L. Baxandall, Director, Social Service Policy Unit, Anti-Cancer Council of Victoria: Transcript of evidence, p 783.

> Oncology Clinic, Royal Adelaide Hospital, South Australia: Transcript of evidence, p 520, 521).

ix Physiotherapy

1.68 Despite the critical role that physiotherapy can play in the on-going quality of the breast cancer patient's life, the need for physiotherapy is either poorly recognised or difficult to access. Whether or not a woman receives some instruction on appropriate post-operative physiotherapy is, therefore, more a matter of may receive than will receive. Most hospitals are unable to provide on-going physiotherapy care[26]:

> "A lot of my patients who are pensioners are undergoing very expensive physiotherapy because the wait in our institution for massage is six months at least, probably more. They are waiting to be fitted with a stocking and possibly undergo a form of treatment." (Dr Stephen Birrell, Director, Oncology Unit, Flinders Medical Centre, South Australia: Transcript of evidence, p 581).

x Data Collection

1.69 It is a matter of common agreement that a properly resourced national data collection system which can access and compare State/Territory information, enabling the comparison of treatments and outcomes must be set in place. If a proper data collection had been available to the Committee, the Inquiry would have been greatly assisted.

1.70 However, while some work has been done in South Australia on establishing prototype hospital based registers, funding has not been provided nationwide to support adequate staff numbers and levels for the wide establishment of similar registers:

> "It is essential that long term funding is provided to make available outcome data on diagnostic and treatment strategies. To do so, cancer registries based on individual hospitals and

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[26] Dr Christine Bennett et al, Royal Hospital for Women, New South Wales: Volumes of submissions, p 671, Transcript of evidence, p 461.

> health areas must be funded and developed as a matter of priority. This requires financial support for Area, State and National co-ordination. Additional funding is also required to ensure that Hospitals have access to the appropriate biostatistical advice and computing facilities adequately supported." (Professor Allan O. Langlands, Chairman, National Breast Study Committee, Australian Cancer Society: Volumes of submissions, p 383).

1.71 The Committee was told that the costs involved in the establishment of suitable registers is not prohibitive:

> "[Currently 2.5 positions work in hospital registries in South Australia] ... with five extra people we could cover the entire state for all cancers, not just breast cancers." [This would cost approximately $200 000 for those five extra people who are on an annual salary of about $27 000 per annum.] (Mr David Roder, Director of Epidemiology, South Australian Health Commission: Transcript of evidence, p 544-545).

1.72 There is agreement that properly maintained hospital based cancer registries in combination with State based registers:

> "...can lead to modification of treatment regimes, better record keeping, and provide up to date results for study by hospital staff". (Professor J.D. Martin, Consultant Emeritus Obstetrician and Gynaecologist, Department of Obstetrics and Gynaecology, King Edward Memorial Hospital for Women, Western Australia: Volumes of submissions, p 79).

1.73 The failure to provide such information results in a serious problem for practitioners in measuring cancer treatments and outcomes both on geographical and long term bases. The situation in the United States of America shows how highly data collection is valued there:

> "...the American College of Surgeons requires that there be an ongoing monitoring of breast cancer care and its outcomes through hospital based cancer registries". (Dr David Roder, Director of Epidemiology, South Australian Health Commission: Volumes of submissions, p 25).

1.74 Ignorance of treatment regimes and their outcomes is incompatible with the proper management and treatment of breast cancer, and of other cancers:

> "Cancer registries properly maintained can exert a beneficial influence on medical staff concerned with patient care in hospital. Its maintenance can lead to modification of treatment regimes, better record keeping, and provide up to date results for study by hospital staff. Unless this is done one finds the staff, even medical staff, have a total ignorance of what is being accomplished within their own hospital. I have absolutely no doubt that if earmarked funding was provided for public hospital breast cancer registers, preferably using an agreed history, examination and treatment proforma, that advances in the treatment of these patients would become available more rapidly, particularly if the hospitals were able to pool their data." (Professor J.D. Martin, Consultant Emeritus Obstetrician and Gynaecologist, Department of Obstetrics and Gynaecology, King Edward Memorial Hospital for Women, Western Australia: Volumes of submissions, p 79).

1.75 There is also a lack of data which shows the long term outcomes of treatment. Once a patient is discharged, and if that patient has not been treated by a team which actively keeps in touch with them, often nobody knows what happens to the patient in the ensuing years.

1.76 It is noted that the national conference on hospital-based cancer registries organised by the Australian Cancer Society on 1 July 1994, produced an outcome report which made a number of recommendations on the establishment and maintenance of cancer registries.

xi Research

1.77 Research into breast cancer is currently pursued in two major forms: research at the cellular level, particularly molecular biology; and clinical trials where differing types of treatment are tested. Clinical trials, while discussed in this section, will also be dealt with in Chapter Two of this Report. The need for research into the psycho-social aspects of patient welfare is discussed under the heading "Psycho-social Needs" in Chapter Two.

1.78 Funding is tending to favour research at the cellular level despite the fact that funding also:

> "...needs to be available for collection of data, for clinical research and the actual management of the patient. For instance, how long do you leave your drain in, after you had done a mastectomy." (Dr Neil Wetzig, Surgeon, Breast and Endocrine Surgical Unit, Princess Alexandra Hospital, Queensland: Transcript of evidence, p 164).

1.79 There has been a lack of emphasis on exploring primary prevention strategies[27].

1.80 There is still concern about some clinical trials currently being undertaken:

> "Given that many of the past and present studies into chemo-hormonal therapy of breast cancer have been funded by pharmaceutical companies there has been concern expressed in relation to the propriety of such trials and the relevance of the questions which these trials address.
>
> .... few, if any, studies have addressed the relative roles of either surgery or radiotherapy in the management of breast cancer despite the important role which these two treatment modalities play." (Professor John H. Kearsley, Chairperson, Working Party, The Royal Australasian College of Radiologists, New South Wales: Volumes of submissions, p 251-252).

1.81 There is an overall lack of financial support for medical research despite the fact that:

> "...unless you know the data [from research] you cannot offer solutions; you cannot offer patients choice". (Dr Stephen Birrell, Director of Flinders Surgical Oncology Unit, Flinders Medical Centre, South Australia: Transcript of evidence, p 574).

1.82 Indeed, in this area of research Australia has managed to achieve recognition as a third-world country by the United States of America:

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[27] Professor David Ingram, Surgeon, Queen Elizabeth II Medical Centre, Western Australia: Transcript of evidence, p 1245.

> "I have recently got a grant from the NIH [National Institute of Health] in the US as a third world country. Because of our funding proportion per capita, they have funded us as a third world country." (Dr Stephen Birrell, Director of Flinders Surgical Oncology Unit, Flinders Medical Centre, South Australia: Transcript of evidence, p 576).

1.83 This poor level of funding is in spite of the fact that Australia makes a significant contribution to internationally organised attempts to acquire empirical evidence which will lead to a greater understanding of what is the best treatment for the patient.

1.84 Just over 20% of the total international data for the International Breast Cancer Study Groups Trials of adjuvant therapy comes from Australia and New Zealand, with half of this contribution coming from Victoria. Australian clinicians have also made significant contributions to the design and analysis of these studies[28].

1.85 Restricted support at government level fails to recognise the fundamental importance of research in establishing "best practice" treatment to the ultimate benefit of the breast cancer patient population because clinical trials:

> "... **can be used to conduct quality research in different settings relevant to breast cancer.** For example, **treatments can be compared** to determine if a "new" treatment is superior; **an intervention strategy to prevent breast cancer** can be tested; or alternative strategies for **early detection** can be compared." (Professor John F. Forbes, National Group Co-ordinator, Australian & New Zealand Breast Cancer Trials Group: Volumes of submissions, p 516).

1.86 Current outcomes from clinical trials have resulted in:

> "Virtually every established component of modern breast cancer treatment has only been established by testing in randomised trials. **In addition, much of the key biological information that we have about breast cancer is the result of 'spin off' data from clinical trials. It is certainly not true that mortality of breast**

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[28] Dr Raymond Snyder, Chairman, Medical Oncology Group of Australia Inc., New South Wales: Volumes of submissions, p 309.

cancer is unchanged, it is improved substantially when current treatments are made available to women. It was recently estimated that an additional 150,000 people with cancer per year are alive now in the United States, compared with 1970, as a result of the United States National Clinical Trials Program." (Professor John F. Forbes, National Group Co-ordinator, Australian & New Zealand Breast Cancer Trials Group: Volumes of submissions, p 516-517).

1.87 There is insufficient flexibility within the small amount of funding provided by the National Health and Medical Research Council to allow the transfer of funds overseas. This inflexibility fails to take into account the necessity of having clinical trials for breast cancer take place at the international level so that there are sufficient data cohorts[29]. Consequently, the Australian contributors have had great difficulty in financially supporting their share of the central activities in the areas of data management and statistical analysis[30].

1.88 Very little is known about the period of time following the diagnosis and primary treatment of breast cancer and a woman's eventual death - whether from cancer or other causes.

1.89 Given that recurrence is one of the major difficulties confronted in the treatment of breast cancer, it is essential that the period of time during which a woman may be either in remission or cured is tracked and factors such as initial diagnosis, types of treatment, incidence of lymphoedema, quality of life, psycho-social disorders, and outcomes, catalogued. Of necessity, this type of longitudinal research over ten or more years requires funding commitments which, currently, are not forthcoming. This longitudinal research would complement the information gained in the clinical trials and by cancer registers.

1.90 It is noted that the Commonwealth Government has taken

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[29] Professor John F. Forbes, National Co-ordinator, Australian & New Zealand Breast Cancer Trials Group: "The need for early results ... makes it essential to conduct **multicentre** large scale trials to ensure high accrual in the shortest possible time frame. **This dictates that breast cancer treatment trials in Australia must also be national and international in scope.**": Volumes of submissions, p 518.

[30] Dr Raymond Snyder, Chairman, Medical Oncology Group of Australia Inc., New South Wales: Volumes of submissions, p 309.

steps towards increasing its support for breast cancer research by its allocation of funds in the 1994-95 budget. An example is the annual contribution of $1 million for three years from 1994-95 towards the establishment of the Kathleen Cunningham Foundation for Breast Cancer Research. This also includes a commitment to match any donations to the Foundation from the public, dollar for dollar, up to a limit of a further $1 million per year for three years. The Foundation's role is to support and promote clinical, biomedical, social and epidemiological research of relevance to breast cancer.

1.91 Additional funds were also provided by the Commonwealth Government in the 1994-95 Budget to the National Health and Medical Research Committee, to give an increased emphasis to research in breast cancer by nominating it as a priority area. However, this may not achieve the Government's stated objective in its 1993-94 election platform to increase funding for health and medical research to 2% of the total health budget by the year 2000.

PART 1: THE CURRENT SITUATION

CHAPTER TWO - PATIENTS

> *"Perhaps at 38 years old I was caught in a system that assumed patients are older and more willing to give in to the medical pressure. ....Decisions were being made on my behalf and I was expected to agree and not be a problem. This kind of pressure is very difficult to withstand. ....I don't think women are considered as equals in the decision making process. I don't know how this attitude can be turned around but I certainly felt I was treated like a child who should leave everything to the grownups." (Ms Shirley Tucker, Victoria: Volumes of submissions, p 874, 875).*

> *"I suspect that, whether the medical profession likes it or not, women will vote with their feet and go to centres where they perceive there to be excellence in the treatment of each individual disease - and breast cancer would be prime among them." (Professor Alan S. Coates, Vice-Chairman, Australian-New Zealand Breast Cancer Trials Group, Oncology Clinic, Dubbo Base Hospital, New South Wales: Transcript of evidence, p 1104).*

i Women as Patients

2.1 There does not appear to be any difficulty in Australian women accessing some form of treatment for breast cancer, (the type of treatment received often depending upon geographical location[1]). There is, however, concern about how treatment services are provided. Far too often, it appears that a woman is not treated as a complete person but rather as individual parts of anatomy that need treatment.

2.2 The standard of the facilities at which treatment is given does not always provide for the patient's physical comfort, emotional needs and personal dignity. Some members of the medical profession also appear to have an inadequate understanding of the emotional and privacy needs of the patients:

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[1] Mr Phillip Carson, Specialist Surgeon, Northern Territory Department of Health and Community Services: Transcript of evidence, p 8.

> "My own experience in a highly-regarded radiotherapy clinic was very distressing although I knew the standard of care was high. It was demeaning and depersonalising, with patients handed a coloured card on arrival to indicate the site of the cancer, patients weighed in full view of the waiting room and a serious lack of regard for privacy. After I undressed for a follow-up consultation with my specialist ... a registrar entered, whom I had never seen before and who did not introduce himself. The specialist was not at the clinic even though I had rung to confirm that he would be, and none of the staff had mentioned his absence." (Dr Ruth McKenzie, New South Wales: Volumes of submissions, p 472).

2.3 Lack of sensitivity to the way in which some services are provided is also echoed in the seeming inability of some professionals to address the psychological needs of the patient:

> "I had a young doctor resident there ... I was talking to him just casually one day ... and I said something about the future. He said to me, 'Oh, if I were in your situation, I wouldn't plan the future! And I said, 'Oh! What do you reckon?! He said, 'You might live two months' and he sat back. ... Then he looked at me and said, 'Of course, you might live 20 years, but neither one of them is really very likely. But do not plan your future too far ahead, will you? (Councillor Susan M. Dethridge, New South Wales: Transcript of evidence, p 444).

2.4 The effects of such a conversation upon a patient should be self-evident, yet it would appear that this is not an isolated incident of extreme insensitivity to the emotional and psychological needs of a patient.

ii <u>Participation in Clinical Trials</u>

2.5 Participation by breast cancer patients in clinical trials seems to be encouraged by the medical profession for two major reasons. The first is that clinical trials provide valuable information on treatment outcomes. This is discussed in more detail under the heading "Research" in Chapter One. Participation in clinical trials is also encouraged because it is of benefit on an individual basis because of access to a more expert level of attention[2].

2.6 However, an alternative view is that participation in a clinical trial may not automatically be of value to the patient:

> "We certainly hear very strongly from the clinicians about the value of trials, but for women it is becoming fairly obvious in the research that being a partner in the choice of treatment actually has a beneficial outcome. ...In a randomised trial you are not provided with that element of control and that lack of choice could be an influence on the outcome of the trial. I think the cancer registries or some sort of population database, where we actually record the treatment that people get and the outcomes and look at it on a total basis and research it that way, rather than doing these randomised trials, may provide another way of getting that information, and women are not so disadvantaged in doing that." (Ms Marcia O'Keefe, Victoria: Transcript of evidence, p 848).

2.7 Currently, approximately 5% of breast cancer patients in Australia participate in clinical trials (as opposed to 3% in the United Kingdom and 2.5% in the United States of America)[3]. It would appear that the majority of these patients are recruited by multidisciplinary teams:

> "We try to enrol as many women as possible [in clinical trials] or offer them the chance of going into international trials." (Dr Stephen Birrell, Director, Flinders Surgical Oncology Unit, Flinders Medical Centre, South Australia: Transcript of evidence, p 574).

2.8 While the Committee is of the opinion that the concerns expressed above about the inherent value of clinical trials for the individual women involved should not be dismissed, it is also clear that clinical trials are an invaluable, if not the only, means of testing new methods of treatment. Their outcomes have been instrumental in the implementation of better treatment methods:

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[2] Dr Peter Jeal et al, Peter MacCallum Cancer Institute, Victoria: Volumes of submissions, p 422.

[3] Mr John P. Collins, Chairman, Breast Study Committee, Anti-Cancer Council of Victoria: Transcript of evidence, p 745A.

> "Clinical trial participation is an important part of medical oncological practice. It reflects the fact that we do not know all the answers and we recognise that we do not and that we have demonstrated over the past 20 years that sequential clinical trials lead to the saving of lives in the treatment of early breast cancer." (Professor Alan S. Coates, Vice-Chairman, Australian-New Zealand Breast Cancer Trials Group, Oncology Clinic, Dubbo Base Hospital, New South Wales: Transcript of evidence, p 1089). (See also Chapter One "Research".)

2.9 Concern was expressed to the Committee that, because of casemix funding, hospitals, and even radiotherapy centres, are competing for patients. This competitive environment is acting as a disincentive for practitioners to enter patients into trials for which they are not remunerated. In Victoria, where casemix has been in operation for 12 months, evidence was given that:

> "I suppose you could say advertising is the name of the game at present and because of casemix funding each of the hospitals in this state [Victoria] is competing with the other. Even in the radiotherapy world, the bottom line of radiotherapy in this state is competition between centres and it is not easy to work in that kind of environment. But we will do everything that we can within the bounds of sensibility and restrictions. ....
>
> The whole system is now competitive and the arrangement of radiotherapy services in this state and what is happening to them is now driven entirely by competitive mechanisms.
>
> The casemix .... does not pay me to not treat patients. In a randomised trial, for instance, the non-invasive trial of radiotherapy versus no radiotherapy, every patient that is randomised to no radiotherapy loses my department money. Therefore, one has to take that into account. It does not persuade me at all, because my staff and I work on the basis that patients are offered radiotherapy when it is appropriate and not for any other reason. But if you are seeing patients and you are funded and you get extra funding for treating patients, then there is a disincentive not to treat them." (Professor Alan Rodger, Director and Professor of Radiation Oncology, William Buckland Radiotherapy Centre, Alfred Hospital, Victoria: Transcript of evidence, p 842).

2.10 Concern was also expressed to the Committee about the limited focus of investigation undertaken by current clinical trials (see also Chapter One "Research"):

> "Although there has been considerable interest and activity in breast cancer clinical trials in Australia over the past 10 years, the vast majority of studies have examined the role of chemo-hormonal therapy for breast cancer patients. .... It is a matter of concern that few, if any, studies have addressed the relative roles of either surgery or radiotherapy in the management of breast cancer despite the important role which these two treatment modalities play." (Professor John H. Kearsley et al, The Radiation Oncology Standing Committee, Royal Australasian College of Radiologists, New South Wales: Volumes of submissions, p 251-252).

iii Psycho-Social Needs

2.11 One study has estimated that one year after mastectomy, 39% of women experience serious depression, anxiety or sexual difficulties, yet there has been little research into the best ways to minimise the psycho-social difficulties experienced by women with breast cancer[4].

2.12 It is not known whether conservative surgery alters the incidence of psychomorbidity, when a woman is having to cope with the fact that she has cancer.

2.13 Despite the proven high incidence of serious psychomorbidity in breast cancer patients, very little has been done either to investigate the extent and severity of that morbidity, or to provide a suitable means of addressing it either as a preventative measure or as a therapeutic measure:

> "While there is substantial research documenting these effects [psychomorbidity], in Australia at least, practical psychosocial and psychosexual counselling and support are seldom offered either to women with breast cancer or their partners and families, either

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[4] The Cancer Foundation of Western Australia Inc., *Breast Cancer - The Need for Urgent Action - An Overview with particular reference to Western Australia,* March 1994, p 8.

> initially or on a continuing basis. Emphasis has been mainly on treatment modalities." (Dr Christine Bennett et al, Royal Hospital for Women, New South Wales: Volumes of submissions, p 668).

2.14 The importance of having access to information and to emotional support is, for example, fully acknowledged by the Flinders Surgical Oncology Clinic's Breast Unit, which has given due emphasis to the provision of that support:

> "All breast cancer patients and their families receive counselling as required from clinicians, social workers, and in particular from the specialised nurses attached to the Unit. If necessary a referral to the Unit's Liaison Psychiatrist is made." (Dr Stephen Birrell et al, Flinders Surgical Oncology Clinic, South Australia: Volumes of submissions, p 722).

iv <u>Decision Making</u>

2.15 The importance of having the patient involved in the decision making process is reflected in at least one outcome:

> "Recent evidence .... suggests that women who were involved in their treatment decision and where medically possible, offered some choice tended to be better psychologically adjusted at a three year follow-up. It did not matter which surgery type they had chosen." (Ms Miriam Stein, Clinical Psychologist, Department of Psychiatry and Behavioural Science, University of Western Australia: Volumes of submissions, p 895).

2.16 Yet the importance of that involvement appears to be ignored far too often:

> "The worst case, I am aware of, concerns a woman placed on 'Tamoxifen' only after she developed secondaries as the surgeon maintained he was keeping the drug 'up his sleeve' to be used if it was needed. He did not discuss his decision with the patient and she is now in the terminal stages of breast cancer." (Ms Barbara L. Newton, Queensland: Volumes of submissions, p 355).

2.17 While it is agreed that a woman should be informed about all the treatment options available to her, and about the advantages and disadvantages associated with each option, there is considerable evidence to show that this does not translate into practice:

> "... surveys show that patients are often dissatisfied with the amount of information they receive and the lack of consultation about treatment decisions." (Ms Elaine Henry, Executive Director, NSW Cancer Council: Volumes of submissions, p 403).

2.18 This unsatisfactory situation is not unique to the patient with breast cancer and has been acknowledged by the publication of the National Health and Medical Research Council's "General guidelines for medical practitioners on providing information to patients" which outline the need to foster a better level of communication between doctor and patient, "... so that patients are able, with their doctors, to make the best decisions about their medical care."[5].

2.19 Implied in the need to have a better level of communication between doctor and patient is the ability of the doctor to effectively convey the information to the patient. As mentioned previously, there is evidence to show that many general practitioners, who are often the first point of contact for a woman, are not well informed about breast cancer. Many specialists also, unless they deal frequently with breast cancer cases, will have a less than comprehensive understanding of modern management and treatment options.

2.20 The ability of the patient to grasp immediately the implications of the information that they are given is also reduced further by the stress under which they are placed:

> "One of the general practitioners on the panel had, in fact, had breast cancer, and was willing to let that be known. She described her own experience in being required to make a decision about her primary treatment on the day of first consultation, and made the point that even a medical education is no preparation for making that decision under stress." (Professor Alan S. Coates, Vice-Chairman, Australian-New Zealand Breast Cancer Trials Group, Oncology Clinic, Dubbo Base Hospital, New South Wales: Transcript of evidence, p 1093).

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[5] National Health & Medical Research Council, *General guidelines for medical practitioners on providing information to patients,* Commonwealth of Australia, 1993, p i.

2.21 The difficulties experienced by women in having their views about their treatment sought and addressed are echoed in cases where younger women fall outside the stereotypical patterns of risk:

> "...younger women [i.e. under 50 years of age], in particular, continually report the difficulty they have in being taken seriously when they present to their GP with lumps. They have to be very persistent to have those lumps examined." (Ms Marcia O'Keefe, Victoria: Transcript of evidence, p 847).

2.22 All too frequently, women are not given the opportunity to access any form of adjuvant therapy after their surgery, a lack of referral which also appears not to have been discussed with the patient:

(1) "RDNS staff are surprised by the number of breast cancer clients they see post-operatively who have not been referred to an oncologist for follow-up. ...women have a right to an oncological opinion and follow-up." (Miss Beverley Armstrong, Director of Nursing, Royal District Nursing Service, Victoria: Volumes of submissions, p 447).

(2) "[There *is*] ...[l]*imited access to radiation and medical oncology* opinion and centres for treatment. Ideally patients should be offered treatment of choice by centres of excellence with multi-disciplinary specialist Breast Cancer Clinics." (Dr Roger Allison et al, Division of Oncology, Royal Brisbane Hospital, Queensland: Volumes of submissions, p 388).

v Information

2.23 "I was given no information on breast cancer prior to my first appointment. At the first appointment, I was told my disease was incurable. I was offered hormone treatment, with participation in a trial of Zoladex and Tamoxifen taken simultaneously, compared with Zoladex only. The oncologist offered the treatment then asked what I wanted to do. I had never heard of hormone treatments, I knew nothing about breast cancer, I had no information about treatments, what else could I do but follow his recommendation. It did not cross my mind to get a second opinion.

> Subsequent information provided by the hospital on breast cancer was very brief and general, and contained no information about treatments. Because I was losing weight as a result of modifying my diet to a healthy, low fat diet (the sort that all well people are encouraged to follow), I was given pamphlets instructing me to eat as much sugar, cream and butter as possible. ....
>
> When the recurrence hit, I knew little more than I did the first time around about what would happen next. After that, I decided it was time to find out more for myself. I tried the Anti-Cancer Council of Victoria, but their material was supportive rather than informative. I asked my oncologist if he could recommend any reading material. He was vague and did not provide any references. .... The only option I could then see was to spend time at the University of Melbourne medical library, going through medical texts and journals. I spent many hours doing this, piecing together a history of breast cancer treatments and their current status. Subsequently, I have found a book which covers the material very well for a non-medical person, called Dr. Susan Love's Breast Book. However, the library hours provided a deeper insight as to how treatments have developed, and how much agreement there is on treatments." (Ms Marcia O'Keefe, Victoria: Volumes of submissions, p 602-604).

2.24 Patients as the consumers of health services need to be in a position to make informed decisions about their treatment. Unfortunately, the supply of written information for the layperson on the management and treatment of breast cancer is, at best, both sparse and inadequately written:

> "I think we need more written material. You would be horrified at the lack of written material for women about these things which are so basic, so everyday. There are 12 women diagnosed with breast cancer in Australia every day. Most of them are not given any written information either about breast cancer or about their choices." (Dr Cherrell Hirst, Medical Director, The Wesley Breast Clinic, Queensland: Transcript of evidence, p 124).

2.25 Along with being provided with a supply of adequately written material, there is a need for the patient to have the opportunity to discuss their options and to properly comprehend what they have been told. There is very real neglect in this area:

> "...surveys show that patients are often dissatisfied with the amount of information they receive and the lack of consultation about treatment decisions." (Ms Elaine Henry, Executive Director, NSW Cancer Council: Volumes of submissions, p 403).

2.26 Even when attempts are made to overcome the paucity of readily available written material by speaking to the patient, the patient commonly has difficulty in "hearing" what they are being told due to the extreme stress they are experiencing.

2.27 While a purely technical approach to a patient's condition is one way for the medical practitioner to cope with the situation, it is clear that to rely solely on this mode of communication is an inadequate response to the patient's needs. It is acknowledged that one person cannot be all things to all people. It is essential, therefore, that this situation be recognised as one in which paramedical staff such as specially trained nurses or counsellors must be used to provide the additional dimensions of care which will address the patient's emotional and psycho-social needs. Support organisations may also have a role to play in addressing the patient's emotional and psycho-social needs.

vi <u>Rural and Remote Area Patients</u>

2.28 Forty-seven percent (1 459 599) of women aged 35 years and over reside in non-capital city areas (Bureau of Statistics - 1991 census figures). Most of these women are disadvantaged in terms of their access to breast cancer multidisciplinary teams and allied treatments.

2.29 It is an undisputed fact that this considerable portion of Australian women undergo a significantly higher number of mastectomies than do women in metropolitan areas and have a lower referral rate for radiotherapy. A lower survival rate for non-metropolitan women with breast cancer has been reported in South Australia[6].

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[6] Professor John H. Kearsley et al, The Radiation Oncology Standing Committee, Royal Australasian College of Radiologists, New South Wales: Volumes of submissions, p 247.

2.30 While the reasons put forward to explain the fact of the number of mastectomies performed on country women are complex or contentious, three dominant factors appear to be involved:

(1) a current lack of mammography screening programs in country areas which has led to most lesions presenting at the palpable stage with a consequent need for more radical surgery to be undertaken: "Metropolitan patients were more likely than non-metropolitan patients to have their cancer detected by mammographic screening (28% versus 6% $\chi^2=17.3$, $P<0.001$) and to present with early disease (78% versus 70% in Stages 0 and I; 22% versus 30% in Stages II and III; $\chi^2=5.1$, $P<0.05$)"[7];

(2) difficulties in accessing radiotherapy facilities; and

(3) some country-based surgeons failing to use current "best practice" procedures or multidisciplinary teams: "... [they say] 'I am an unashamed mastectomist. If a woman is referred to me, I will not do conservative surgery ..." (Mrs Elizabeth A. Trevan, Director, North Coast Breast Screening Program Inc., New South Wales: Transcript of evidence, p 355).

2.31 The difficulties in accessing radiotherapy facilities arise from a number of issues.

2.32 In all country areas in Australia, women who require radiotherapy currently need to go to a capital city or regional centre for treatment which can take between six to eight weeks. It has been suggested that this period of time away from home results in women choosing not to have conservative surgery, which will possibly require radiotherapy even though choosing not to spend time away from home could compromise a woman's optimal course of treatment:

(1) "...the lack of financial (and emotional) support, particularly for non-metropolitan women, to attend a metropolitan centre for 6 weeks of radiotherapy may mean that women are compelled for economic reasons to have a mastec[t]omy, rather than lumpectomy and radiotherapy. Increased resources should be allocated to ensure that the decisions on the most appropriate

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[7] Hill, David J. et al, *Changes in the investigation and management of primary operable breast cancer in Victoria*, The Medical Journal of Australia, Vol 161, 18 July 1994, p 121.

treatment are not dictated by financial necessity." (Professor John H. Kearsley et al, The Radiation Oncology Standing Committee, Royal Australasian College of Radiologists, New South Wales: Volumes of submissions, p 244).

(2) "Patients requiring radiotherapy travelled to Newcastle, Sydney, Wollongong, Canberra or interstate sometimes, to have radiotherapy. This means a month or six weeks away from home, and this has definitely deterred women from having conservative surgery." (Dr Robert A. North, Private Practitioner, Dubbo, New South Wales: Transcript of evidence, p 1120).

2.33 Some of the reasons which seem to influence a woman's decision not to undertake radiotherapy are:

(1) the logistical difficulties which a prolonged absence from home creates for women running households and rural businesses;

(2) the psychological burden created by a lengthy absence from home in an unfamiliar environment, often without companionship, while dealing with a life-threatening disease;

(3) the limited financial support available to women 200 kilometres or more from a radiotherapy centre;

(4) a lack of advice as to its importance in her treatment regime; and

(5) difficulties associated with arranging child care:

> "I think it is very hard for them to make decisions, if they need radiotherapy, to be away from their family and their children for so long. .... if the mother has to go away and have radiotherapy, sometimes it is hard if there is no family support - if there is no-one who can come and look after the children while she is away having radiotherapy or surgery." (Ms Pamela M. Christopherson, Clinical Nurse Specialist, Oncology Unit, Dubbo Base Hospital, New South Wales: Transcript of evidence, p 1050, 1054).

2.34 The variety of travel assistance schemes (such as the Isolated Patients Travel Assistance Scheme) which are meant to enable patients from country areas to access medical facilities in metropolitan areas, are failing to provide adequate support for those patients. These schemes, previously controlled by the Commonwealth Government, are now the responsibility of the State/Territory governments with consequent differences in interpretation. All appear to have restrictions which seriously limit their value to the target group:

(1) "In the context of the criteria for patients to receive travel assistance, it should be noted that any form of retrospectivity has been abolished. This has resulted in numerous problems for breast cancer patients who were unaware of either the scheme or the rules prior to making their journey. In addition the PATS scheme is inflexible in terms of patients who wish to return to their homes at weekends and public holidays. This may relate to anecdotal evidence of women with breast cancer refusing radiotherapy due to the significant inconvenience to their lives. ...If the patient chooses to seek her own onward referral to a specialist clinic or physician via a GP she may then be precluded from any PATS benefit." (Dr Michael Byrne et al, The Cancer Foundation of Western Australia: Volumes of submissions, p 909).

(2) "There would be women who would prefer to go and see a specialist breast surgeon, who are unable to do that because patient travel will not pay. .... They [the travel assistance scheme] maintain that we have several surgeons in town who can provide that service." (Ms Susan M. Hearn, Support Services Co-ordinator, Northern Territory Anti-Cancer Foundation: Transcript of evidence, p 25).

2.35 Despite the considerable stresses that social isolation can cause for the patients not all schemes provide for someone to accompany the patient.

2.36 This limited financial support creates disincentives which could play a major part in a patient's decision about the type of treatment to be undertaken, apart from any medical considerations.

2.37 Because of the difficulties associated with a woman from a rural or remote area accessing a multidisciplinary team, she is at a distinct disadvantage in receiving optimal care. Access to an appropriate support group and to written information is also severely limited.

vii Aboriginal and Torres Strait Islander Women

2.38 It is a matter of regret that the Inquiry was unable to obtain direct evidence from Aboriginal and Torres Strait Islander communities about their concerns and opinions on the management and treatment of breast cancer.

2.39 While it appears that the incidence of breast cancer in Aboriginal and Torres Strait Islander women is lower than for non-Aboriginal women[8], the Committee could find no data to substantiate that claim. Nor can any factual data be quoted about the incidence of breast cancer amongst rural or urban Aboriginal and Torres Strait Islander women.

2.40 Aboriginal and Torres Strait Islander women with breast cancer have the same problems with accessing a broad range of facilities as do other women in areas 200 kilometres or more from a metropolitan area.

2.41 Aboriginal and Torres Strait Islander women for whom English is not their first language would have similar problems in accessing adequate information to those experienced by other women from a non-English speaking background.

viii Women from a Non-English Speaking Background

2.42 "She received a letter from the hospital in English and it was translated by a person next door who did not speak very much Spanish. So she duly went into the hospital expecting to have a biopsy. Her husband went to work after he dropped her at the hospital in the morning, and said he would come back at lunchtime to see what was going on. When he arrived back at the hospital at lunchtime she was

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[8] The Hon Marshall Perron, Chief Minister, Northern Territory Government: Volumes of submissions, p 634. Mr Phillip Carson, Specialist Surgeon, Northern Territory Department of Health and Community Services: Transcript of evidence, p 2.

> just leaving the ward to go to the theatre for surgery. The surgeon also arrived in the ward at the same time. He explained to her husband that he intended to do a mastectomy, whereupon her husband fainted. She went to surgery, not knowing that she was likely to have a mastectomy. Her primary concern was about her husband. She woke up having had a mastectomy; she did not know that she was even going to have the surgery." (Mrs Marguerite Menon, Victoria: Transcript of evidence, p 810).

2.43 This story succinctly demonstrates the major disadvantages that language difficulties alone can present for the non-English speaking background woman with breast cancer, her family, and the medical staff.

2.44 The post-operative state of the woman can only be imagined. By no stretch of the imagination, however, could it be argued that the emotional and psychological needs of the patient had been, at the very least, adequately attended to, or that she had been able to give informed consent to the surgery.

2.45 Nor does this story allow us to understand fully just what losing her breast meant for that Uruguayan woman and her husband, because of differing cultural concepts about body image and health. In some communities the very issues of cancer, breasts and surgery are considered unsuitable for discussion. In some households it is forbidden:

> "...to even utter the word 'cancer'. [and] These women were forced to deny any needs and to continue with normal duties and routine because family members refused to acknowledge any existence of their illness." (Miss Yolanda D'Agostino, Convenor of Task Group on Cancer in the Ethnic Community, Ethnic Communities Council of Victoria: Transcript of evidence, p 884).

2.46 Few people realise that access to medical interpreters is not at the instigation of the patient:

> "...it is up to the nurses to bring the translators and interpreters in. Generally speaking, they do not..." (Mrs Marguerite Menon, Victoria: Transcript of evidence, p 818).

2.47 Access to appropriate bi-lingual counselling is difficult.

2.48 There is a shortage of research into non-English speaking background women and their experience of breast cancer in Australia.

2.49 The lengths to which some professionals currently go in an attempt to address some of these issues, despite the inherent costs in money and time, is acknowledged:

> "I met people at [the] Western Hospital who had been visiting the consultants two or three times a year on a regular basis for 20 years. ...The one that they [the consultants] have coming back are ones that they are concerned about. And the non-English speaking people are the ones that fall into that category, because the consultants do not believe that someone else who does not know about their history is likely to check up on them. And they know that because the clients do not speak English they are not likely to be able to explain what has actually happened to them in the past." (Mrs Marguerite Menon, Victoria: Transcript of evidence, p 819, 820).

vix <u>Waiting Times for Surgery</u>

2.50 Waiting lists for some public patients are inordinately long for surgery which could not possibly be deemed to be elective:

> "There are, in some parts of the country, waiting lists for all kinds of surgery, including also for breast cancer or suspected breast cancer, in the public hospital system." (Dr Brendan Nelson, Federal President, Australian Medical Association, Australian Capital Territory: Transcript of evidence, p 674).

2.51 Fragmentation in the provision of services also leads to delays for the patient in having symptoms diagnosed and a plan of treatment formulated:

> "Currently, they may come to a surgical clinic, they may go to see the oncologist and they may even go to see a radiotherapist at another clinic. I have treated women in the past who first came to see me, and then they went to an oncologist and then a radiotherapist. It means going to three different clinics at three

> different times." (Professor Michael Stacey, Associate Professor of Surgery, Multidisciplinary Breast Group, Fremantle Hospital, Western Australia: Transcript of evidence, p 1141).

2.52 Within the multidisciplinary team setting, this fragmentation and its consequent delays can be avoided:

> "...mammography will be available at the same time, so women will be able to go directly from the [assessment] clinic to radiology and then return with their results. Also, fine needle aspiration and cytology will be available at the same time. If they are awaiting a cytology result, they will be able to come back to the clinic the following day or the following clinic, which will be with a different surgeon, but the advantage we see there is that they are not waiting for a week for [diagnostic] follow-up.
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> .... The other aspect .... is that we will have established a standardised information recording system so that the notes will be able to be passed on." (Professor Michael Stacey, Associate Professor of Surgery, Multidisciplinary Breast Group, Fremantle Hospital, Western Australia: Transcript of evidence, p 1134).

x Lymphoedema

2.53 It is unclear what percentage of women who undergo surgical treatment for breast cancer will develop lymphoedema, although the overall incidence is thought to be 25-38%[9].

2.54 Lymphoedema is not curable and, if untreated, can lead to a severe disability. The earlier treatment is implemented, the better the result[10].

2.55 Lymphoedema can occur after particular types of treatment for breast cancer[11]. It causes the arm to swell due to the impairment of the axillary lymphatics:

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[9] Mrs Carol Bishop, President, Lymphoedema Association of Western Australia: Volumes of submissions, p 734.

[10] Ms Anne Fletcher, Breast Care Consultant, Queensland: Volumes of submissions, p 216, 217.

[11] Ms Anne Fletcher, *Op cit.*

> "Treatment of lymphoedema is massage therapy, bandaging, measuring and wearing of a compression garment and use of compression pumps. It is time consuming and expensive." (Mrs Carol Bishop, President, Lymphoedema Association of Western Australia: Volumes of submissions, p 734).

2.56 Women who have had breast cancer treatment make up the largest group of people seeking health professional advice and treatment when lymphoedema occurs. (Lymphoedema may also occur following treatment of melanoma, prostate cancer, and cervical cancer.)

2.57 Yet the impact of this condition on a woman's life with its loss of function of her arm, pain, and disfigurement, is frequently not adequately recognised by medical practitioners:

> "Among comments made by women when approaching their Medical Practitioner in regard to their swelling arm have been 'it's a small price to pay,' or 'you will have to live with it.'" (Mrs Carol Bishop, President, Lymphoedema Association of Western Australia: Volumes of submissions, p 736).

2.58 The difficulty of accessing treatment in public hospitals for this condition has been outlined previously under "Physiotherapy" in Chapter One.

2.59 There appears to be a lack of easy access to compression garments which are an essential part of treatment for the condition[12].

xi Mammary Prostheses

2.60 The cost of mammary prostheses (false breasts) is very high with each State/Territory having a different scheme for access to them:

> "Each state is different ..... In the Northern Territory, if you are a public patient or a private patient in the public hospital, you get your first prosthesis free. If you are a private patient, you have to pay for all your prosthesis [sic]. After that, if you are a social security beneficiary, or under financial hardship, the health

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[12] Mrs Carol Bishop, Lymphoedema Association of Western Australia: Volumes of submissions, p 736.

> department will provide that prosthesis and women have to pay a $50 fee." (Ms Susan M. Hearn, Support Services Coordinator, Northern Territory: Transcript of evidence, p 33). They have to be imported from America and France, are expensive (costing around $200), and need frequent replacement[13].

2.61 The costs are considerable, with a wide variety of assistance being provided depending on the State/Territory in which the woman lives:

> "Finding out who might qualify under what scheme for which co-payment for what type of prosthesis is a mammoth task - not only does each state and territory have different regulations, the rules vary even from hospital to hospital and they are constantly changing. As a member of a private health fund you might get some of your expenses back." (The Australian Consumers' Association, Choice, *Lingerie with a difference*, November 1994, p 27).

xii Palliative Care

2.62 There would appear to be a general reluctance to confront the fact that in many cases of breast cancer the outcome will be the woman's death. The consequence of this reluctance appears to be a failure to address the issue of how the process of dying can best be managed for and by the patient; how adequate levels of pain relief can be best administered; and what treatment might provide the best quality of life in the time left. The term "palliative care" does not refer solely to the medical management of the act of dying, but also to the provision of pain relief and the general care and comfort of the patient.

2.63 This reluctance to address the issue of palliative care is understandable given that our society prefers to focus on the achievement of good health, and on medical cures when good health is threatened.

2.64 If it is believed that the very best management and treatment of a disease should incorporate all aspects of that condition,

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[13] Ms Susan Hearn, Support Services Coordinator, Northern Territory Anti-Cancer Foundation: Transcript of evidence, p 33.

then to avoid the issue of palliative care is to do a disservice to the patients by denying them the very best care possible:

> "There is a model that is drawn from diagnosis to death, that at diagnosis the input of palliative care is very small but it gradually increases and the curative gradually decreases. .... but in reality what usually happens is that it is all curative, then no more curative, all palliative, and that is not good." (Mrs Marie J. Watts, Manager, Hospice Care Service, Silver Chain, Western Australia: Transcript of evidence, p 1200).

2.65 There is evidence which shows a common failure to properly address palliative care needs. Those needs encompass the provision of services either within purpose built facilities or within the community, and an informed approach to the provision of pain and other symptom relief:

> "I did a survey some years ago .... I asked them the question: where do you think your patients die? The result was surprising and most GPs thought that their patients died at home. These were palliative care patients. That was totally wrong. .... our last report was that the vast majority of patients died in hospital." (Dr Bruce C. Stafford, Chairman, Palliative Care Association, Queensland: Transcript of evidence, p 79).

2.66 Purpose built facilities (hospice care) which can provide privacy as well as terminal palliative care are in high demand but in poor supply, with distressing consequences:

> "We were fortunate to have the ward to ourselves at the time my wife died because the other women very kindly arranged to move temporarily to a lounge room. .... What struck me forcefully about our experience with breast cancer was how little control we had in determining the physical circumstances in which my wife was to die and that when we desperately wanted privacy there was no way we could be sure of securing it. This came as a shock and stands in contrast with most other aspects of our personal lives in this society." (Mr Geoff Hogbin, New South Wales: Volumes of submissions, p 506, 507).

2.67 Community based palliative care services are currently labouring under the restrictions imposed by the Home and Community

Care Program's "no growth" funding. These restrictions and possible solutions have been fully surveyed by this Committee in the recent report "*Home But Not Alone, Report on the Home and Community Care Program*", July 1994. The final Government response has not yet been received.

2.68 The provision of pain relief also appears to be inadequately addressed with some forms of treatment being withheld because of logistical difficulties:

> "The role of radiotherapy in the palliation of the many distressing symptoms of cancer, when cure is no longer possible, is also well established. In particular, radiotherapy is the 'best drug' for bone metastases, resulting in a significant reduction in pain in about 90%, with no further treatment required before death in 60% of patients. Where there is centralisation of radiotherapy services, and the patient is bed-bound the benefits of radiotherapy are often withheld because of the problems associated with transporting the patient, even for a single fraction treatment."[14]

2.69 The lack of teaching in oncology at the undergraduate and postgraduate levels for medical practitioners is reflected in a poor understanding of the curative and palliative roles of radiotherapy[15].

xiii Family, Friends and Support Groups

2.70 Many women are unable to develop a rapport with their specialist or general practitioner for a variety of reasons, not all of which are within the control of the medical practitioner. However, the positive outcomes for the patient which can be achieved from the establishment of that rapport, can also be achieved through the help that family, friends and support groups can provide:

> "After the surgery, it was my family and friends who sent me information about stress management, emotional wellbeing, diet,

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[14] Morgan, G., *The Problems Facing Radiation Oncology in Australia in the 1990's*, Cancer Forum Vol. 17 (1) March 1993, p 4.

[15] Morgan, G., *Op cit.*, p 10; Professor John H. Kearsley et al, The Radiation Oncology Standing Committee, Royal Australasian College of Radiologists, New South Wales: Volumes of submissions, p 250.

> supplements, support groups and acupuncture to assist with regaining movement in my arm. .... The information and counselling provided by the Women's Health Centre was most suitable to my needs at that particular time. However, I must emphasise that finding information was not easy - it took considerable tenacity. It took many phone calls just to locate a support group, when it turned out that the hospital where I had my surgery ran a support group. This information was not conveyed to me because each health professional thought that somebody else would have told me about it." (Ms Ann K. Mitchell, Queensland: Volumes of submissions, p 296).

2.71 This story illustrates yet another result of the fragmented nature of the current management and treatment of breast cancer, where there is little co-ordination and communication between the different medical groups and where the systematic provision of counselling services in any form is a rarity.

2.72 The importance of accessing such support has been made clear in a study conducted by Dr David Spiegel, which demonstrated that when patients with metastatic breast cancer participated for a year in a weekly intervention (support) group, they lived on average for twice as long as similar patients who did not attend such a group[16].

2.73 Failure to provide a woman with information about and access to a variety of support structures is, therefore, of major significance, yet there appears to be little practical recognition of the need to help the patient identify the various types of post-operative support available to them. While not all patients would use a support group as their chosen form of emotional support, the existence of these groups and access to them is rendered more difficult because of the unstructured availability of information about them.

2.74 The needs of the family of the patient are sometimes not taken into account through any structured approach and access to a counsellor is not guaranteed:

> "My mother was very fortunate in being selected in a 'trial' which entitled her to the services of the unit counsellor. .... The

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[16] Spiegel, David et al, *Effect of Psychosocial Treatment on Survival of Patients with Metastatic Breast Cancer*, The Lancet, October 14, 1989, p 888 ff.

> services of the counsellor were also available to the rest of the family." (Ms Era Wellsmore, New South Wales: Volumes of submissions, p 150-151).

2.75 The difficulties encountered by family and friends in accessing financial help to accompany the woman with breast cancer to a radiotherapy unit or specialist breast cancer group, have been outlined above in the discussion about the shortcomings of the assisted travel schemes. The ability of family or friends to support the patient is severely curtailed as a direct result of these shortcomings.

PART 2: IMPROVING THE CURRENT SITUATION - RECOMMENDATIONS

CHAPTER THREE - DOCTORS AND PARAMEDICS

3.1 *"I think it is all too easy to think that breast cancer management simply involves the treatment of a superficial appendage of the body and that therefore management requires limited resources." (Dr Neil R. Wetzig, Surgeon, Breast and Endocrine Surgical Unit, Princess Alexandra Hospital, Queensland: Transcript of evidence, p 152).*

"... when I started surgery 10 or 12 years ago, [breast cancer] was a small section of general surgery and it was quite simple: you removed the breast and you occasionally gave radiotherapy, and that was it. Refinements have occurred which have made the situation much more complex." (Dr Stephen N. Birrell, Director, Flinders Surgical Oncology Unit, Flinders Medical Centre, South Australia: Transcript of evidence, p 557).

"Treatment of impalpable lesions demands a high level of skill and specialised knowledge and involves very different approaches than those used in the treatment of palpable lesions. Research and experience in both Australia and overseas suggest that lesions detected through screening are best treated by a specially trained multidisciplinary team and by practitioners who undertake a large volume of work associated with the treatment of impalpable lesions." (Ms Onella Stagoll, BreastScreen, Victorian Breast Screening Co-ordination Unit: Volumes of submissions, p 350).

3.2 The Committee recommends, as a matter of urgency, that members of the medical profession who deal with breast cancer, liaise under the auspices of their respective Colleges, with a view to developing more accredited groupings of multidisciplinary teams which are based on what is now generally considered to be a "best practice" model. This model incorporates a team approach by multiple medical and paramedical disciplines. Through their combined understanding of current knowledge and practice about the best use of the options

available in individual circumstances, all members of the team liaise and co-operate together and with the patient to diagnose, treat and manage the condition of breast cancer to the highest possible standard of care.

3.3 The Committee recommends that Commonwealth and State/Territory governments and hospital administrators plan for and fund, as a priority, multidisciplinary teams to treat women with breast cancer.

i Undergraduate Education

> 3.4 "... the curricula committees of the medical schools [need] to address this issue [general practitioners not having any knowledge about radiotherapy]. I think we also have to address the issue of educating postgraduates." (Professor Alan Rodger, Director and Professor of Radiation Oncology, William Buckland Radiotherapy Centre, Alfred Hospital, Victoria: Transcript of evidence, p 829).

3.5 The lack of training about the diagnosis, treatment, and management of cancer in the curricula for medical undergraduates is difficult to understand given the incidence of cancer within the community. (Cancer as a whole is the second most common cause of death in Australia[1]).

3.6 There is also evidence to suggest that the lack of training at the undergraduate level about cancer can result in poor outcomes for the individual patient.

3.7 The lack of that training and its subsequent impact in particular on the diagnosis and management of breast cancer has been shown to be a matter of concern amongst the medical profession.

3.8 The Committee recommends that medical schools, as a matter of urgency, examine their curricula with a view to initiating courses which will enable their undergraduates to access information

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[1] Australian Cancer Society, *Cancer Control in Australia - An Overview*, March 1994, p 6.

about the diagnosis, management and treatment of cancer[2] with particular reference to breast cancer. Attention must be given to educating undergraduates about the emotional and psycho-social context within which patients must deal with their malignant disease.

ii Postgraduate Education

> 3.9 "It is a great privilege to be able to go into someone's home on a home visit and learn about them and their family. It gives you a very different knowledge and different understanding of what health care is. My concern is that perhaps in the tertiary sector people do not get those sorts of opportunities. I was very taken by the models that were being developed for the judiciary in relation to their awareness around domestic violence and so on. I wondered whether, as part of an ongoing quality assurance and training commitment that most health professionals have nowadays, whether there was not some option to offer something like a community placement for a surgeon, perhaps with a GP, so that they have a chance to look at the world through different eyes." (Dr Lesley Shorne, Medical Officer, Combined South Australian Women's Health Centres, South Australia: Transcript of evidence, p 659).

3.10 The current lack of interaction between the various Colleges which deal with breast cancer appears to reflect the belief held by some individuals or groups that they "own" the breast cancer patient, despite such an attitude being at odds with the concept of "best practice" which today is considered to be a multidisciplinary approach.

3.11 This attitude is also at odds with the increasing assertiveness of the patient who believes that, as the consumer of health industry services, their views and needs should be actively and fully taken into account. While some individuals within the medical profession may feel uncomfortable with this increasing assertiveness by the patient there is every indication that the redefinition of the practitioner/patient relationship will continue to take place and,

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[2] See also: Commonwealth Department of Human Services and Health 1994, *Better Health Outcomes for Australians - National Goals, Targets and Strategies for Better Health Outcomes Into the Next Century*, Commonwealth of Australia, November 1994, p 121-122.

willingly or otherwise, will need to be taken into account in the day-to-day relationship between practitioner and patient.

3.12 The Committee recommends that medical Colleges liaise with a view to co-operating to provide their Fellows and Members with cross-professional education and information on breast cancer, its diagnosis and treatment, keeping in mind that such sharing is in the best interests of the patient and is not a matter of "ownership" but a matter of "best practice". This sharing should involve areas such as diagnosis, co-operating with mammography programs, hospital management such as multidisciplinary teamwork, hospital based data collection, and research.

iii General Practice

3.13 The role of the general practitioner in the early diagnosis of breast cancer and in the ongoing management of the breast cancer patient cannot be overemphasised. However, this primary role is one which requires the general practitioner to be fully and currently informed about the diagnosis, treatment, and management of breast cancer in all its complexity. The current paucity of undergraduate and graduate exposure to cancer in general and breast cancer in particular necessitates a conscious effort by general practitioner groups and individuals to inform themselves about the issues.

3.14 The Committee recommends that greater and urgent attention be given by the Royal Australian College of General Practitioners to address the lack of exposure by general practitioners to training about the management and treatment of cancer, and in particular of breast cancer. That training should include: the need to encourage both self examination of breasts and regular examination by the general practitioner; the need to encourage appropriate patients to undergo mammography screening; the role of multidisciplinary teams in the diagnosis, management and treatment of breast cancer and appropriate referral to such teams; and, aspects on the benefits to the patient and their family of counselling and support groups.

3.15 The Committee recommends that the Royal Australian College of General Practitioners include as a compulsory core topic, training about the management and treatment of breast cancer.

3.16 The Committee recommends that the Royal Australian College of Medical Administrators address the issue of hospital discharge practices and how better communication links can be provided between the hospital, the patient's general practitioner and community based care groups.

3.17 The Committee recommends that, for the purposes of discharge planning in public hospitals, general practitioners be eligible for a Medicare rebate.

iv <u>Surgery</u>

(1) "I think it would be in the interests of women and it would allow facilities like ours to develop further if there were specifically defined criteria for breast surgeons within the college of surgeons." (Dr Cherrell Hirst, Medical Director, The Wesley Breast Clinic, Queensland: Transcript of evidence, p 111).

(2) "The Royal Australian [sic] College of Surgeons has a Breast Group, membership of which reflects a surgeon[']s interest in the field rather than any particular special training.

One solution to this 'jack of all trades' general surgeon is to encourage hospitals to make appointments specifically for surgeons with an interest in breast disease, and that for these selection committees, an external assessor, who is a member of the College of Surgeons Breast Group should normally be sought. .... In the future, it may well be important for surgeons with these special interests to document the number of new breast disease patients that they see each year, and that in due course a minimum number be set in order for a surgeon to remain accredited." (Professor Martin H.N. Tattersall, Professor of Cancer Medicine, University of Sydney: Volumes of submissions, p 116).

3.18 The evidence gathered by the Inquiry, points to a growing concern within the medical profession about the lack of compulsory accreditation or audit required by the Royal Australasian College of Surgeons for a general surgeon, who performs operations for breast cancer.

3.19 While most breast surgery is relatively simple, it is now known that specialised information about pathology, radiotherapy, adjuvant therapy etcetera, is essential in determining the type of surgery performed and the ongoing management of the breast cancer. An accreditation and audit process wherein knowledge, work load, treatments and outcomes are examined would be seen to be the most meaningful way of ensuring that expertise and standards are maintained.

3.20 The Committee recommends that The Royal Australasian College of Surgeons give high priority to considering the role of the general surgeon in the management and treatment of breast cancer, with a view to the early implementation of a scheme which will allow for a compulsory form of accreditation and audit process for surgeons performing breast cancer operations.

3.21 Although there is some evidence of the increasing use of a two stage process, which relies more upon the considered assessment of risk factors and varied treatment options, more attention needs to be given to a logical assessment of the perceived need for extreme haste between diagnosis and surgery.

3.22 While some may claim that quick action alleviates the woman's distress, that distress can also be addressed by counselling and the ready availability of information - a role that the specialist nurse in breast cancer treatment teams currently performs in some groups in Australia and the United Kingdom.

3.23 A more measured approach to treatment will also take into account the psychological needs of the patient at this time.

3.24 The Committee recommends that the National Health and Medical Research Council working party which is developing clinical practice guidelines on the treatment of diagnosed breast cancer give due attention to the optimal period of time required for proper patient and medical considerations to be made between diagnosis and surgery.

v Pathology

3.25 The complexity of the numbers and types of pathological lesions, combined with the intricacies created by the increasing number of early diagnoses, makes it essential that pathologists have a level of specific expertise in dealing with the diagnosis of breast cancer.

3.26 The Committee notes that The Royal College of Pathologists of Australasia is currently working on a process of recertification.

3.27 The Committee recommends that pathologists working on the diagnosis of breast cancer be specially trained and have sufficient experience in the area in which they are working.

3.28 The Committee recommends that a pathologist be a member of all multidisciplinary teams.

vi Radiotherapy

3.29 There is an urgent need for medical undergraduates and graduates to be trained about the use of radiotherapy.

3.30 The Committee recommends that general practitioner education and reskilling sessions in Departments of Radiation Oncology be provided by the Colleges as a matter of urgency.

3.31 The Committee recommends that greater exposure of medical undergraduates to Radiation Oncology Departments be provided by the medical schools as a matter of urgency.

3.32 It is clear that the debate about the required number of radiotherapy units and their location needs to be resolved.

3.33 The Committee recommends that the Australian Technology Advisory Committee address immediately the distribution of radiotherapy units and the required number of radiation oncologists and technical staff.

3.34 In view of certain claims that radiotherapy treatment is not always beneficial, and other claims that it is not administered when it should be, attention is urgently needed to address this issue.

3.35 The Committee recommends that the National Health and Medical Research Council working party which is developing clinical practice guidelines on the treatment of diagnosed breast cancer, pay particular attention to determining when radiotherapy for breast cancer should be administered.

vii Medical Oncology

3.36 While it must be recognised that chemotherapy is, at times, the treatment of choice, it appears that more attention must be given to the rationale for its use. To this end it is necessary for a medical oncologist to be involved in considerations about a patient's management and treatment.

3.37 The Committee recommends that the National Health and Medical Research Council working party which is developing clinical practice guidelines for the treatment of diagnosed breast cancer, address the best use of chemotherapy and other adjuvant therapies, taking into account quality of life issues as well as medical imperatives.

viii Counselling

3.38 It is clear that counselling provided by either specialist nurses or other paramedical staff, with psychological and counselling training, is an essential component in the management and treatment of breast cancer. Ideally, that access to counselling should be provided on a basis which incorporates pre and post-operative care as well as long term management.

(1) "[In Edinburgh] ... it was a nurse-counsellor who would sit down with a book of photographs of reconstructions and say, 'These are the possibilities and these are the results'. So the nursing staff play a crucial role." (Professor Alan Rodger, Director and Professor of Radiation Oncology, Alfred Hospital, Victoria: Transcript of evidence, p 844).

(2) "Another area often neglected in breast cancer management .... is the provision of counselling facilities for women who suffer from the condition. ....

> Provision of counselling services would allow more adequate emotional, psychological, and social support for women with breast cancer. A counsellor could be involved with both outpatients and inpatients, particularly in the pre-operative and post-operative support of women ....
>
> A model of such positions currently operates in the UK and in the USA. Such patient counsellors are quite common in those countries and have contributed greatly to the care of breast cancer patients ...." (Dr Neil R. Wetzig, Consultant Surgeon, Queensland: Volumes of submissions, p 279, 280).

3.39 The Committee recommends that when a multidisciplinary team is set up, counselling services be an integral part of that team.

ix Physiotherapy

3.40 The lack of ease of access to physiotherapy for public health patients is a matter of concern given the essential need for physiotherapy to help alleviate post-operative conditions such as arm movement and lymphoedema.

3.41 The Committee recommends that the essential need of some breast cancer patients for physiotherapy for post-operative conditions be recognised by those treating the patient, and that steps be taken at the Commonwealth and State/Territory government levels to ensure that public breast cancer patients can easily access physiotherapy.

x Data Collection

3.42 Without proper data collection it is impossible to assess the outcomes of diagnoses, treatment, and management. Cancer registers should be funded in hospitals to gather a body of comparable information which should feed into State/Territory registers.

3.43 It is also necessary for a comprehensive national data base on breast cancer to be immediately established and maintained. This data base should include information gathered from hospital and State/Territory registers and could also include data on prevalence and mammography screening.

3.44 It is noted that the national conference on hospital-based cancer registries, organised by the Australian Cancer Society on 1 July 1994, recommended that priority be given to establishing hospital-based cancer registries to work in conjunction with State/Territory central cancer registries. The Committee wholeheartedly supports that recommendation.

3.45 The Committee recommends that the Australian Health Ministers' Advisory Council address, as a matter of urgency, the setting up of a comprehensive national data base on breast cancer[3]. This should be collected and monitored by the National Breast Cancer Centre.

xi Research

3.46 Because the causes of breast cancer are, in the main, unknown, research across a broad spectrum of issues is essential. Given the limited funding currently provided, a higher funding priority must be given to a broad range of applied and pure research.

3.47 The Committee has noted:

- the limited range of clinical trials currently being undertaken ("... the vast majority of studies have examined the role of chemo-hormonal therapy for breast cancer patients." (Professor John H. Kearsley et al, The Radiation Oncology Standing Committee, Royal Australasian College of Radiologists, New South Wales: Volumes of submissions, p 251));
- the limited funding available to the National Health and Medical Research Council;
- the limited funding provided by the National Health and Medical Research Council for clinical trials for breast cancer;
- the lack of research in the bio-medical and psycho-social

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[3] See also: Commonwealth Department of Human Services and Health, *Better Health Outcomes for Australians - National Goals, Targets and Strategies for Better Health Outcomes Into the Next Century*, Commonwealth of Australia, November 1994, p 124-127.

areas;

- the lack of financial recognition by the National Health and Medical Research Council that clinical trials for breast cancer take place at the international level so that there are sufficient data cohorts; and

- the lack of funding for longitudinal research into the period of survival.

3.48 The Committee recommends that the Commonwealth Government provide more funding for the National Health and Medical Research Council to conduct bio-medical research and clinical trials.

3.49 The Committee recommends that the National Health and Medical Research Council initiate action to:

(1) address the current lack of emphasis in clinical trials on a variety of treatment methods for breast cancer and how a greater variety of clinical trials might be funded;

(2) provide funding to allow participation in internationally conducted clinical trials for breast cancer consistent with Commonwealth Government current research and development policies; and

(3) provide funding towards longitudinal research into the period of survival.

PART 2: IMPROVING THE CURRENT SITUATION - RECOMMENDATIONS

CHAPTER FOUR: PATIENTS

> ***"Very few women receive continuing medical care in a truly multi-disciplinary medical setting or receive adequate psychosocial and rehabilitation services." (Dr Christine Bennett et al, Royal Hospital for Women, New South Wales: Volumes of submissions, p 672).***

i Women as Patients

4.1 The concept of providing "best practice" management and treatment of breast cancer must be seen to encompass more than just the technical aspects of management and treatment. It is clear from the evidence submitted that too little thought has been given to the need to provide services which address issues such as privacy and ease of access.

4.2 The Committee recommends that service providers examine the conditions under which services are provided and how they might be altered to better address issues such as privacy and ease of access.

4.3 It is also clear that on too many occasions, medical practitioners have not been exposed to the need to address sensitively the emotional and psychological needs of the patient. Attention is drawn to one instance where the medical undergraduate was able to experience the broader context of patient care:

> "I know that, in our hospital, we went through a phase where the medical student actually had to work with the nurses and wash the patient and take their temperature. It was a bit of a shock to some of them. The feedback we got from those medical students was that it really opened their eyes about what was happening to the women with cancer. They would sit there when the husband came in and talk to the children, and things like that. That was very beneficial." (Ms Jill R. Storey, Clinical Nurse Consultant in

> Breast Education and Cancer Support, Breast Cancer Support Service Nurses, Royal Women's Hospital, Victoria: Transcript of evidence, p 793).

4.4 The Committee hopes that medical schools and Colleges will provide undergraduates, Fellows and Members, with the opportunity to expand their awareness of the need to look beyond the disease to the whole person.

ii Participation in Clinical Trials

4.5 In Australia approximately 5% of women with breast cancer currently participate in clinical trials.

4.6 However, while it has been claimed that "patients who participate in clinical trials have an improved outcome over patients treated outside such trials" (Professor Alan Coates, *Canberra Times,* 7 November 1994, p 4), these claims again illustrate the fact that, outside the trials, a woman is deemed to be receiving less than the best management and treatment available.

4.7 Nor does it appear that these claims take into account the belief that participation in a clinical trial may not be to the best advantage of the individual woman:

> "...many women do not want to actually be part of a trial; they would rather have accepted current management. They feel, I would perceive, that they are being guineapigs, whereas that is not actually the case. .... In some of the trials - for instance, one in the management of an early stage breast cancer - a woman is randomised to either take in tamoxifen, an anti-oestrogen tablet or a placebo effect. Once you explain that to them and they find that they only have a fifty-fifty chance of actually getting the tamoxifen, many will say, 'I do not want to have it; I do not want to be part of that'. I think that is one of the other reasons that we need to accept as to why women do not go into trials." (Dr Neil R. Wetzig, Surgeon, Breast and Endocrine Surgical Unit, Princess Alexandra Hospital, Queensland: Transcript of evidence, p 165).

4.8 Current clinical trials have a heavy emphasis on chemotherapy and hormone therapy, more it appears as the result of where funding is most easily found. There is a need to have more clinical trials which explore a wider range of possibilities in, for example, surgical technique and other forms of therapy.

4.9 The Committee recommends that the Colleges and the Commonwealth and State/Territory governments address the lack of guaranteed "best practice" care outside clinical trials.

4.10 Because of casemix funding, hospitals, and even radiotherapy centres, are competing for patients. This competitive environment is acting as a disincentive for practitioners to enter patients into trials for which they are not remunerated.

4.11 The Committee strongly recommends that the Commonwealth and State/Territory Ministers for Health address the problem of casemix disincentives for participation by women in clinical trials by ensuring that practitioners are given adequate time and funds.

iii Psycho-social Needs

4.12 "Data suggests that at least 40% of women undergoing treatment for breast cancer undergo significant psychomorbidity. If treatment for breast cancer is to be truly effective .... then a means of addressing this problem and encompassing it within the ambit of 'standard' treatment must be sought and implemented." (Dr Cherrell Hirst, Director, Wesley Hospital Breast Clinic, Queensland: Volumes of submissions, p 587).

4.13 The Committee recommends that the National Health and Medical Research Council provide adequate funding for research to investigate the extent and severity of psycho-social morbidity and how it can be addressed.

iv Decision Making

4.14 There are two aspects involved in having patients actively participate in decision making about the management and treatment of their disease. The first is that their participation in this process has positive psychological outcomes; the second is that for both ethical and legal reasons the patient must be in a position to make an informed choice, even if that choice is to leave the decision making to the medical practitioner.

4.15 The Committee recommends that the appropriate Colleges address the need for medical practitioners to be aware of the requirement to actively involve their patients in the decision making process about the management and treatment of their disease.

4.16 The Committee recommends that the appropriate Colleges address the need for medical practitioners to be aware that a woman should be given adequate time and counselling in order to make an informed decision about her choice of treatment.

v <u>Information</u>

4.17 The provision of adequate written information is of paramount importance in helping the patient and her family to address their concerns and to enable her to make informed decisions. There is, however, a lack of appropriate written information available, despite the importance of its role:

(1) "From the women I have spoken to, there is a misunderstanding that women do not want to know about breast cancer, about when they have actually been diagnosed. They are put a little bit to one side and the doctors and surgeons only tell them what they think they will understand and what they can cope with. But I think women want to know exactly where they stand so they can provide for their family if anything serious is going to happen to them or so they can just come to terms with it themselves. You should know everything, not just that you have got a stage 4 tumour. People do not really know what a stage 4 tumour is; they want to know what that means in terms of their health. Does that mean that if you have got a stage 4 tumour you have five years, two years or one year to live? Does it mean something like that or do they not know what it means?" (Ms Alison McC. Bridges: Transcript of evidence, p 667).

(2) "The information should be in written form, so that it can be read by the woman or her support person, at a time suitable to her, and in an environment where she is most likely to be able to

> absorb information. The information may be useful immediately, or may be referred to later." (Ms Marcia O'Keefe, Victoria: Volumes of submissions, p 604).

4.18 The Committee recommends that women be provided by practitioners with written information about breast cancer to which they and their families can refer repeatedly. The information should be written to meet the differing needs of individuals by encompassing approaches which range from the purely supportive to the medically sophisticated. Information should be presented in a manner which will not make assumptions about which level of information the recipient will require.

4.19 The Committee recommends that the National Breast Cancer Centre as a matter of priority, and as part of its educational role, co-ordinate the production and distribution of information on breast cancer in the major community languages.

vi Rural and Remote Area Patients

4.20 "In 1994 proper initial assessment for women with suspected breast cancer is best performed in a multidisciplinary assessment setting. .... Rural women would benefit by travelling to their regional centre for this type of complete assessment. They can then better assess and discuss their options prior to surgery." (Mr Tony Green, Secretary, Divisional Group of Rural Surgeons, Royal Australasian College of Surgeons, Victoria: Volumes of submissions, p 335).

4.21 Women from rural and remote areas should be able to access the services of a multidisciplinary team. Therefore, they must either be assisted to go to the team or to access a team which has an outreach program such as the one conducted jointly by the Royal Prince Alfred Hospital and the Dubbo Base Hospital in New South Wales:

> "... we are now conducting more like two days a week of regular specialist services. .... One of the advantages of running a clinic like this is that many treatments which might otherwise require travel [by the patient] to Sydney can be given here." (Professor Alan S. Coates, Vice-Chairman, Australian-New Zealand Breast

> Cancer Trials Group, Oncology Clinic, Dubbo Base Hospital, New South Wales: Transcript of evidence, p 1085).

4.22 It is imperative that women who need to undertake radiotherapy are provided with sufficient travel assistance which will enable them to access that radiotherapy easily.

4.23 Similarly, women should be provided with travel assistance if they choose to access a medical practitioner or multidisciplinary team other than one deemed to be available within their geographic area:

> "There would be women who would prefer to go and see a specialist breast surgeon, who are unable to do that because patient travel will not pay. .... they [the travel assistance scheme administrators] maintain that we have several surgeons in town who can provide that service [breast cancer surgery]." (Ms Susan M. Hearn, Support Services Coordinator, Northern Territory Anti-Cancer Foundation, Darwin: Transcript of evidence, p 25).

4.24 If a woman has received travel assistance to access treatment she should on occasion be able to return home during intervals in her treatment.

4.25 It is also imperative, given the additional stresses that a woman must undergo if she has to go away from home to receive radiotherapy or other medical help for breast cancer, that she is able to receive travel assistance towards having a support person accompany her.

4.26 The provision of child care while a woman is absent from her home while she receives treatment, is a significant matter for the patient.

4.27 The Committee recommends that the Commonwealth and State/Territory governments, along with practitioners and professional bodies and all other service providers, give urgent priority to addressing the problems faced by women from rural and remote areas in accessing multidisciplinary teams, adjuvant therapy, clinical trials, counselling, support groups, and information.

4.28 The Committee recommends that the Commonwealth Government, in conjunction with State/Territory governments,

standardise and broaden the travel assistance schemes. In the event that this cannot be achieved the Commonwealth should assume full responsibility.

4.29 The Committee recommends that the Commonwealth and State/Territory governments address the issue of the provision of child care while a woman from a rural or remote area is absent from her home while receiving treatment.

vii <u>Aboriginal and Torres Strait Islander Women</u>

4.30 During the course of this Inquiry it became apparent that there was very little information about the experience of Aboriginal and Torres Strait Islander women with breast cancer.

4.31 The Committee recommends that the Commonwealth and State/Territory governments address the issue of acquiring more information on the incidence of breast cancer in rural and urban Aboriginal and Torres Strait Islander women, and their experience of the management and treatment of that disease. The means of addressing any revealed problems should then be implemented by the Commonwealth and State/Territory governments.

viii <u>Women from a Non-English Speaking Background</u>

4.32 The woman from a non-English speaking background who has breast cancer is placed in an additionally difficult position because of her lack of English speaking skills. While she may well be able to cope with minimal English on a day-to-day basis, the stresses under which her diagnosis has placed her are compounded by her lack of fluent English language expression and understanding. These pressures in turn may well be escalated by cultural factors.

4.33 The ability of the non-English speaking background woman to make a judgement about her treatment and to give informed consent is severely limited. It appears that little systematic effort has been made to address these issues:

(1) "The provision of information to non-English speaking women with breast cancer is a high priority." (Ms Miriam Stein, Clinical

Psychologist, Department of Psychiatry and Behavioural Sciences, University of Western Australia: Volumes of submissions, p 894).

(2) "... family members are still very often used in hospital settings. It is surprising in 1994 that people such as food caterers and allied service providers will still be utilised in very difficult and critical situations. This is not about telling you, 'I want tea or coffee.' This is about, 'Sign this consent form.' .... If a family member is there, they [the medical practitioner] need to differentiate between the role of the interpreter and the role of the family member. The family member may be in crisis himself, or herself, just hearing the news about what is happening to their dear family member. So it is very difficult, for example, to ask a 16-year-old girl to tell her mum that she has got a very serious illness ....

With interpreters I think that there is a need for women to have access to women interpreters. .... it is a very basic point" (Ms Mirta C. Gonzalez, Director, Centre for Ethnic Health, Victoria: Transcript of evidence, p 888).

4.34 It is noted that *The National Non-English Speaking Background Women's Health Strategy*[4], described a broad outline of the problems faced by non-English speaking background women with their health and in accessing health service provision, and made a number of recommendations.

4.35 The Committee recommends that the Commonwealth and State/Territory governments through the Australian Health Ministers' Advisory Council address the issue of how a woman from a non-English speaking background can be assured of easy access to appropriate interpreter services and suitably written information during the course of her diagnosis and treatment for breast cancer.

4.36 The Committee recommends that the appropriate Colleges address the need for practitioners to be aware of the requirement to provide interpreter services for non-English speaking background patients.

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[4] *The National Non-English Speaking Background Women's Health Strategy*, Australian Government Publishing Service, Canberra 1992.

ix Waiting Times for Surgery

4.37 It is of grave concern that any woman with suspected breast cancer could be kept waiting for up to 17 weeks for admission to hospital (see paragraphs 1.37-1.38).

4.38 The Committee recommends that the Australian Health Ministers' Advisory Council examine the reasons for any inappropriate delays between the diagnosis and treatment of breast cancer.

x Lymphoedema

4.39 Lymphoedema can occur after particular types of treatment for breast cancer. The two main treatments for this condition are compression garments and physiotherapy. Therefore, while recommendations have been made by this Committee about access to physiotherapy, the Committee also considers it essential that further efforts are made to address the difficulties women have in accessing the compression bandages and garments, which are also essential in the management of this condition.

4.40 The Committee recommends that the Minister for Human Services and Health investigate the issue of how women with lymphoedema can receive financial or other assistance in accessing compression bandages and garments and what role the Commonwealth Rehabilitation Services might play in the provision of treatment programs.

xi Mammary Prostheses

4.41 "If I lost an arm and walked down the street, people would say, 'That poor bugger has lost an arm'. But if I walked down the street without my prosthesis, everybody would be offended, and I would be devastated." (Councillor Susan M. Dethridge, New South Wales: Transcript of evidence, p 444).

4.42 The supply of a properly fitted mammary prosthesis is not just a matter of community values and aesthetics. Prostheses are also about balancing the weight of the remaining breast; if they are not balanced, the shoulders can move out of alignment, putting pressure on the spine and causing problems with posture[5].

4.43 Given that the majority of women having treatment for breast cancer still undergo mastectomy and require a prosthesis, and that there is a population of women who have undergone mastectomy in the past, there is a fundamental need to have a nationally consistent policy on the provision of mammary prostheses and how much they should cost the patient.

4.44 The Committee recommends that the Minister for Human Services and Health, as a matter of urgency, amend the Medicare rebate schedule to include the provision of mammary prostheses.

xii Palliative Care

4.45 The need for palliative care in all its forms, should be seen as an integral part of the continuum of management and treatment of breast cancer.

4.46 Community based palliative care services provide a form of care which enables people to stay at home for as long as possible. Central to the provision of that care is the community nurse:

> "I think ... one of the best persons is the community nurse. I think her role is pivotal. And, if you are talking about palliative care, nursing care is the pivotal care for good palliative care. As medical practitioners you may see the patient for 10 minutes a day, you might see them for half an hour a day if there is a particular problem, but the real ongoing care is given by the nursing staff." (Dr Bruce C. Stafford, Chairman, Palliative Care Association, Queensland: Transcript of evidence, p 85).

4.47 The Committee considers that meeting the need for community based palliative care services is an essential component in the continuum of management and treatment of breast cancer.

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[5] The Australian Consumers' Association, Choice, *Lingerie with a difference*, November 1994, p 26.

4.48 The Committee recommends that the Commonwealth and State/Territory governments review the adequacy of funding arrangements for community based palliative care services.

4.49 When a patient can no longer remain at home and needs more intensive nursing care, it is apparent that an acute hospital is not the most appropriate place to be providing palliative care. A facility specifically dedicated to such care will provide the most appropriate environment. The positive support that a hospice can provide to the patient and her family appears not to be fully realised within the medical profession and the community:

> "...the dying patients. They do not get the care that they need because once again there is a misconception that dying patients do not need a lot of care. That is not true at all. Dying patients often need very intensive care to keep good control of their symptoms." (Dr Bruce C. Stafford, Chairman, Palliative Care Association, Queensland: Transcript of evidence, p 81).

4.50 The Committee recommends that the Australian Health Ministers' Advisory Council investigate the supply of, and access to, hospice care in Australia with a view to increasing specific purpose facilities. An assessment of the forms they should take in rural and urban communities should also be conducted.

xiii Family, Friends and Support Groups

4.51 It is essential that the valuable help provided by support services is incorporated into treatment regimes:

> "...there is nothing so reassuring to a woman who has just been diagnosed with breast cancer or who has undergone treatment for it than to have somebody who looks pretty normal come and talk about the experiences they had." (Professor John F. McCaffrey, Chairman, Medical Advisory Committee, Queensland Cancer Fund: Transcript of evidence, p 205).

4.52 The patient should have the choice of having their family and friends included within the management of their condition. In this way their emotional needs can be met:

> "The other thing that needs to be made available to patients - this should start at presentation, before the patient is admitted to hospital - is psychosocial care. That would take in counselling and support at the time of diagnosis, through surgery and getting home. It takes in not just the patient, but her partner, her support person, her family and her children." (Dr Paul Garvey, Senior Staff Specialist, Royal Hospital for Women, New South Wales: Transcript of evidence, p 461).

4.53 The Committee recommends that the counselling services provided within a multidisciplinary team, provide those services to the patient's family and support person if desired.

4.54 The Committee recommends that the appropriate Colleges bring to the attention of their members the need for patients to be made aware of the value and availability of support groups and counselling services.

CONCLUSION

> ***"... could you conceive paediatric leukaemia being treated willy-nilly by GPs? Could you conceive renal transplantation programs not being focused on centres where there is experience and expertise and renal programs developed? I submit that the care of patients with breast cancer involving the disciplines and high technology and the advancing frontiers of surgery, medical oncology, radiation oncology, molecular biology, laboratory, pathology, radiology - and I could go on at great length - demands that expertise be focused." (Professor John F. Forbes, National Group Co-ordinator, Australian New Zealand Breast Cancer Trials Group Ltd., Department of Surgical Oncology, University of Newcastle, New South Wales: Transcript of evidence, p 922).***

There would be few who would openly disagree with the belief that the primary focus of the management and treatment of breast cancer should be the welfare of the patient.

The evidence compiled during the course of this Inquiry disclosed a diverse opinion on breast cancer management and treatment. This is not surprising as the past twenty years has seen a dramatic change in the options available to individual women with breast cancer. That change has resulted in the recent formation of specialised teams and networks which encompass all the health professionals required to give optimal care to breast cancer patients.

Although these teams are a relatively new concept, in South Australia the rapid acceptance of this multidisciplinary management has led to the majority of breast cancers being treated in this way.

With some very notable exceptions, throughout the rest of Australia, there has been only a partial acceptance of the need for a multidisciplinary approach to management and treatment of breast cancer. This is despite evidence that such an approach is to the benefit of the patient and, indeed, creates a working environment for the medical and paramedical staff in which they can provide an optimal level of management and treatment.

The Committee recognised the considerable difficulties experienced by women from rural and remote areas in accessing treatment based on the multidisciplinary model. Strategies must be developed to enable these women to have the choice of accessing optimal treatment.

The Inquiry has also revealed a failure on the part of some medical Colleges to address the need to have their Fellows and Members undergo compulsory accreditation and audit processes for breast cancer, despite the evidence of the increasing complexity of diagnosis and treatment. Similarly, general practitioners are not being provided with the opportunity to redress the lack of exposure in their undergraduate and postgraduate training in the diagnosis and treatment of breast cancer.

There has also been a failure to clearly define the areas in which there is consensus about what constitutes "best practice" and to define those areas which remain unclear or controversial, although a number of positive steps have recently been taken to address this issue.

The wide ranging activities that have occurred during the past twelve months, towards resolving some of the issues of management and treatment of breast cancer, are an important part of that process.

More, however, must be done.

Training must be undertaken at both the undergraduate and postgraduate levels and must encompass more than medical technique. Such training should address the patient as a whole, ranging from their psycho-social needs to the provision of an interpreter where required.

As outlined in the Committee's recommendations, it is deemed essential that while "best practice" guidelines are drawn up and implemented, a compulsory accreditation and audit process must also be implemented for all the specialist practitioners involved in the various aspects of diagnosis and treatment for breast cancer. In this way, the guidelines can be assured of being implemented and constantly weighed against practice and outcomes. The patient would also then be assured of being able to access those professionals who are most experienced in their particular field for the treatment of breast cancer:

> "... women themselves could feel more comfortable that the doctors caring for them had made a special commitment and been accredited for their knowledge of breast disease and breast cancer

> management." (Professor Martin H.N. Tattersall, Professor of Cancer Medicine, University of Sydney: Volumes of submissions, p 116).

At the same time, it is essential that general practitioners be required to undergo postgraduate training to better understand the diagnosis and treatment of breast cancer, and that medical schools teach their students more about oncology.

It is hoped that the recommendations made by this Committee will be received by the medical profession, the respective Colleges, and Commonwealth and State/Territory governments, as a catalyst to further action: action which is also being urged from within the medical profession and by the general community.

Further action can only result in a greater satisfaction for the medical and paramedical professions that comes from the knowledge that they are providing the best management and treatment for women with breast cancer. The patient and her family will have the security that comes with the clear understanding that she has been provided with service which meets Australian and international "best practice" standards of care.

The current lack of data collection about breast cancer must be addressed quickly and, while acknowledging that some steps have been taken, those initiatives must be supported at all levels of government.

Finally, while this Inquiry was one of a number of initiatives which have recently taken place in an attempt to address perceived problems in the management and treatment of breast cancer in Australia, it is clear that greater progress will be made by having a National Strategy to deal with breast cancer. Such a strategy would involve a co-ordinated approach by Commonwealth and State/Territory governments, and the medical profession. It would be a more efficient way of initiating and assessing change within this area and is one which the Australian community both needs and deserves.

Speaking at the Breast Cancer Consensus Conference held in June 1994, the Convenor, Professor Alan Coates said: "All Australian women are at risk of contracting breast cancer. These women deserve access to the best possible treatment in a co-ordinated National Strategy that encompasses all aspects of breast cancer control. The need for a national approach has been recognised at all levels from patients and the community to government. We must and can do more to stop the devastation caused by breast cancer." (Exhibit 59 A refers.)

In Australia, six women a day die from the complications of breast cancer. To place this in an international context:

> ***"There are some 150,000 living women in the U.K. who have been treated for breast cancer, of whom one dies each 30 minutes. In the United States one woman dies from breast cancer each 13 minutes. From USA it is reported that during the 10 years of the Vietnam war there were 57,000 deaths from combat, while 330,000 women died from breast cancer at home .... And there are reports from all developed countries that the incidence of the disease is rising, particularly in younger women, even when the impact of earlier diagnosis and better cancer registration are taken into account .... Were breast cancer a communicable or an acute disease, an epidemic would be declared. Yet, unlike communicable diseases of the past, it is not even registrable by law."*** (Forrest, P., *Breast Cancer: the decision to screen*, The Nuffields Provincial Hospitals Trust, Burgess & Son (Abingdon) Ltd., 1990, p 26.)

This Report provides an opportunity for Australia to demonstrate its commitment to excellence in the provision of health care to the community. This can be achieved by building on existing levels of expertise and leadership in the area of management and treatment of breast cancer and requires a concerted effort by government and the medical profession to effect a change to some current attitudes and practices.

ALLAN MORRIS MP
(Chairman)

HON WENDY FATIN MP
(sub-Committee Chair)

17 February 1995

APPENDIX 1

LIST OF SUBMISSIONS

Individuals

Mrs M Abbott, Wagin, WA
Ms W Aitkenhead, Coutts Crossing, NSW
Dr K Alle, Kingswood, NSW
Ms S Anderssen, Lane Cove, NSW
Ms J Barnett, Narromine, NSW
Ms H Beatty, Yarraville, VIC
Ms P Belfield, Winmalee, NSW
Mr D Benjamin, Crows Nest, NSW
Ms E Burrell, Forrestfield, WA
Mrs M Cain, Winmalee, NSW
Ms M Calder, Balmain, NSW
Ms A Chandler, Taylors Lakes, VIC
Mrs C Choake, South Penrith, NSW
Dr R Cilento, Alderley, QLD
Dr E Cobbold, Sandy Bay, TAS
Ms J Collier, Berri, SA
Ms Y D'Agostino, Shepparton, VIC
Ms H de Koning, Green Point, NSW
Ms M Dean, Springwood, NSW
Mrs P Demetre, Sans Souci, NSW
Ms S Denham, Quaama, NSW
Cr S Dethridge, Bellingen, NSW
Ms E Duffy, Perth, WA
Mrs J Einikis, New Farm, QLD
Ms M Fergusen, Herne Hill, VIC
Ms M Flanagan, Hamilton, NSW
Ms A Fletcher, Hawthorne, QLD
Ms B Forgeard, Lawson, NSW
Ms L Fullarton, Rockingham, WA
Mrs M Fullarton, Rockingham, WA
Ms M Garnett, Artarmon, NSW
Mrs M Goldstein, North Buderim, QLD
Ms J Green, Lane Cove, NSW
Ms S Harding, Budgewoi, NSW

Mrs P Hartley, Renmark, SA
Mrs A Hayes, North Bundaberg, QLD
Mr G Hogbin, Waverton, NSW
Ms L Holford, Nambour, QLD
Mrs D Holland, Bribie Island, QLD
Ms J Holmden, Peterhead, SA
Ms E Janes, Wentworth Falls, NSW
Mr H Johnson, Whiteside, QLD
Miss D Kelly, Karratha, WA
Ms S Kennedy, Orange, NSW
Ms J Klingler, Rowville, VIC
Mr D Langford, Kilaben Bay, NSW
Ms M Langford, Kilaben Bay, NSW
Mrs W Lawrence, Beenleigh, QLD
Ms R Lewandowski, Mount Pleasant, NSW
Mrs L Libregts, Peterhead, SA
Ms G Lyon, Edgewater, WA
Dr A Macaulay, Blackheath, NSW
Mrs K Mackenzie, Stanwell Tops, NSW
Ms T Matthews, Bundanoon, NSW
Mr K May, Broadbeach Waters, QLD
Mrs P McGovern, Glasshouse Mountains, QLD
Ms J McHardy, Greenvale, VIC
Dr R McKenzie, Abbotsford, NSW
Ms A Mitchell, The Gap, QLD
Ms L Moyes, Bermagui, NSW
Mrs K Moyses, Werribee, VIC
Ms B Newton, Jindalee, QLD
Miss P O'Brien, Canowindra, NSW
Ms M O'Keefe, North Carlton, VIC
Ms S Paull, Peterhead, SA
Ms M Petersen, Gelorup, WA
Ms E Pilgrim, Blackheath, NSW
Ms A Preiss, Peterhead, SA
Mrs P Rappapport, Collaroy, NSW
Mr K Rex, Paddington, NSW
Ms C Riddle, Doncaster, VIC
Mrs M Rondello, Dover Gardens, SA
Ms C Sheil, Tamborine, QLD
Ms W Sierp, Peterhead, SA
Mr B Sims, Southport, QLD
Mrs A Smith, Lilydale, TAS

Ms S St.Ledger Maitland, Rushcutters Bay, NSW
Ms M Stewart, Gold Coast, QLD
Mrs Y Strawbridge, Mariginiup, WA
Mrs N Sumner, Templestowe, VIC
Ms M Tassicker, East Kew, VIC
Ms A M Tong, Lawnton, QLD
Mr H Towers, Torrensville, SA
Mrs C Trenorden, Summertown, SA
Ms S Tucker, Geelong, VIC
Ms S Tulley, Katherine, NT
Mrs P Turner, Carey Bay, NSW
Ms E Ward, Springwood, NSW
Ms E Wellsmore, Carey Bay, NSW
Dr N Wetzig, Brisbane, QLD
Mrs M Wilson, Blaxland, NSW
Mrs L Wood, Mermaid Beach, QLD

Organisations

ACT Cancer Society Inc.
ACT Cancer Society Inc., Breast Cancer Support Services
ACT Division of General Practice Inc.
ACT Government, Deputy Chief Minister
Anti-Cancer Council of Victoria, Social Service Policy Unit
Anti-Cancer Council of Victoria, Victorian Cooperative Oncology Group, Breast Study Committee
Anti-Cancer Foundation of the Universities of South Australia
Austin Hospital, Breast Clinic
Australian Association of Surgeons
Australian Cancer Network
Australian Cancer Society
Australian Institute of Health and Welfare
Australian Institute of Radiography
Australian - New Zealand Breast Cancer Trials Group
Australian Nursing Federation
Australian Red Cross, Tasmanian Division
Awabakal Medical and Dental Service
Breast Cancer Support Service Tasmania
BreastScreen, Victorian Breast Screening Coordination Unit Inc.
Brisbane Cancer Self-Help Group
Bunbury Regional Hospital, Division of Obstetrics,

Surgery and Anaesthesia
Cancer Foundation of Western Australia Inc.,
Breast Cancer Support Service
Cancer Support Association Inc.
Cancer Support Group of Victoria
Catholic Nurses Guild of Australia, Tasmanian Branch
Centre for the Management of the Menopause
Commonwealth Department of Human Services and Health,
Health Advancement Division
Dale Street Women's Health Centre
Diet Hormones Ageing Advisory Centre
Dubbo Base Hospital, Palliative Care Services
Dubbo/Plains Division of General Practice Ltd.
Endeavour Forum
Ethnic Communities Council of Queensland Ltd.
Flinders Surgical Oncology Clinic
Health Department of Western Australia, Radiological Council
Inner South Community Health Service
Jumbunna Neighbourhood Centre Inc.
Keith Community Health and Welfare Centre
King Edward Memorial Hospital for Women,
Centre for Women's Health
Ludwig Institute for Cancer Research
Ludwig Institute Oncology Unit
Mater Misericordiae Adult Hospital
Medical Oncology Group of Australia Inc.
Mount Hospital Medical Centre
National Council of Women of Victoria Inc.
Natural Therapy Centre
New South Wales Nurses' Association
North Coast Breast Screening Program Inc.
Northern Territory Government, Chief Minister
Northern Territory Anti-Cancer Foundation Inc.
NSW Cancer Council
NSW Department of Health
NSW Department of Health, Public Health Unit Dubbo
Oncology/Cell Biology Institute
Osborne Division of General Practice Ltd.
Parkes/Forbes Breast Cancer Support Group
Perth Breast Clinic
Peter MacCallum Cancer Institute
Public Health Association of Australia Inc.

Queensland Cancer Fund, Medical and Scientific Advisory Committee
Queensland Radium Institute
Royal Adelaide Hospital
Royal Adelaide Hospital, Department of Radiation Oncology
Royal Adelaide Hospital, Department of Surgery
Royal Australasian College of Surgeons,
 Divisional Group of Rural Surgeons
Royal Australasian College of Surgeons, Section of Breast Surgery
Royal Brisbane Hospital, Division of Oncology
Royal College of Nursing, Australia
Royal District Nursing Service
Royal Hospital for Women
Royal Perth Hospital
Royal Prince Alfred Hospital, Department Breast and Surgical Oncology
Silver Chain Nursing Association
South Australian Breast Cancer Study Group
South Australian Breast X-Ray Service
South Australian Health Commission
St. John of God Hospital, Division of Obstetrics,
 Surgery and Anaesthesia
Tasmanian Premier
The Alfred Group of Hospitals, Department of Radiation Oncology
The Australian Society for Medical Research
The Bunbury Breast Clinic
The Cabinet Office of New South Wales
The Cancer Foundation of Western Australia
The East Metropolitan Region Health Service, WA
The Gawler Foundation Inc.
The Lymphoedema Association of Western Australia
The National Council of Women of Launceston
The Prince of Wales Hospital, Hereditary Cancer Clinic
The Royal College of Pathologists of Australasia
The Royal Australian College of General Practitioners
The Royal Australasian College of Radiologists
The South Australian Country Women's Association
The University of Canberra, Nursing Science
The University of Queensland, Department of Surgery
The University of Sydney, Department of Cancer Medicine
The University of Sydney, Department of Surgery,
 Working Party on the Treatment of Diagnosed Breast Cancer
The University of Western Australia,
 Department of Obstetrics and Gynaecology

The University of Western Australia,
 Department of Psychiatry and Behavioural Science
The University of Western Australia, Department of Surgery
The University of Western Australia, Department of Surgery,
 Multidisciplinary Breast Group
The Wesley Hospital, Breast Clinic
Townsville & Suburban Medical Practice
University of Technology Sydney
Victorian Minister for Health

APPENDIX 2

LIST OF EXHIBITS

Individuals

Ms S Anderssen, Lane Cove, NSW
Mr D Benjamin, Crows Nest, NSW
Ms E Burrell, Forrestfield, WA
Ms H de Koning, Green Point, NSW
Ms L Holford, Nambour, QLD
Ms R Lewandowski, Mount Pleasant, NSW
Ms T Matthews, Bundanoon, NSW
Ms M Menon, Malvern, VIC
Ms M O'Keefe, North Carlton, VIC
Ms C Riddle, Doncaster, VIC
Ms S St.Ledger Maitland, Rushcutters Bay, NSW
Mr H Towers, Torrensville, SA
Ms S Tucker, Geelong, VIC
Mrs P Turner, Carey Bay, NSW
Mrs L Wood, Mermaid Beach, QLD

Organisations

Anti-Cancer Council of Victoria, Social Service Policy Unit
Anti-Cancer Council of Victoria, Victorian Cooperative Oncology Group, Breast Study Committee
Australian - New Zealand Breast Cancer Trials Group
Australian Association of Surgeons
Australian Cancer Network
Australian Medical Association
Australian Nursing Federation
BreastScreen, Victorian Breast Screening Coordination Unit Inc.
Brisbane Cancer Self-Help Group
Commonwealth Department of Human Services and Health
Diet Hormones Ageing Advisory Centre
Dubbo Base Hospital
Dubbo Base Hospital, Oncology Clinic
Endeavour Forum

Health Department of Western Australia, Radiological Council
Mater Misericordiae Adult Hospital
North Coast Breast Screening Program Inc.
NSW Cancer Council
NSW Department of Health
Perth Breast Clinic
Queensland Radium Institute
Royal Adelaide Hospital
Royal District Nursing Service
Royal Hospital For Women
Silver Chain Nursing Association
South Australian Health Commission
The Alfred Group of Hospitals, Department of Radiation Oncology
The Cancer Foundation of Western Australia
The Gawler Foundation Inc.
The Prince Of Wales Hospital, Hereditary Cancer Clinic
The Royal Australasian College of Radiologists
The South Australian Country Women's Association
The University of Queensland, Department of Surgery
The University of Sydney, Department of Cancer Medicine
The University of Western Australia, Department of Surgery
University of Technology Sydney
Victorian Minister for Health

APPENDIX 3

DETAILS OF PUBLIC HEARINGS AND WITNESSES

DARWIN - 12 APRIL 1994

Individuals
- Mrs Susan Tulley

Northern Territory Anti-Cancer Foundation
- Ms Susan Hearn, Support Services Coordinator

Northern Territory Department of Health and Community Services
- Mr Phillip Carson, Specialist Surgeon

BRISBANE - 13 APRIL 1994

Individuals
- Dr Ruth Cilento
- Miss Anne Fletcher
- Mrs Catherine Sheil

Brisbane Cancer Self-Help Group
- Mr Raymond Perich, Coordinator

Mater Public Hospital
- Dr Christopher Pyke, Senior Lecturer, Department of Surgery

Palliative Care Association Queensland
- Dr Bruce Stafford, Chairman

Princess Alexandra Hospital
- Dr Neil Wetzig, Surgeon, Breast and Endocrine Surgical Unit

Queensland Cancer Fund
- Professor John McCaffrey, Chairman,
  Medical Advisory Committee

Queensland Radium Institute
- Dr Roger Allison, Director, Division of Oncology, Royal Brisbane Hospital

Royal Australasian College of Surgeons
- Dr Colin Furnival, Chairman, Section of Breast Surgery

The Wesley Breast Clinic
- Dr Cherrell Hirst, Medical Director

SYDNEY - 14 APRIL 1994

Australian Association of Surgeons
- Dr Donald Sheldon, Immediate Past President

Australian Cancer Network
- Professor Thomas Reeve, Executive

Australian Cancer Society
- Professor Allan Langlands, Chairman, National Breast Cancer Study Committee

Hereditary Cancer Clinic, Eastern Sydney Area Health Service
- Dr Katherine Tucker, Clinical Geneticist

North Coast Breast Screening Program Inc.
- Ms Mollie Strong, Department of Health Contracting Nominee
- Mrs Elizabeth Trevan, Director

Royal Australasian College of Radiologists
- Professor John Kearsley, Member
- Dr Graeme Morgan, Secretary, Radiation Oncology Standing Committee

Royal Australian College of General Practitioners
- Dr Michael Bollen, Secretary General
- Ms Elizabeth McMaugh, Policy Officer

SYDNEY- 15 APRIL 1994

Individuals
- Dr Kathryn Alle
- Councillor Susan Dethridge
- Professor Martin Tattersall

New South Wales Cancer Council
- Mrs Elaine Henry, Executive Director

New South Wales Department of Health
- Dr Glenn Richard, Acting Director,
  Health System Planning and Performance Branch
- Dr Gregory Stewart, Acting Deputy Chief Health Officer

Rachel Forster Hospital
- Dr Stuart Renwick, Head, Breast and Surgical Oncology Unit

Royal Hospital For Women
- Dr Christine Bennett, General Manager
- Dr Paul Garvey, Senior Staff Specialist
- Dr Stan Goldstein, Director of Medical Services

Royal Prince Alfred Hospital
- Dr Stuart Renwick, Head, Breast and Surgical Oncology Unit

ADELAIDE - 27 APRIL 1994

Individuals
- Ms Alison Bridges

Anti-Cancer Foundation of South Australia
- Mrs Kathleen Tobin, Coordinator, Breast Cancer Support Service
- Dr Fedora Trinker, Executive Director

Flinders Medical Centre
- Dr Stephen Birrell, Director, Flinders Surgical Oncology Unit

Royal Adelaide Hospital

- Professor Peter Gill, Director, Breast and Surgical Oncology Clinic
- Mr Murray Schirmer, Chief Radiation Therapist, Radiation Oncology Department

South Australian Breast Cancer Study Group

- Dr Clive Hoffman, Surgical Specialist and Coordinator
- Dr Jill Robinson, Secretary

South Australian Breast X-Ray Service

- Dr Clive Hoffman, Surgical Specialist and Coordinator
- Dr Jill Robinson, Clinical Head

South Australian Health Commission

- Dr David Roder, Director of Epidemiology

Women's Health Centres of South Australia

- Ms Bernadette Roberts, Clinical Nurse Consultant
- Dr Lesley Shorne, Medical Officer

CANBERRA - 9 MAY 1994

Australian Medical Association

- Dr Brendan Nelson, Federal President

CANBERRA - 11 MAY 1994

Australian Institute of Health and Welfare

- Dr Bruce Armstrong, Director

Department of Human Services and Health

- Dr Margaret Dean, Medical Services Adviser, Health Advancement Division
- Mrs Joan Lipscombe, Assistant Secretary, Workforce Policy Branch, Policy Development Division
- Dr Vivienne McLoughlin, Assistant Secretary, General Practice Branch
- Ms Frances Parker, Director, Breast Cancer Screening Section
- Dr John Primrose, Medical Adviser, Health Care Access Division
- Ms Mary Scott, Principal Adviser, Health Advancement Division, Public and Environmental Health

MELBOURNE - 26 MAY 1994

Individuals
- Mrs Marguerite Menon
- Ms Marcia O'Keefe

Anti-Cancer Council of Victoria
- Ms Susanne Baxandall, Director, Social Service Policy Unit
- Mr John Collins, Chairman, Breast Study Committee

Austin Hospital
- Mr Peter Hart, Surgeon to Breast Clinic

Centre for Ethnic Health
- Ms Mirta Gonzalez, Director

Ethnic Communities Council of Victoria
- Miss Yolanda D'Agostino, Convenor of Task Group on Cancer in the Ethnic Community

Inner South Community Health Service
- Ms Francis James, Community Health Nurse
- Ms Ann O'Connor, Community Health Nurse
- Ms Ruth Scharley, Community Health Nurse

Ludwig Institute for Cancer Research
- Dr Russell Basser, Clinical Research Fellow, Royal Melbourne Hospital
- Dr Jonathan Cebon, Head, Clinical Program, Melbourne Tumour Biology Branch
- Dr Darryl Maher, Deputy Group Head, Clinical Research Program

Victorian Breast Screening Coordination Unit Inc.
- Ms Teresa Capetola, NESB Information Officer

Royal District Nursing Service
- Ms Beverly Armstrong, Director of Nursing and Deputy Chief Executive Officer
- Miss Joanne Krakouer, Clinical Coordinator
- Ms Carolyn Steele, Breast Cancer Support Nurse and Health Aide Coordinator

Royal Women's Hospital

- Ms Jill Storey, Clinical Nurse Consultant in Breast Education and Cancer Support, Breast Cancer Support Service Nurses

William Buckland Radiotherapy Centre

- Professor Alan Rodger, Director and Professor of Radiation Oncology

Women in Industry and Community Health

- Ms Terri Smith, Organisational Advocate

CANBERRA - 30 MAY 1994

Australian-New Zealand Breast Cancer Trials Group

- Professor John Forbes, National Group Coordinator

Royal Australasian College of Surgeons

- Mr Anthony Green, Secretary, Divisional Group of Rural Surgery

CANBERRA - 6 JUNE 1994

Australian Institute of Health and Welfare

- Mr Paul Jelfs, Research Fellow, National Cancer Statistics Clearing House

Department of Human Services and Health

- Dr Tony Adams, Chief Medical Adviser
- Dr Margaret Dean, Medical Adviser, Health Advancement Division
- Dr Vivienne McLoughlin, Assistant Secretary, General Practice Branch
- Ms Frances Parker, Director, Breast Cancer Screening Section
- Dr John Primrose, Medical Adviser, Health Care Access Division
- Ms Mary Scott, Principal Adviser, Public and Environmental Health

Peter MacCallum Cancer Institute

- Dr James Bishop, Director, Division of Haematology and Medical Oncology
- Dr Roslyn Drummond, Deputy Director, Radiation Oncology and Deputy Head Breast Unit
- Dr Michael Henderson, Consultant Surgeon, Breast Unit

DUBBO - 21 JUNE 1994

Individuals

- Mrs Mary Brown
- Mrs Heather Engel
- Dr Robert North
- Mrs Jessie Purseglove

Australian-New Zealand Breast Cancer Trials Group

- Professor Alan Coates, Vice-Chairman

Dubbo Base Hospital

- Dr Warwick Adams, Chairman, Palliative Care Committee
- Ms Pamela Christopherson, Clinical Nurse Specialist, Oncology Unit
- Professor Alan Coates, Oncology Clinic
- Mrs Mary Mathews, Chaplain
- Dr Peter Stein, Visiting Radiologist

Dubbo Plains Division of General Practice Ltd

- Dr Margaret Weyand, Member

Western New South Wales Public Health Unit

- Ms Gwenyth Cosier, Women's Health Adviser

PERTH - 24 JUNE 1994

Individuals

- Dr Elizabeth Nottage
- Ms Miriam Stein

Cancer Foundation of Western Australia Inc.

- Mrs Carol Bishop, Coordinator, Breast Cancer Support Service
- Dr Michael Byrne, Chairman, Research and Scientific Advisory Committee

Fremantle Hospital

- Dr Ann Harvey, Radiology Consultant
- Professor Michael Stacey, Associate Professor of Surgery, Multidisciplinary Breast Group

Mount Medical Centre

- Mr Harry Sheiner, Consultant Surgeon

Osborne Division of General Practice, Osborne Park Hospital
- Dr Mary Surveyor, Medical Director

Perth Breast Clinic
- Dr Erica Luke, Coordinator and Breast Physician

Queen Elizabeth II Medical Centre
- Professor David Ingram, Surgeon

Royal Perth Hospital
- Dr Christopher Harper, Chairman, Multidisciplinary Breast Service, East Metropolitan Health Service

Silver Chain Nursing Association
- Mrs Marie Watts, Manager, Hospice Care Service

University of Western Australia, Department of Pathology
- Dr Hugh Dawkins, Senior Scientific Officer
- Dr Jennet Harvey, Head
- Dr Peter Robbins, Pathologist

APPENDIX 4

SELECTED PATIENTS' STORIES

Breast Cancer Inquiry
Submission No 32

17 Ambrose St.,
Carey Bay N.S.W. 2283
17-2-94

RECEIVED
23 FEB 1994

Cheryl Samuels
Inquiry Secretary
House of Representatives
Standing Committee on Community Affairs

Dear Ms Samuels.

I would like contribute to the Inquiry on breast cancer treatment. My point of view is based on my experience of my mother's treatment at The Mater Hospital in Newcastle (1990-the present). I would like to comment on the following-
(a) Counselling/Support.(b) Massage training.(c) Tamoxifen trial.

My mother was first diagnosed in Sydney and the recommended treatment was a radical masectomy. The method of telling her was abrupt and gave her no other option. There was no support offered to help her to deal with this shock. She was not given any opportunity to talk so that she could get herself together and drive home. She lives on her own and the only course of action that she seriously considered was suicide. I believe that this decision was very much an outcome of the unsupportive approach that she received from the hospital. It seems to me that at the time of diagnosis of breast cancer it is vital to have trained people who can help the woman begin to deal with the shock and thus not make hasty irrational decisions. Luckily, instead of committing suicide she phoned me and I was able to arrange for her to come to Newcastle and to see Professor Forbes in the Mammography section at the Mater Hospital. It seems obvious that any woman would benefit from having a consistent support person that can help them through this trying time. I would like to see this encouraged by the treating clinicans/nurses.

When we saw Professor Forbes my mother was given adequate time to discuss the options ie.partial or radical masectomy as well as being informed as to what each option may mean in regards to ongoing treatment and prognosis. Having the information and being involved in the decision making was very reassuring to her and to the rest of the family. This process gave her realistic hope, put the cancer into perspective and eased the overwhelming dread of the disease.

My mother was very fortunate in being selected in a "trial" which entitled her to the services of the Unit counsellor. This person saw my mother before each step in the treatment process and checked my mother's understanding of that next step. My mother was able to ask questions.voice any concerns and generally prepare herself. The counsellor did not overload my mother with information but fed it to her gradually and as required. This process enabled my mother. (who is of non English speaking background) to absorb the information. The information was both verbal and written. The counsellor had an information kit available out of which she gave the pertinent information. The finer details of treatment/care etc were left to the counsellor to explain. The fact that my mother had developed a close relationship with the counsellor meant that the finer details were better understood eg. massage and care of the arm once the patient is home. The counsellor conducted follow up phone calls and home visits which gave my mother a chance to ask questions and express concerns.

The services of the counsellor were also available to the rest of the family. As I was the person most involved I too benefited from the empathy and information provided by this counsellor. My mother was very lucky to be one of the chosen patients. Being in hospital away fom her own home meant that she did not receive as many visitors as she may have, so the counsellor was a friendly face during a very frightening and painful time for us all.

Since my mother's time at the Mater there is a full time counsellor who is available to all patients. I can not believe that one person can provide the same level of service that my mother received. It is vital that the "trial" that my mother was involved with is made the "standard". There must be a recognition of the benefits of such support. Any downgrading of the psychological support network is to be regretted.

To control the oedema patients are urged to take care or their arm in various ways eg wearing an elastic sleeve/massage. The following suggestion would apply to all who have had lymph nodes removed. The Mater hospital had a designated physiotherapist who had trained in the special massage used to alleviate the oedema. This massage even though important, is simple to perform and could therefore be taught to lay people. I would like to see courses run so that family members could learn this massage and thus take the load off the Physiotherapy Departments in hospitals. This massage needs also to be part of the general physiotherapy course. It seems that this is not the case.

Tamoxifen has been presented to us as a possible breast cancer preventative and is at this time being trialled world wide. If this trial proves to be successful I would like to see this drug made avaliable to daughters and sisters of women who have contracted breast cancer in the past.

Thank you for this opportunity to comment

I remain Yours Sincerely Era Wellsmore

Era Wellsmore

Breast Cancer Inquiry
Submission No 86

Dr. Ruth McKenzie
Provider No. 326212J

350 LYONS ROAD
FIVE DOCK, N.S.W. 2046
Phone: 713 9754
After Hours: 798 3760

409 Great North Rd
Abbotsford
2046.

HOURS: 9 am - 11 am
Monday to Saturday
4 pm - 6 pm
Monday to Friday

RECEIVED
01 MAR 1994
House of Representatives
Community Affairs
Committee

28 Feb 1994

The Chairman
Standing Committee on Community Affairs
Parliament House
Canberra.

Dear Sir,

re "Speak out on breast cancer"

I read with interest the article in Australian Doctor magazine inviting submissions on improvements in the management of breast cancer. I consider I am in a unique position to offer suggestions, given that I am a general practitioner and have had treatment for breast cancer. I graduated with honours in 1976 and have 14 years full-time experience in solo and group practice.

In December 1992 I had a wide excision of a malignant breast lump and an axillary dissection followed by radiotherapy and 6-months of chemotherapy.

My suggestions to improve management are listed:

(i) Arrangements for admission and surgery seem to be made in the same consultation as the diagnosis is imparted. This is inappropriate because the patient is in a state of shock and unable to make any rational choices (e.g. between mastectomy and lumpectomy, clearly an important decision). This decision should be made at a second consultation, possibly best arranged after the initial consultation with a medical oncologist. The latter specialist is usually in the best position to give unbiased expert opinion about the various treatment options.

(ii) Before my "illness" I would have thought that support groups were simply interfering do-gooders with no significant medical role. I now, belatedly, understand the crucial role that such groups could provide if properly trained and resourced. The existing Cancer Council service made up largely of well-meaning volunteers is inadequate. I found the best support came from the Liason Psychiatry unit but this probably reflected a local specific interest rather than any formal policy development. The support groups should be associated with or run by Oncology departments because they have access to patients who have undergone similar treatments and who, frequently, live in the same area. However, to be maximally efffective the groups would need professionally trained leaders. There is controlled trial evidence that intensive support improves long-term survival significantly in patients with advanced,

RUTH McKENZIE PTY LTD
A.C.N. 003 224 673

metastatic, breast cancer but these data reqire confirmation.

(iii) Follow-up of breast cancer patients seems to be *ad hoc* with little or no scientific rationale for the intervals or tests ordered. In my case I had a surgeon, a radiotherapist and an oncologist all of whom wanted to review my case at 3-monthly intervals. From my understanding of the literature there is scant evidence *that this sort of surveillance will result in early* detection of metastases or that early detection would alter prognosis. The early detection of local recurrence is said to be beneficial, mainly for palliative reasons, but I believe the patient and/or the GP would be the best to perform this, in conjunction with annual mammography/ultrasound. I have no doubt that any patient could be taught how to perform self-examination specifically to detect local recurrence.

I do not believe that setting up numerous "Breast Cancer Centres" is the ideal approach, unless these are to be attached to existing oncology units. A better and more cost effective strategy would be the development of a "shared-care" program between tertiary centres and referring GPs. In this way it could be ensured that patients are referred to appropriate specialists. My own experience in a highly-regarded radiotherapy clinic was very distressing although I knew the standard of care was high. It was demeaning and depersonalising, with patients handed a coloured card on arrival to indicate the site of the cancer, patients weighed in full view of the waiting room and a serious lack of regard for privacy. After I undressed for a follow-up consultation with my specialist (to whom I had been referred as a private patient) a registrar entered, whom I had never seen before and who did not introduce *himself. The specialist was not at the* clinic even though I had rung to confirm that he would be, and none of the staff had mentioned his absence. I will not return to that "clinic".

I believe I am in a position to "speak out on breast cancer" with authority and passion. I feel strongly that not enough has been said or done and have taken action already to remedy this deficiency. I am now lecturing to Year 5 medical students at the University of NSW on the experience of cancer from the patient's perspective including how to break bad news. I have also been interviewed by ABC Radio National for the "Coming Out" show which is preparing a series on breast cancer to go to air shortly.

I would be pleased to act as a consultant to your committee or to help in any other way.

Yours faithfully,

Ruth McKenzie

Breast Cancer Inquiry
Submission No 93

HOGBIN ERCOLE & ASSOCIATES PTY LTD ACN 003 322 076
Economics and Human Resources Advisory Services

RECEIVED
04 MAR 1994
House of Representatives
Community Affairs Committee

3rd March, 1994

Cheryl Samuels
Sub-committee Secretary
House of Representatives Standing Committee on Community Affairs
PARLIAMENT HOUSE
CANBERRA ACT 2600

Dear Ms Samuels,

Inquiry Into the Managment and Treatment of Breast Cancer in Australia

Enclosed is a submission to the above Inquiry. If you have queries please contact me.

Yours sincerely,

Geoff Hogbin

Geoff Hogbin

UNIT 70, 2 CROWS NEST ROAD
WAVERTON NSW 2060
AUSTRALIA

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A SUBMISSION
TO
HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON COMMUNITY AFFAIRS

INQUIRY INTO THE MANAGEMENT AND TREATMENT OF BREAST CANCER IN AUSTRALIA

Introduction

This submission gives a consumer perspective on the services available from hospitals for the palliative care of women suffering from terminal breast cancer. It pertains to the Sydney area and is informed by the experiences of my wife, who died recently from breast cancer, and by her mother's and my experiences in seeking to provide suitable care for her.

There is no sign of a major advance in the state of the art in the medical treatment of breast cancer. Accordingly, for the foreseeable future the scope for government initiatives to lengthen the lives of women afflicted by breast cancer appears to be limited.

However, our experiences indicate that the welfare of women with terminal breast cancer (and others requiring palliative care) could be improved during the often lengthy period of intense pain and anguish prior to death by provision of buildings designed to satisfy better their preferences, principally by providing more single-bed rooms to give them more privacy.

Hospital Configuration and Stress

The consequences of the shortage of single-bed rooms and other design deficiencies in hospital buildings currently used for palliative care may be illustrated by our experiences.

My wife's disease had progressed to the stage where a specialist palliative care physician judged that she could no longer be cared for adequately at home and arranged for her to be admitted to the Palliative Care Unit of Greenwich Hospital. I wish to emphasise that criticisms of the services provided at Greenwich Hospital outlined below relate purely to physical facilities and not in any way to the staff, who provided outstandingly good care and to whom I am intensely grateful.

The period of about two weeks leading to the decision to move my wife to hospital had been stressful. We were reluctant to break up the home. We had experienced difficulties in dealing with the pain my wife was experiencing and with the side-effects of pain control. In particular, she had had little sleep for several days and was also suffering from nausea and a general feeling of malaise. We were hoping very much that when she entered hospital the pain and side-effects of pain control could be properly controlled so that she would be able to rest peacefully.

It was therefore most distressing for the three of us to find that her neighbour in the four-bed ward to which she was assigned initially was an extremely talkative woman who had a series of visitors. The atmosphere was anything but restful.

After some intense negotiations we arranged for my wife to be moved the next day to one of the three single-bed rooms in the Palliative Care Unit at Greenwich, on the condition that, in the event that the hospital was requested to admit a male patient, she would agree to move back to one of the two four-bed wards available for women.

Two aspects of this were unsatisfactory from our perspective. First, uncertainty about when we might be required to vacate the single-bed room added to the stress we were already under. Second, the negotiations required to gain admission to the single-bed room were also stressful, even though the hospital staff were very understanding and did their best to help us.

The single-bed room was satisfactory except that it was small – to the point where it was somewhat difficult to provide adequate support in moving my wife from the bed to a mobile commode, a minor point but nevertheless indicative of the inadequacy of the capital stock in the health care system.

After several days we were required to vacate the single-bed room and move either into a four-bed ward or an inferior single-bed room. My wife chose the former. For several hours during the second night my wife was in this ward we could not avoid listening to the laboured breathing of a woman with a brain tumour until she eventually died. I felt great sympathy for her family who were deprived of their privacy by us and others in the ward at this time.

For the remaining time until my wife died, there was only one other woman in the four-bed ward and she, too, was dying of breast cancer. This accommodation was satisfactory. However, periodically the other woman was obliged to suffer the humiliation of losing control of her bowels while we were in the immediate vicinity.

We were fortunate to have the ward to ourselves at the time my wife died because the other women very kindly arranged to move temporarily to a lounge room.

The irritations outlined above may seem inconsequential. However, to place them in perspective consider whether similar irritants would be acceptable to a healthy person occupying a hotel room and also consider how much money terminally ill patients and their families might be willing to pay to avoid them.

When I first realised that the bed arrangements at Greenwich Hospital might not conform closely to our preferences I began to search for alternatives. However, to my knowledge there are few, if any, establishments in the Sydney area with specialist palliative care staff and with the capacity to offer normally a single-bed room on request. The best on offer appeared to be the recently constructed Hospice at St. Vincent's in Darlinghurst. Although they could not guarantee a single-bed room, the probability of getting one was much higher than at Greenwich. However, there was the offsetting disadvantage that visiting would be difficult because of traffic conditions and difficulties in finding parking space.

Hospital Accommodation and Patients' Preferences

Our experience has caused me to reflect on the characteristics of the hospital buildings that would have suited our preferences and that might be generally suitable for most families forced to deal with terminal breast cancer. My view is that a generally suitable configuration would be a ward with almost all single-bed rooms, each with easy mobile-bed access to one or more public areas to provide opportunities for developing the camaraderie that characterises multi-bed wards. The crucial characteristic is that the patient and her family should have access to privacy when others are placing stresses on them (as is inevitable for palliative care patients in multiple bed rooms) and especially also when death is imminent.

Although I have not seen it, I understand the new Hospice at the Mater Misericordiae Hospital in Newcastle is configured much as outlined above – 13 x single bed rooms; 2 x 2-bed rooms;

and 1 x 3-bed room – all with access to common areas and verandahs. This was partly funded (approximately 30 per cent) by a telethon in the Newcastle area which raised $1.4 million.

Consumer Sovereignty

What struck me forcefully about our experience with breast cancer was how little control we had in determining the physical circumstances in which my wife was to die and that when we desperately wanted privacy there was no way we could be sure of securing it. This came as a shock and stands in contrast with most other aspects of our personal lives in this society.

For example, when we are in good health we can normally obtain temporary accommodation that ensures privacy and with other characteristics that match our preferences quite closely, simply by choosing amongst a wide range of hotel rooms, motel rooms, guest house rooms and furnished flats. This, of course, requires that there be sufficient capacity to allow choice between alternatives and to avoid being forced to take the first available room regardless of the extent to which it matches our preferences.

The general principle is that people are normally able to obtain accommodation that matches their preferences quite closely, provided their willingness to pay exceeds the cost of provision.

This ability to control the characteristics of purchased accommodation by choosing from an array of alternatives when we are in good health (and therefore relatively well placed to tolerate additional stresses) contrasts starkly to our lack of control when seeking care for the terminally ill, a time when we are desperate to obtain facilities which minimise extraneous stresses and when we are extremely anxious to ensure that a person we love has the best of care for her remaining days.

Accordingly, I strongly urge the Committee of Inquiry into Breast Cancer to recommend that there should be an urgent investigation of ways of providing buildings better configured to satisfy the demands of women with terminal breast cancer. This, I believe would improve their welfare substantially.

Funding and Hospital Facilities

The following points may be helpful in considering whether funding to improve palliative care facilities for women with terminal breast cancer (and others requiring palliative care) is justifiable.

1. There are numerous dimensions or attributes of palliative care which together determine how closely it matches the preferences of a terminally ill patient. These dimensions extend beyond merely providing a comfortable bed, controlling pain and keeping the patient's body functioning – however important these basic dimensions may be. As a society we make great efforts and *use substantial quantities of resources to ensure ready availability of temporary accommodation* with characteristics that match people's diverse preferences and circumstances. For example qualities of motel rooms vary according to characteristics of toilet facilities; presence or absence of a telephone, a breakfast table, a writing table, etc.; decor; size; amount of space to hang clothes, etc.. Relatively, there appears to be much less effort and fewer resources devoted to ensuring that hospital accommodation matches the preferences of patients.

2. The guiding principle in determining whether to undertake investments in hospitals should be: "Are substantial numbers of women with breast cancer and their families likely to be *notionally* willing to pay at least enough to cover the cost of making those hospital facilities available?". This is the principle that determines whether we have access to housing, food, clothing, hotels and holiday accommodation, etc..

The appeal of this principle is that if sufficient numbers of such people are willing to pay enough to cover the full cost of provision of better hospital facilities, then the sum of the benefits they would derive from these facilities can be expected to be greater than the benefits that they would experience if they spent an equivalent amount of money on any other set of marketed goods and services. The reason is that the money cost of resources used to build hospitals measures the dollar value that people place on the other goods and services that could have been produced, were those resources to be deployed in their next best alternative uses, other than building or improving hospitals.

Thus failure to provide hospitals when aggregate willingness to pay exceeds the cost of provision is tantamount to adopting the attitude "Let them eat more cake and go on more holidays", when the people concerned would prefer to have better hospitals rather than more cake and more holidays.

3. In the absence of freely functioning markets it is virtually impossible for any person to judge whether aggregate willingness to pay exceeds aggregate cost of extending or reconfiguring a hospital. This lack of reliable information on willingness to pay makes the problem of achieving efficient use of resources in health care (i.e. assigning resources to their highest valued uses as perceived by the people in a society) also virtually impossible.

However, in attempting to judge the magnitude of aggregate willingness to pay for better palliative care facilities some points which may be helpful are as follows.

- The judgement should be based on the assumption that the people concerned would have extra spending power equivalent to a substantial part of the share of their taxes that is currently spent on health care.

- Large numbers of families in our society pay substantial sums of money for holiday travel and accommodation each year. Most of them would have the capacity and willingness to pay some multiple of their expenditure on vacations to care for a dying member of their family, a once-off event.

- Many cancer patients outlay large sums of money for "alternative" cancer remedies e.g. infusions of shark cartilage.

- Most families are willing to pay substantial sums of money annually for comparatively trivial things such as keeping their motor cars free of dents and of scratches on painted surfaces.

- Many people with terminal cancer outlay large sums to give themselves a "treat" before they die e.g. a holiday abroad.

- Many families outlay large amounts on funerals.

Each of these factors suggests that families may be willing to pay substantial amounts of money to provide comfortable circumstances for terminally ill members.

4. If it is the case that aggregate willingness to pay would cover the cost of the hospital buildings configured as outlined above, it is reasonable to ask why such buildings are not in fact supplied by private hospitals? There are two broad explanations. One is that investing in such facilities is not commercially viable because of the perceived increase in risk which has been engendered by frequent changes in government health care policies. The second is that it is difficult for private suppliers to compete with government-supplied palliative care which is given away free of charge – despite the fact that the quality of the government-provided care does not match closely the preferences of users (i.e is of low quality in certain dimensions, primarily the configuration of the buildings used to produce that care).

The fact is that government provision of goods and services free of charge to consumers tends to reduce the closeness of the match between what people actually consume and what they would prefer to consume or, in other words, to reduce the value consumers derive from the resources available in society (i.e. to reduce efficiency in use of resources).

This important notion can be grasped by considering what would almost certainly happen if the government produced a car with quality attributes similar to those of a Suzuki Swift and gave it away free of charge. The proportion of Suzuki Swifts in the stock of cars would rise dramatically. Many people who manifestly (by their previous choices) would prefer to drive Commodores, Honda Civics, Toyota Corollas, etc. would under such a policy drive Swifts because the market would have been rendered dysfunctional by the Government. Importantly, given that Swifts are generally considered to be of inferior "quality" in the sense of being small and with no frills (though not technically inferior), the average quality of the stock of cars would decline – a point of major significance in provision of health care in Australia.

5. The argument that the government does not have sufficient funds to provide palliative care buildings with characteristics suited to the demands of terminally ill breast cancer patients should not be regarded as acceptable if it is judged to be the case that aggregate willingness to pay for those buildings exceeds the cost of provision. It is true that the Commonwealth Government may find it difficult to raise the extra revenue required to improve the hospital building stock but that it is distinctly different issue from the issue of whether the nation "has the necessary resources" or can "afford" better hospital buildings. If we have the resources to provide hotel and holiday accommodation in cities and resorts, then it is difficult to sustain an argument that we do not have the resources to provide comparable accommodation for the terminally ill. Note that use of hotel and holiday resort facilities is not confined to the rich.

Inability to fund hospital building programs that are justified on a cost-benefit basis is better interpreted as a manifestation of the adage that in trying to do too many things, governments do many things badly.

6. There is a danger that adoption of *ad hoc* devices such as Quality Adjusted Life Years ("QALYs") to guide the allocation of funds for health care will restrict the funding for palliative care services relative to the funding palliative care would receive under a system based on willingness to pay. Such measures tend to imply that to outlay funds for people whose life expectancy is short is "a waste".

7. Similarly the *ad hoc* objective of "holding down health care costs" (to some proportion of Gross Domestic Product ("GDP")) is likely to conflict with the objective of assigning resources

to their highest valued uses. Of course we should attempt to minimise the cost of producing whatever quantities of goods and services we decide collectively (either through political or market processes) to produce, but to decide *how much* health care to produce and *what qualities* to produce on the basis of holding costs to some proportion of GDP is simply not compatible with efficient use of resources. The poor state of many of our hospital buildings (compare the average ages and states of the nation's stocks of hospital and hotel rooms) is a manifestation of resource allocation decisions based on such ill-founded notions. (Imagine what our restaurant industry would be like if the Commonwealth Government attempted to restrict aggregate expenditure on restaurant meals to some arbitrary percentage of GDP!)

Conclusion

In my view the benefits (as measured by willingness to pay) from providing more suitable hospital facilities for women with terminal breast cancer can be expected to justify the cost of resources required to provide those facilities. If this view is correct the Commonwealth and State Governments should either make funds available to establish better facilities or else create an environment in which private institutions attempting to provide such facilities are not handicapped by the existing health care market distortions.

Geoff Hogbin
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WAVERTON NSW 2060
Tel: (02) 955 7121

3rd March, 1994.

TRANSCRIBED FROM HAND WRITTEN LETTER

Breast Cancer Inquiry
Submission No 99

1 Carroll Place
KARRATHA WA 6714
5 March 1994

Mrs Cheryl Samuels
Sub-Committee Secretary
House of Representatives Standing
Committee on Comunity [sic] Affairs
Parliment [sic] House
CANBERRA ACT 2600

Dear Cheryl.

Further to our recent communications with regard to the Inquiry into the Management and [T]reatment of Breast Cancer in Australia, I would like to touch on a few points of interest which were highlighted during my Mothers illness and eventual death from Breast Cancer.

All indications given to the family were that Mum's case was unusual. Initially diagnosed at aged 41, a lumpectomy was performed followed by a short course of Radiotherapy. At the time, 10 years ago, Radiotherapy was relatively new to W.A. and was the only alternative given to Mum over a complete masectomy [sic]. Unfortunately, much of this period is sketchy to me as I was a teenager and not involved in the medical side of things.

At age 50 another cancerous lump was found in the same breast. Mum was devestated [sic] due to being told that the only option was to have the breast removed and it was recommended that she also have Chemotherapy, which she did for six months.

At no stage was her G.P. involved, even during the Chemotherapy for which she travelled some 1300km from her home in Exmouth, to Perth every four weeks.

A mere six weeks after finishing her Chemotherapy, Mum found a lump in her remaining Breast. Her G.P. initially told her it was highly unlikely to be cancerous and advised her to simply "monitor" the lump. Mum bent under family pressure and booked herself in to the specialist in Perth within a further 4 weeks and once again the news was bad.

A full masectomy [sic] was performed without question or delay and the lymph nodes were also removed. Mum was advised that Chemotherapy had obviously not worked in the last instance, therefore it was pointless to repeat the treatment and anyway, they were confident they would stop the spread of the disease by removing the lymph nodes.

Throughout the next eleven months, Mum was required to visit the specialists once every three months in Perth for a check-up. This was funded through the P.A.T. Scheme which freed Mum from driving the 1300km it took to access the treatment & management facilities. This scheme, however, did not cover accomodation [sic] expenses or allow for an escort to accompany Mum, which was crucial towards the end. Bearing in mind that this lady was so far from home and playing a game of life and death, I found myself travelling from my home, some 1600km from Perth to be with Mum and support her on these visits.

On the first visit after the second masectomy [sic], we visited the Cancer Foundation to seek financial assistance for Mums Prosthesies [sic]. The Cancer Foundation was the only specialist Cancer Centre with which we had contact. After the first masectomy [sic], the Foundation sent a support worker to council [sic] Mum on the operation and the upcoming Chemo[therapy]. Unfortunately, once Mum returned to Exmouth, all counselling and support was via the telephone as we did not know of any Breast Cancer support volunteers close enough in location to visit her.

When I visited Mum during the eleventh month after her second masectomy [sic], I found her extremely run down and having severe difficulty breathing. Mum was due for her next visit in three weeks (to Perth) but I convinced her to go the following week. During my stay, Mum started coughing up blood. I took her to the local hospital where she was put on oxygen and given a Chest X-Ray. Although the X-Ray showed no collapse of the lungs, there was a shady grey area of concern. Mum was flown to Perth two days later and diagnosed with secondary cancer of the lungs, liver and hip bone. The specialists bluntly told us there was no point doing further tests to see where the cancer was as it had already hit vital organs.

We were told that mum would immediately commence Chemo[therapy], but that the treatment (Drugs) would be different to that she had undergone the previous year. The therapy was every third week to which she travelled from Exmouth each time. Due to her weak viens [sic], a "PORT" was inserted into her upper chest to enable blood to be taken and intravenous drugs could be administered.

Back home, Mum's GP appeared to have a very limited knowledge of the exact nature of the treatment and the extent of the Cancer. He was often on the telephone trying to make contact with Mum's specialists in order to answer our questions and assist Mum with the side effects of the Chemo[therapy].

This was a terrible period for the family. As the[re] is no Local Government or Community Services support for Cancer Patients in Exmouth, another family member and myself split the nursing into 10 day shifts when Mum was home. For me, this meant taking leave without pay and driving an 1100km round trip alone in order to be with her.

We made enquiries through Mum's GP regarding Silver Chain etc, but were advised that the only service available was "Meals on Wheels". The Community Nurse made one visit to discuss Meals on Wheels, but advised if we required home nursing, we would have to employ a casual nurse and fund it ourselves. This lady promised to look in on Mum, but we never saw her again as she was "busy" doing all the other things her hectic job required of her.

We never ended up using Meals on Wheels as Mum was too sick to eat more than jelly or ice-cream and during the times when a family member was not available, Mum was put into the local Hospital. For a short time, we trialled our own "support network" of neighbours and friends calling in all day, but Mum was too scared to stay alone at night and not enough people could commit to being there. I neglected to tell you that by this stage, we had arranged to loan a portable oxygen bottle and mask from the local hospital and due to the fact that the tumors were weakening Mum's lungs, she was on and off the oxygen constantly. It was this that made Mum too scared to be left alone, that she would be unable to breath in the middle of the night and no one would be their [sic] to assist her.

Although the hospital and Mum's GP were great with "comfort care" and counselling, we found ourselves organising all of Mum's care ourselves. The diagnosis was made in September, and in early December the specialists decided there was nothing more they could do and that Chemo[therapy] was to be discontinued. It was at this stage that Mum was on permenant [sic] oxygen (even to go to the toilet) and virtually bed-ridden.

We were given two alternatives, to put Mum in a Hospice or to risk flying her to Exmouth on the RFDS to remain in the Hospital there. It was here when the Hospital provided Comfort care and counselling, allowing one family member to remain with her 24 hours a day. One specialist advised that we would be lucky to have Mum for a month, another said it could drag on for two or three months. The entire family put their lives on hold (Mum has been seperated [sic] from my Step-Father for some 7 years, so it was us three children left to bear the load). Mum died 10 days after arriving in Exmouth and we buried her this New Years Day.

I am sorry that my story has so many holes. As you can appreciate, it is still difficult to go through it all again, particularly as my Mother was my Best Friend. However, Mum deteriorated so quickly from diagnosis to death that even 3 days before she died, her G.P and all the nurses still believed she may have held on for weeks. Things happen so fast it is often hard to remember when or what!

I would be happy to answer any questions you may have, or to fill in any "holes" but more than anything, I really want the decision makers of our day to feel the pain not just of the victims of Breast Cancer, but of their families too.

To live as I did for so many months with my own career and family on hold, with a suitcase always packed and ready at the door to make the 1100km drive, but most of all, to see some-one you love so much suffering in a way we wouldn't even allow a pet to suffer in, I have to wonder if anyone still has a heart.

It is criminal to see the pitiful $ value given to research of a fatal "WOMENS" disease and the Treatment and Management of these victims, particularly in remote areas is a National Disgrace. I intend to do all I can to establish a support and action group in my locality with the assistance of the Cancer Foundation.

If one good thing can possibly come out of my mother's death, I am sure she would like it to be that I can feel safe and secure knowing that the

Government of the day is doing all it can to prevent me and my family going through the same pain and heartache that she endured.

I wish you every sucess [sic].

Yours sincerely

Signed
Miss Danielle Kelly

Breast Cancer Inquiry
Submission No 109
Exhibit No 21 Refers

RECEIVED
18 MAR 1994
House of Representatives
Community Affairs
Committee

169 Fenwick Street,
North Carlton 3054
Ph. 03 347 4362
Fax 03 662 2581
15th March 1994

Cheryl Samuels,
Sub-committee Secretary,
House of Representatives Standing Committee on Community Affairs,
Parliment House,
CANBERRA ACT 2600

Dear Ms. Samuels,

Please find attached a submission to the inquiry into the management and treatment of breast cancer in Australia. I have also enclosed a copy of my submission to the recent inquiry by the Senate Standing Committee on Community Affairs, on breast cancer screening and treatment in Australia. I was advised by this Committee that this latter submission would be forwarded to you from them, but I thought it best to present both submissions together here.

I would welcome the opportunity to expand on any of the issues I have raised in either submission in person to the Committee, or to answer any questions the Committee members might have. I feel it is crucial that this inquiry explores breast cancer treatment from the point of view of women themselves, as I strongly believe that women's perspectives are very different from the medical profession's perspectives, and these perspectives are most often overlooked.

Yours sincerely,

Marcia O'Keefe

Inquiry Into The Management And Treatment Of Breast Cancer In Australia

Submission To House Of Representatives Standing Committee On Community Affairs

Marcia O'Keefe B.E.(Elec), M. Eng. Sci.
Consumers' Health Forum nominee on the NHMRC Working Party on the management and treatment of diagnosed breast cancer
Consumers' Health Forum nominee on the NHMRC Working Party on the long term effects on women from assisted conception
Member of the Board of BreastScreen in Victoria
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Executive Summary

Currently, much work is being done in Australia towards exploring ways that breast cancer treatment car be improved. This is an opportunity for us to co-ordinate these efforts, and develop a national strategy to ensure that women diagnosed with breast cancer not only achieve better survival rates, but also experience less unnecessary suffering as a result of their disease.

As well as the points made in my Senate submission, I think we need to:

- ensure that GPs are adequately informed on modern breast cancer treatments, to improve both their patients' access to appropriate treatment, and the support provided by GPs
- develop written information, as a minimum, for women and their support people about treatment options for breast cancer
- listen to women to establish what they want from treatment. Carry out qualitative research for feeding into working partys, where anecdotal experience may not be not highly regarded.
- determine protocols for the management of breast cancer. These protocols should cover treatment of both early and advanced disease, with all required outcomes as goals, both clinical outcomes and those seen as important by women
- develop a national strategy for implementation of those protocols, ie. to ensure that as many treating professionals as possible use the information in the protocols
- develop a national strategy for provision of services to provide treatment as defined in the protocols, eg. establishment of specialist centres, provision of adequate radiotherapy equipment

14th March 1994

Introduction

Although I made a submission to the Senate Inquiry on Breast Cancer Screening and Treatment, and I have been advised that that submission will be forwarded to you, I would like to address specifically some of the terms of reference in the House of Reps enquiry that I did not address in the Senate submission, hence an additional submission. (I have attached the Senate Inquiry submission to ensure that it reaches you).

There is currently much attention being given to breast cancer in the medical world, with at least two Working Parties looking at the development of practice guidelines, and a consensus conference to be held in June this year. Apart from some concern that these appear to be duplicating effort to a large extent, the focus on breast cancer treatments is long overdue. As has been illustrated by the results of the survey taken in Victoria on treatment of primary operable breast cancer (Hill et al), the state of breast cancer treatment was of serious concern in 1986. Apparently it had improved somewhat when the survey was repeated in 1990, but we are still waiting to find out by how much, as the 1990 survey results have still not been published in 1994. It would seem reasonable to assume that we still have a long way to go towards providing every woman with breast cancer with optimum or even adequate treatment for her specific needs. This is borne out by the many stories I continue to hear from women.

I have referred only to women in the following submission, realising that there is also a small number of men who require treatment for breast cancer. While men's perspective may be quite different from the breast surgery point of view, most of the issues here will be common to both men and women.

Personal diagnosis and treatment experiences

My diagnosis was an unusual one, as my main symptom was severe nausea and vomiting each time I ovulated. After borderline results of a bone scan and X-rays, a bone biopsy found secondary cancer cells. Breast cancer was the first suspect, but as both breasts were abnormal following ovarian hyperstimulation during IVF treatment a few months earlier, a mammogram was inconclusive. Unfortunately I then embarked on a sequence of diagnostic procedures to find the unknown primary, including stomach endoscopy (?), colonoscopy, barium enema, CAT scan. These were also inconclusive so the surgeon returned his focus to breast cancer and did a needle biopsy, with a local anaesthetic in his rooms taking about 3 mins, and the results showed breast cancer. A later open biopsy confirmed this.

After the initial diagnosis of cancer had sunk in, and following a week of these diagnostic procedures, I was at the point where I could not function even to the extent of making myself a cup of tea.

The diagnosing physician referred me to the oncology unit at a major Melbourne public hospital for treatment. I was given no information on breast cancer prior to my first appointment. At the first appointment, I was told my disease was incurable. I was offered hormone treatment, with participation in a trial of Zoladex and Tamoxifen taken simultaneously, compared with Zoladex only. The oncologist offered the treatment then asked me what I wanted to do. I had never heard of hormone treatments, I knew nothing about breast cancer, I had no information about treatments, what else could I do but follow his recommendation. It did not cross my mind to get a second opinion.

Subsequent information provided by the hospital on breast cancer was very brief and general, and contained no information about treatments. Because I was losing weight as a result of modifying my diet to a healthy, low fat diet (the sort that all well people are encouraged to follow), I was given pamphlets instructing me to eat as much sugar, cream and butter as possible.

I was offered a course on 'Living with Cancer' at the hospital, but I found the whole scenario so awful that I declined.

I was not happy in that treatment scenario for a number of reasons:

- treatment was very impersonal. It appeared to be policy that doctors did not address patients by their first names, and each attempt to establish some sense of human identity met a brick wall. This was particularly disturbing given that I was looking at a long term relationship with these people, ie for the rest of my life, however long that was going to be.
- questions were courteously answered but no unsolicited information was provided
- the physical surroundings were extremely depressing, dark, crowded, dilapidated, shabby, everything was brown.
- if you required assistance outside office hours you had to go to Casualty, there was no telephone advice. On one occasion I spent 3 hours in Casualty only to be told eventually by a registrar to go home and take Panedeine.

To be fair, there were a number of positive points in their favour:

- although telling me that my illness was 'incurable', I was not given a time frame (eg. "You have between 6 and 12 months to live"), which for so many people is a limit to their lives more powerful than the cancer itself.
- they appeared to have a multi-disciplinary approach
- they gave me appropriate treatment, although the combination of Tamoxifen and Zoladex was not, I now believe, in my best interests. (Studies have shown that sequential hormone treatments will give longer survival time than simultaneous treatments, and I personally want the best for me, not the best for science. This is a general problem with most trials).

After 6 months of searching I found an oncologist with whom I am happy. He recommended that I stop the Tamoxifen and continue only with Zoladex, advice that I followed after thinking about it for two months. Two years from commencement of treatment I suffered a recurrence, with extensive secondaries developing in the liver, ovaries, bones, lining of the peritonuem. With a change of treatment to progesterone, I have been in remission for an additional 3 years now.

Remission time is very important to me, as my son was only just 6 years old at the time of my diagnosis. My mother died in childbirth at the age of 42, leaving 4 children from the ages of 14 to newborn. Having experienced it myself, and seeing the life-long effects on my siblings, I do not wish my son to grow up without a mother under any circumstances. This is something that is often overlooked with breast cancer. The death of a mother has devastating implications for all her family, and even their families in many cases.

To find the additional support I required, I contacted an independent support group in Victoria, then called the Melbourne Living Centre (headed by Ian Gawler). There were no programs specifically for breast cancer, but their general cancer program was extremely helpful to both myself and my husband. The program was held in a location away from medical environments, with an emphasis on the whole person, not just on the cancer. After diagnosis this is the only environment in which you can be a normal person. In the rest of the world, you are the person with death hanging over you every moment and no-one around you can comprehend what that is like. As well as being a great emotional release, a *lot of practical advice was provided and strong bonds were formed with others in the* group.

For the first two years before the recurrence, I had vague plans to find out more about treatment options, but didn't get around to it. When the recurrence hit, I knew little more than I did the first time around about what would happen next. After that, I decided it was time to find out more for myself. I tried the Anti-Cancer Council of Victoria, but their material was supportive rather than informative. I asked my oncologist if he could recommend any reading material. He was vague and did not provide any references. My husband wrote to a leading Melbourne oncologist with whom he had attended school and met at a recent reunion, with the same question. He didn't reply. The only option I could then see was to spend time at the University of Melbourne medical library, going through medical texts and journals. I spent many hours doing this, piecing together a history of breast cancer treatments and their current status. Subsequently, I have found a book which covers the material very well for a non-medical person, called Dr. Susan Love's *Breast Book. However, the library hours provided a deeper insight as to how treatments* have developed, and how much agreement there is on treatments.

Information

Although I have covered this issue in the Senate submission, I believe it is very important and would like to say more here. When (or if) I experience the next recurrence, I know roughly what the treatment options are and what they involve. I know that the most likely treatment will be another hormone, probably aminoglutethimide, and that I have a good chance of a response to that treatment. This knowledge greatly reduces the trauma and anxiety associated with a recurrence, and with all the false alarms that you inevitably experience on a day to day basis, eg the sore back or gastro attack. When I last experienced a recurrence, I had no knowledge of possible treatment options beforehand, and did not even know whether there would be any.

As well as reducing the anxiety and trauma, information allows you to participate more actively in treatment decisions, and this is increasingly being recognised as beneficial. Only an individual has an intimate knowledge of themself, their illness and their view of quality of life, so this participation is important. The act of participation also contributes to reducing the terrible feeling of lack of control.

It would be ideal if all women knew the basics about breast cancer and its treatment before they received a diagnosis, since they then would be well prepared and not have to deal with a great deal of new information at a time when they were least able to absorb it. I don't know how practical this would be to implement, as generally people are not interested in information unless it is directly relevant to them. The next best thing is to provide information at the time of diagnosis. Although it is a difficult time, the information is urgently relevant. The information should be in written form, so that it can be read by the woman or her support person, at a time suitable to her, and in an environment where she is *most likely to be able to absorb information. The information may be useful immediately,* or may be referred to later.

The information should cover:

- general information about breast cancer
- information about different treatment options for different states of breast cancer,
    - different types of surgery
    - adjuvant chemo
    - radiotherapy
    - hormone treatments (not just Tamoxifen)
    - chemo for advanced breast cancer
    - new treatments such as Taxol
- options for breast reconstruction
- information about support groups available, and what they offer
- current research into breast cancer treatments

The information must be presented in clear language, suitable for a reader without medical qualifications.

The preparation of such an information booklet, and distribution to all women diagnosed with breast cancer, should be a high priority goal in a national strategy to improve breast cancer treatments.

Role of GPs in the management and treatment of breast cancer

GPs play such an important role in our health services as they are usually our first port of call when something is wrong. With breast cancer, it is usually the GP who refers the woman to a surgeon, determining her pathway into a treatment scenario. This is a crucial role for GPs, as it currently seems to be a matter of luck if you go to a surgeon giving up-to-date treatment in a multi-disciplinary environment, or a surgeon with little knowledge of the range of treatments available today.

After diagnosis and initial treatment, woman live with the fear of recurrence, and it is the GP who will most often be consulted first if symptoms are suspected. It is important that the GP is equipped to both recognise these symptoms and support the woman in a further traumatic event.

Women with advanced disease either in remission or undergoing treatment have an ongoing need for support and general medical treatment compatible with their situation.

When palliative care is required, the GP should also play a major role in the arrangemant and monitoring of this. In these circumstances, the woman and her family need the ongoing care and support of someone familiar with their situation.

In view of these roles, consideration must be given to methods of ensuring that GPs are adequately equipped with knowledge.

Development of a National Treatment Strategy

This year we have at least two Working Parties looking at practice guidelines for treatment of breast cancer, the COSA consensus conference on treatment, and plans afoot in NSW to set up a breast cancer centre. There does not appear to be any co-ordination of the efforts of these activities, nor any plans towards a national strategy to improve breast cancer treatment in Australia.

The national program for early detection of breast cancer, on the other hand, appears to have been well planned and implemented, with philosophy, objectives, targets and quality requirements made clear to all states, and a budget adequate to meet these targets.

It has been inspiring, as a Board member of the Victorian early detection program, BreastScreen, to see a medical program implemented so efficiently and with such empathy for women. A good screening program is not enough, however, if it is not followed by a good treatment program.

A good treatment program can be defined in many ways. Most important for women will be survival, however there are other outcomes which are also critical. For some women minimising the aesthetic effect of breast surgery is critical, for others it is critical to be treated with dignity, others must be allowed to hang on to the slightest hope to make each day bearable. As a consumer representative on predominantly medical committees, I do not always succeed in convincing others that these sorts of outcomes are important to women. We need to carry out qualitative research to establish these outcomes from women's viewpoints, so that attempts are made to achieve these outcomes as well as the clinical outcomes. Funding will be required for such research.

We need to develop:

- a national strategy for determining protocols for the management of breast cancer. These protocols should cover treatment of both early and advanced disease, with all required outcomes as goals, both clinical outcomes and those seen as important by women
- a national strategy for implementation of those protocols, ie to ensure that as many treating professionals as possible use the information in the protocols
- a national strategy for provision of services to provide treatment as defined in the protocols, eg. establishment of specialist centres, provision of adequate radiotherapy equipment

Because so little has been done in Australia towards a systematic approach to treatment of breast cancer, we have an opportunity now to organise and use our resources in the most effective way. Not only will this produce measurable success in terms of improved survival rates but we can also improve the quality of life of the many women and their families who have been effected by breast cancer.

References

Hill DJ, Giles C C, Russell I S, Collins J P, Mapperson K J (1990). Management of primary, operable breast cancer in Victoria. Med J Australia 152:67-72

DETHRIDGE, Councillor Susan Margery, North Dorrigo Road, Dorrigo, New South Wales 2453, was called to appear before the committee.

CHAIRMAN—The proceedings today are legal proceedings of the parliament and warrant the same respect that proceedings of the House demand. Although the committee does not require you to give evidence on oath you should be aware that that does not alter the importance of the occasion and that deliberate misleading of the committee may be regarded as a contempt of parliament. The committee has received your submission. Do you wish to propose to the committee any amendment or to table any supplementary material?

Councillor Dethridge—No, not written material.

CHAIRMAN—Do you wish to make a statement further to that contained in your submission?

Councillor Dethridge—Yes.

CHAIRMAN—We would be very pleased. I note here that you say you would like to talk to us about your experience. I understand you are writing a book. How is it going?

Councillor Dethridge—Yes, it is almost finished.

CHAIRMAN—Yes, thank you very much. As you can appreciate, we do need to hear from people who have cancer but also from those involved in the management and treatment of it.

Councillor Dethridge—I should first say that a few days ago I nearly did not come. I almost chickened out. I decided it might be too much to do this thing. Then I rang the other ladies who live in the town with me who also have breast cancer and said to them, 'What would you do if you were going down there?'. They all said the same thing to me in different words. They said, 'Tell them what it is like to be us'. So that is what I am going to do. I am going to tell you what it is like to be us.

The only way I can really do this is to tell you what happened to me, but I would like to make it clear that it is not important that it is my story because what happened to me is mirrored in hundreds of other women in rural Australia.

I would also like to say that some of the things I am going to say to you I probably have not said to anybody else before because I have buried them on the backburner for a long while. So if I do not do it well, you will have to bear with me.

I became mayor of the Bellingen council in September 1991 and it finished a period of tremendous stress in my life. I say that because I believe, for what it is worth, that the stress caused my cancer. Within weeks of that election I knew that I was sick, but I did not know what was wrong with me. I did not ever have a breast lump. I examined my breasts and I did not have a lump in my breasts. But by about a week before Christmas 1991 I had an infected breast. I had a very red breast and a temperature.

I went to a local GP and he put me on antibiotics. At that stage I had not been to a doctor for 15 years. I am an incredibly healthy person; I do not get the flu; I do not get anything. So it is not the medical profession's fault that nobody said to me, 'Have a mammogram', any sooner. He said to me, 'You really need a mammogram but you obviously have an infection. It would be really painful. We will get rid of the infection and then we will look at things'. At that stage nobody thought of cancer.

I had Christmas with my children and I drove to Sydney with one of my children to bring him back here. I realised that I was very ill. Suddenly everything fell apart. I do not know what the difference was between before and after Christmas but I was very sick. So I went to a doctor who said to me—and I suspect probably realised what the problem was—that I should go to a surgeon. She sent me to a surgeon who I will not name for obvious reasons when I tell you why.

I had never met this man before. He sent me to have a mammogram, and I came back to his surgery. He said, 'You have cancer'. He then said to me, 'You have to have a mastectomy', and he told me where he was going to send me. That was my introduction. I had no explanation. I have listened to what the doctor said and I can assure you it is not what happens—not always. He then named the hospital he intended to send me to, which was a private hospital.

My husband is a wood carver. He is a very good wood carver but he is not a very wealthy wood carver so we are not in a private health benefit fund. So I said to this doctor, 'We are not in a private health fund. Does that matter?'. He bashed the table and said, 'Does it matter?'. He then harangued me for 10 minutes on the evils of public medicine and the public health system. He threw his chair back and said, 'I do not treat public patients', and showed me the door. I assure you this is true.

I walked out into the street in Sydney. I know almost nobody in Sydney. I know nobody in the medical profession in Sydney. I was standing on the footpath and had my 19-year-old son on one side of me and I had nobody to treat me and I knew that I had cancer and that is all I knew. It was New Year's Eve and there were not a lot of options on New Year's Eve to go and do things.

So I picked up my address book and rang people who I knew. I would say I could count on the fingers of one hand the number of people I know in Sydney. One of them knew a wonderful lady who is a doctor called, I think, Joan Croll, who has to do with the breast clinic here in Sydney. I landed on her doorstep on New Year's Eve. She was absolutely wonderful. The first doctor that she rang offered to treat me. I flew home for a few days and I came back and had a mastectomy at St Vincent's Hospital.

The morning that I left home our local radio station decided to tell the world that I had breast cancer, which did not help my 16-year old son who then had to face his friends when he was not ready to do it. I just throw that in because I think the media ought to think sometimes about what they do. Anyway, I came to St Vincent's Hospital to have a mastectomy. There was no question that I needed a mastectomy: I had, by all reckoning, had cancer for years. I had no way of knowing. I did not have a lump. I was under 50, and all the ads tell you to have mammograms when you are over 50. I was never sick, so there was no reason for me to go to a doctor. Maybe if I had had regular mammograms, somebody would have realised; but I had had it for years.

St Vincent's Hospital, I have to say, is wonderful: they are wonderful, caring people. The first person that came to see me was a lady—a volunteer—who represents the mastectomy society or something. The first thing she said to me—and I have never forgotten it—was this: 'Do not worry about your mastectomy. I had a mastectomy, and my husband still loves me' You will all be relieved to know that my husband still loves me, too; but it had absolutely no bearing on the fact that I had to have this mastectomy.

I always thought that, if I had my time over again, I would say to her, 'Has your husband had a mastectomy?'. It was a problem to me. But I had my mastectomy. A mastectomy, I have to say, is filthy mutilating surgery: there was nothing nice about having a mastectomy. If I lost an arm and I walked down the street, people would say, 'That poor bugger has lost an arm'. But if I walked down the street without my prosthesis, everybody would be offended, and I would be devastated. I could not do it.

There is an enormous impact on your life when you have a mastectomy. When you get up in the morning and you are running around in a dressing-gown and someone knocks on your door, you cannot rush off to the door, because you have not got your ruddy prosthesis on and it looks terrible—in your mind and in everybody else's. So you do not do it. And it is offensive to people to see people, I believe, in my situation. So there are those sorts of things. Obviously, you do not go swimming. I go away to conferences and things, and I have to think about whether I am going to have someone in the room with me, because I cannot handle that. That is my problem, I guess.

I found, as I say, St Vincent's hospital to be wonderful. Paul Crae, the doctor who looked after me, is a wonderful man and is still looking after me. I had a young doctor resident there whom I will tell you about, because I think it is what is happening. Other women have told me that the same thing happened to them. I was talking to him just casually one day, sitting on the end of my bed chatting, and I said something about the future. He said to me, 'Oh, if I were in your situation, I wouldn't plan the future'. And I said, 'Oh! What do you reckon?'. He said, 'You might live two months' and he sat back.

This was 2½ years ago. Then he looked at me and said, 'Of course, you might live 20 years, but neither one of them is really very likely. But do not plan your future too far ahead, will you?' And I have to say to you, of all the things that happened to me, he probably shattered me the most. I then had my first dose of chemotherapy at St Vincent's Hospital, using their protocol, and I flew home. I realised that there was a cancer clinic at Coffs Harbour which would continue my treatment, and I was told that I needed six treatments of chemotherapy.

Chemotherapy is a violation. It is the most appalling thing to have happen to you. You have to sit and allow people to poison you. You are then terribly ill. It does appalling things to you, because it attacks all the soft tissues. Nobody tells you anything. You try to get all the information you can. For instance, my eyesight blurred for the whole time I was on chemotherapy. At one stage I was totally convinced I had a brain tumour, because I could not see properly, but it was the chemotherapy doing it. And when I said to the doctors, 'My eyesight is blurred', everybody said, 'Oh, that is no good, is it!'.

Nobody said to me, 'Chemotherapy might attack you'. It attacks your tongue and then your sense of taste goes, so then things do not taste the way they used to. I do not eat meat any more, partly because I cannot stand the taste of meat. That is probably a good thing; I do not have a problem with that, but that is what happened to me. Not long ago, only in the last few weeks, I was picking blackberries and I became really ill. I sat down on the ground and thought, 'Why am I ill?'.

I was sitting in the middle of a paddock and, in the back of my hand where I used to have the chemotherapy needle, I had a thorn from the blackberries. Something in my brain had told me they were going to put this chemotherapy in again. I did not even know I had done it but, because I had a blackberry thorn where the chemotherapy used to go in, something had set the whole thing off and I was violently ill, just because of some sort of psychological connection. That is what it does to you. It is awful stuff.

I had my six treatments, I thought; and I came to Sydney to have ray treatment. The biggest problems for country women with ray treatment are that, firstly, you have got to have six weeks away from home and, secondly, you have got to be able to afford it. You have got to have somewhere to live. If you do not know somebody, you have got to go somewhere. IPTAS, which is the isolated patients travel scheme, will only pay certain things. For instance, if you go to Jean Colvin, which is the place that St Vincent's uses, that is actually classified as a private hospital, so IPTAS will not pay for you to go to there, although they will pay for your husband to stay across the road in a hostel. So there were these sorts of problems.

It is a real problem to be away from home for six weeks. I still had a child at school. I have a friend who has breast cancer and she has six children at school. She is not having ray treatment because she cannot leave them for six weeks. Even if she could leave them for six weeks, she could not afford to stay away from home. She has not got the money to pay for being away from home. That really concerns me. I found it very hard to be away from home for six weeks, but these things happen. I got through that and I then went home.

When I originally went home from Sydney I went back to the cancer clinic in Coffs Harbour to continue my chemotherapy. The Coffs Harbour cancer clinic is operated from the Royal North Shore Hospital. The first thing they said to me was, 'You shouldn't have the chemotherapy the way they are giving it to you at St Vincent's. If you do it our way, it will be better'. When you are in my situation—you are totally a non-medical person, you have nobody to back you up—and you have got a doctor saying to you, 'The way we do it is better than the way they do it', it is very unnerving.

I wanted to stay on the protocol that I had started with because I had great confidence in the doctors at St Vincent's. I rang my doctor in Sydney and he said, 'If it was better, we would use it'. So I went back to the clinic and said, 'I am going to do it the way I want to do it'. Every time I had chemotherapy I was told that it would have been better had I had done it their way. I am a pretty tough person but, believe me, there were people who would not have survived some of the things that have happened to me.

So, anyway, I had my ray treatment, and my doctors at St Vincent's Hospital said, 'There is no way we can tell whether you have had enough chemotherapy, because what they are sending us from Coffs Harbour doesn't tell us. You will have to go back and ask them'. I had been told that I needed six treatments. I went back to the Coffs Harbour cancer clinic and I took my husband with me for the first time to me. It is very difficult for men to cope with these things: women cope better on their own, or I do. The doctor said to me, 'No, you haven't had six treatments, you have only had six doses—two doses are a treatment'.

Had I been told it was 12, I would have had in mind all the time that I have got to get through 12, but I had in mind that I had to get through six. I had survived six and I did not want another six. I said to this doctor, 'I think I will go home and think about all this'. He then switched off, as though I was not in the room. I said to him, 'This is my husband; you haven't met him before because he has not been part of this'. My husband was sitting in the chair beside me and he turned to my husband and said, 'If she doesn't have this chemotherapy, and you lose her, it will be your fault'. My husband was not having the chemotherapy, I was having the chemotherapy. I thought, 'I have got to get out of here'.

I got up and I walked over to the door and standing in the door was the nursing sister who ran the clinic at that stage. I said to her, 'I'm going home to think about whether I will have any more chemotherapy'. She said, 'Don't do us any favours'. I then walked out to the car. My husband and I went home and we did not speak to each other for two weeks. We walked round the house but neither of us was going to broach this subject.

I live on the Dorrigo Mountain plateau and I have my council chambers in Bellingen. It is the most beautiful drive. One day I was driving home, and I was looking at the rainforest and I thought, 'I will go home and say that I'm going to have this chemotherapy', because it is the only way he will get better. That was it. I went into the house and I said, 'I'm going to have chemotherapy'. The whole atmosphere relaxed and everything was fine, except that I had to have chemotherapy.

I went back and I did have two more doses. By that time, all the veins in the back of my hand had packed it in. With the last lot, I was black from the tip of my thumb to my shoulder and my husband said, 'Don't have anymore' and I have not been back. All of this finished for me in about August 1992. For someone who was not going to live two months I have not done too badly.

There have been some funny things. For instance, the doctor who told me I was going to have chemotherapy said to me, 'You lose your hair when you are on chemotherapy'. This is a very funny story actually. I made some comment like 'Bloody hell!'. I had had enough by then. He looked at me and he said, 'Does that worry you?'. Now, I do not know any woman who would not be worried about losing her hair. I said to him, without thinking, 'Of course it worries me! What sort of daft idiot wouldn't mind losing their hair?' I then looked up and saw that he was absolutely and totally bald! He did not have a hair on his head. I thought, 'If my life depends on this fellow, I have probably just blown it'. So there are some very funny things.

There are some wonderful people who help you, but you learn that it is possible to be a brilliant doctor and a bloody terrible human being at the same time. You learn a lot of things. You learn that most of the time it is better never to tell anybody that you have got cancer; that most people cannot handle coping with somebody with cancer. Having thought about it a lot, I think it depends where they are with their own mortality. If you do not think you are going to die, you do not want to know that somebody else might be going to. I think that is so in a lot of cases.

It affects everything: it affects your friendships. I have lost a lot of my friends because I was the sort of person that people lent on and I am not that person anymore. I am probably now, but I was not for a long time. The friendships that I had built up really related to people leaning on me. So when I was not there to do that, I lost a lot of those friends just when I really needed them. But I have made some other wonderful friends. It is probably one of the joys of my life that somebody that I was not speaking to, not long before, was the person who really supported me through all of this, and that was a really wonderful thing.

My marriage has survived a lot of things, including the death of a child. We have had a lot of real difficulties. It barely survived cancer. It survived cancer because I can say all the time that I am well. My friend said to me the other day—she has breast cancer too—'We can talk about John's flu but we cannot talk about my cancer'. I think that is the way it is. Somebody said to me that women with breast cancer get together and support each other because nobody else supports them, whereas, men with cancer probably get a lot more support. I think that is probably a fact too.

I guess, what I would like to say to you is this: I do not watch television so I am probably not a typical person. The only two advertisements I ever saw for breast cancer were the ones that show those sorts of stylised breasts; they asked if you had checked your breasts this month or this day or whatever. I checked mine but I never had lumps, so that did not help me at all. But I am sure it does help if you find a lump.

There is another advertisement that I think was put out by one of those health funds. It is a classical painting of a women; she is a million miles away; she died a hundred years ago; she really has no relationship to our lives. If I were going to reach people, I would be putting out advertisements with ordinary people in them saying, 'I was a kindergarten teacher, but I got breast cancer'. We are not reaching the ordinary women. The women in my town are like me. Since I was diagnosed—and that is only, as I say, two and a bit years ago—four other women have been diagnosed. Only 1,100 people live in my town. That is a lot of people. They were all younger than I am. I was 47 when I got it. All these ads say, 'Have a regular mammogram after you're 50'. None of us were 50; we were all younger. I think it has been left too late.

I breastfed all my children for lengthy periods; I had my first child relatively young; I have no history of breast cancer in my family. I had nothing that would say to me that I should worry, that I have got breast cancer. I was never sick and yet I had the ruddy thing for years.

I guess, the other thing is that you will never get a mammogram machine to the people where I live, in my town. But you could, with a bit of creative thinking, get them to a machine. Most towns have clinics but not clinic sisters or home nurses. Those sorts of people are actually there working in the community. Their kids are in the soccer club; their daughters are in brownies. It would help if you could give them a bit of money and say to them, 'Hire the bus; hire the Coffs Harbour mammogram machine; give these women lunch'. A lot of the women in my town cannot afford to drive a car and there is no public transport. There are a lot of people who just cannot even get to Coffs Harbour and that is only an hour's drive away. But if you hired a bus, which would only cost $200, and you filled it with these women—even if it cost you $10 each for their lunch and you hired the machine for the day—you would get them all down there to the mammogram. Even if it was only a day out, at least it would be a way to get a day out.

You need somebody in the community working with them and you need to explain to them just what breast cancer is. Breast cancer does not really kill you; it is the next cab off the rank that kills you, and people like me do not understand that. I thought that you got breast cancer and they would take it away. The big question everybody asks you is, 'Did they get it all?'. That is what everybody wants to know. Nobody really understands cancer. If you are not a medical person, you think cancer is like the black spot on the apple and you cut it out and it is gone. Most of us do not understand. I did not understand. I still do not understand a lot of it. I do not understand why my hair did not fall out. I think it was because I told it not to. I think I am still alive because I have decided to stay alive, but I do not really know.

CHAIRMAN—Did the resident—

Councillor Dethridge—Absolutely. When I left the hospital he was standing in the doorway and as I walked out I said to him, 'I'm coming back in 10 years time to show you that I'm still alive', and he said, 'I won't be here; I'll be in a sidewalk cafe in Paris'. And I said, 'Good. I'm not going over there looking for you'.

I do think that anybody really understands. For instance, I have met two women who had no treatment at all. They had mastectomies. One of them knew she had had cancer for some years. She went and had a mastectomy and went home. She refused all treatment. Now, 10 years later, she is doing very well. One of my frustrations was that nobody could give me statistics. I am sure they exist, but nobody could or would—I am not sure which—say to me, 'If you have this many doses of chemotherapy, your chances are so much better', or 'If you have your ray treatment, you have got a much better chance of getting over it'.

There is not a lot more I can say, I guess, except that I am not here just for me; I am here for a lot of other women out there in the country. Probably some of them are not as tough as I am and they probably would not have got through the medical system as well as I have. That doctor who was here talked about education. Her colleagues need an awful lot of it to know that being a human being and being a part of the human race require certain obligations of one, and the way one treats one's patients should be a part of that. Certainly we need to get to women and explain to them, 'Sure, it happened to me.

It can happen to you'. The earlier you get it, the better, I think.

CHAIRMAN—Thank you very much.

Councillor Dethridge—I have done it.

CHAIRMAN—Yes, you have done it, and you have done it exceedingly well, I might add. I am sure there will be some questions. Are you happy to answer some questions?

Councillor Dethridge—Yes.

CHAIRMAN—A lot of the experiences you have had have obviously been awful. Two are quite astonishing to me. Firstly, there was the resident who sat there. You were sitting on the bed—

Councillor Dethridge—No; he sat on the end of my bed and said—

CHAIRMAN—He said that you were going to be dead in two months, or you could be.

Councillor Dethridge—Yes.

CHAIRMAN—I put that aside. The other one, which is possibly even more extraordinary, was the surgeon who told you to go away because you were a public patient.

Councillor Dethridge—He said, 'I don't treat public patients'. He threw the door of his office open and said, 'I don't treat public patients'. I said, 'What will I do?', and he said, 'Well, you could come back in February. You might get a bed then'. This was New Year's Eve.

CHAIRMAN—He was the person who had given you your diagnosis of cancer?

Councillor Dethridge—Yes; only minutes before, he had told me I had cancer.

CHAIRMAN—At the time, because of the emotion of it all, I guess one could not put in some formal or official complaint, but did you ever at any stage—

Councillor Dethridge—No. I have never told anybody until now. I have never said it to anybody. I possibly have not even told my husband exactly what happened, because I have had too many fights. I have been fighting cancer; I am trying to run a council; I work 65 hours a week. I guess I had to go on and not look back. But I have to say that, if he did it to somebody else, I would fight like blazes.

CHAIRMAN—Have you heard similar sorts of stories from other women?

Councillor Dethridge—I have, but not quite as bad as that. I have heard stories from people who could not get a doctor when they needed one. It is not as easy as you think if you do not know the system. If you are a country woman and if your GP sends you to the city, then you do not seem to have these problems. It is different if you take yourself to the city. For instance, one of my friends, Maggie, who has six boys still at school and has breast cancer and is in an awful mess in Dorrigo, was treated by a Coffs Harbour doctor for three years for breast problems and he kept telling her that there was no problem. In the end she got worried enough to pack herself up and come to Sydney and have some tests. When she got back, the surgeon in Sydney rang her up and said, 'You must have a mastectomy. You have cancer'.

She had been going to this doctor in Coffs Harbour for three years. So she then went back to him, and he abused her and said to her, 'You have no right to go to Sydney. I am your doctor'. But for three years he had been telling her she had nothing wrong with her. She has now had a mastectomy. This was only at Christmas time. So it is happening. There are people all over the place being treated the way I was treated. I do not know what the answer is, except that I think there are doctors who perhaps should not treat women.

Ms DEAHM—I am sorry; I missed the earlier part of your evidence because I had to make some phone calls. What I heard was extremely moving. I was elected to local government at the same time as you were. We need women in local government and we need tough ones that can run councils. So I admire you greatly. I take Wendy's point about complaints. I do not think it is too late for you to put in a complaint to the medical complaints unit.

Councillor Dethridge—I did not even think about what he did to me until I was coming down here.

Ms DEAHM—I think you should.

Councillor Dethridge—I thought, 'I have got to really get into my mind exactly what has happened to me'. It came back to me, and I thought how appalling it was. But at the time I was more concerned about what the hell I was going to do. He knew this, too. I had told him. I had come to Sydney partly because my mother has cancer. She did not have breast cancer. There is no relationship to what I have. But she was at that stage moving between Melbourne and Sydney. I had partly come to Sydney to get her off the plane and take her to her specialist and he knew that. Sitting out in the car was my mother who had cancer and my teenage son was waiting for me outside yet he just said, 'Go, I won't treat public patients'. If he has done it to me he would have to have done it to other people. We have not all got health insurance.

Ms DEAHM—It is only when you make the complaint and it gets followed up that those things can change. As you have said, people who can do that and get away with it will go on doing it and getting away with it. We had a case in Brisbane of a young woman who was only in her early 30s. She did not have the sorts of problems you had but it was a question of when she could go into hospital. She had to pay for a private day to get into hospital more quickly. A bribe is what I would call it.

Councillor Dethridge—It is, yes.

Ms DEAHM—She had not complained to the hospital. I suggested she did but I do not know whether she will or not. But the way I would view it is that if there is a problem and nobody complains about it the problem will keep on happening. If you care about what happens to other women, I think it is really worthwhile to do it.

Councillor Dethridge—It had never occurred to me but I could do that now without any problem at all. I could just explain what happened to me. It is the time when you are the most vulnerable. If you did it to me now I would give into them.

CHAIRMAN—It is absolutely crucial that we hear the sorts of things that you are saying because, as you have probably heard today, there is very little data collection of any sort. So often we hear the sorts of stories that you are bringing to us but different versions if you like. They get written about in the media and one is never sure whether it is just one or two or whether there are many more women out there.

Councillor Dethridge—I am sure there are many more.

CHAIRMAN—They are having difficulties fighting their way through this maze. I thank you for having the courage to come and tell us.

Councillor Dethridge—I am glad I did it now. I nearly did not a few days ago.

CHAIRMAN—I am glad. Thank you very much.

Luncheon adjournment