Services and Treatment Options for Persons with Cancer:

Submission to Senate Inquiry

Cancer Nurses Society of Australia

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Introduction

The Cancer Nurses Society of Australia (CNSA) has a membership of approximately 700 registered nurses dedicated to excellence in patient care, research, and education in cancer nursing. CNSA is committed to achieving and promoting excellence in cancer care through the professional contribution of nurses.

CNSA is governed by a nationally elected Executive Committee, which comprises representatives from each state and territory in Australia. Committees and project teams are appointed by the National Executive to lead activities that assist with achieving the Society's mission of excellence in cancer care. CNSA Regional Groups and Special Interest Groups provide further opportunities for meeting the professional needs of nurses in specific geographical locations.

As the peak national body representing cancer nurses in Australia, CNSA is actively working with other peak organisations to achieve improvements in cancer care in Australia and nationally. The Society is a member body of the National Nursing Organisations, and the International Society of Nurses in Cancer Care.

CNSA is also the nursing group of the Clinical Oncological Society of Australia (COSA). As the nursing group of COSA, CNSA endorses the joint submission to the Senate Inquiry submitted by the Clinical Oncological Society of Australia, the Cancer Council Australia, National Cancer Control Initiative, and the National Aboriginal Community Controlled Health Organisation. The recommendations outlined in the Joint Submission from these organisations address critical areas of cancer service planning and delivery that require action.

This submission is presented on behalf of the Cancer Nurses Society of Australia. The submission presents issues and recommendations which focus primarily on *nursing related issues and perspectives,* and the *nursing contribution* to achieving optimal services and outcomes for people with cancer in Australia.

Recommendations:
The submission includes recommendations focused specifically on issues concerning cancer nursing services. The recommendations are considered to be areas that require action if we are to achieve optimal cancer services and treatment for people with cancer. These recommendations are presented on pages 8-10 of this submission.

Terms of Reference

(a) The delivery of services and options for treatment for persons diagnosed with cancer, with particular reference to:

1. The efficacy of a multidisciplinary approach to cancer treatment

Issues:

- Recent reports emphasise the benefits of multidisciplinary care to people with cancer[1]. Such benefits are likely to result from many different factors such as:
    - Improved opportunity to achieve best practice in management, as many cancers today require multi-modal treatments to achieve optimal outcomes. Planning and delivery of these multiple treatments necessarily requires a team approach to achieve best clinical outcomes.
    - Multidisciplinary approaches to care provide for a better experience from the patient's perspective, in terms of continuity of care, as well as enhanced confidence, and satisfaction with health care professionals.
    - Multidisciplinary approaches to care enable consideration of patient issues and concerns from multiple perspectives, providing a better opportunity for health professionals to understand an individual's needs, social context, preferences and wishes.
- Traditionally, definitions of multidisciplinary care have emphasised the contribution of the various medical disciplines involved in cancer management (e.g. medical oncologist, surgeon, radiation oncologist). Less attention has been given to the contribution of nursing and other allied health professionals to patient and team outcomes, or to the consumer's role in the multidisciplinary team.
- Recent evidence is highlighting the important role cancer nurses play in the multidisciplinary care. The National Breast Cancer Centre (NBCC) Specialist Breast Nurse Project identified that the presence of a specialist breast nurse contributed to a range of improvements, including: improved team functioning and appropriate utilization of each professional's skills and resources; care being delivered more smoothly, including referrals; other health professionals having improved information about patients and breast cancer issues; and women being prepared for each treatment stage[2]. The recent report on the NBCC Multidisciplinary Care Demonstration projects reinforced this important role that specialist oncology nurses play as a coordinator of care and facilitator of effective communication amongst the team and with patients[1.]
- The existence of a number of members of the health team does not in itself translate to improved outcomes for individuals with cancer. Unless there are appropriate structures and processes, individual health professionals can continue to make isolated management decisions. There is also the potential for duplication of effort, role overlap, and role conflict. Effective multidisciplinary care requires supporting structures and processes that will enable the positive benefits that have been identified to be achieved.

However, there has been limited work to date defining what these standards and principles for effective multidisciplinary care should be.

- There is limited evidence about the most effective models, or the specific structures and processes that promote optimal outcomes from multidisciplinary care. The National Breast Cancer Centre demonstration project[1] has begun to address these questions, but more research in this field is urgently required.
- Effective multidisciplinary care requires members of the team to function in different ways to traditional models (e.g. to have a commitment and respect for contributions of other health professionals; to communicate effectively amongst team members; to engage in collaborative rather than individualistic or hierarchical decision making). Such attitudes and skills and their application in the context of multidisciplinary care have traditionally not been a major focus of education and training for health professionals.
- Access to multidisciplinary care is more restricted in rural/regional areas, and flexibility will be required in the delivery of such care outside major metropolitan settings. Cancer nurses in rural and regional areas play a critical role in facilitating multidisciplinary goals, as they are likely to be the 'constant', have knowledge of local networks, and can facilitate appropriate networks with specialist centres[3]. Cancer nurses in rural areas do however sometimes report being isolated from professional networks and experiencing difficulties in obtaining back up from members of the multidisciplinary team[3]. Such experiences highlight the need for more effective systems of professional support for cancer nurses outside major treatment centres to ensure patients receive optimal care.
- Workforce shortages exist for many cancer professionals, and these shortages are likely to become more acute. These workforce issues are especially critical in nursing, with the 2004 assessment of national and state skill shortages identifying oncology and palliative care registered nurses as being professional groups in shortage in all states and territories of Australia except the Northern Territory.[4]

(ii) The role and desirability of a case manager/case coordinator to assist patients and/or their primary care givers

The following section is drawn primarily from extracts from a recent review article *Cancer Care Co-ordinators: Realising the Potential for Improving the Patient Journey*[5] published in ***Cancer Forum*** by Professor Patsy Yates, Past Chairperson, Cancer Nurses Society of Australia. The full text of the article can be found on the following website:
http://www.cancer.org.au/documents/Cancer_Forum_Nov04_Final.pdf/

Issues

- These is substantial evidence that the cancer journey is a complex one, and that people with cancer and their carers experience a range of physical, emotional, practical and spiritual concerns. This complexity requires health care responses that are carefully planned and coordinated, to achieve best outcomes for patients, and to ensure that the system of care does not add to the

burden and distress already experienced by people faced with a cancer diagnosis.

- Nurses are well placed to play a key role in promoting continuing of care, due the profession's focus on comprehensive, person centred models of care, and the central, coordinating role they have in the health system.
- The majority of evidence about care coordination and case management roles has focused on the contribution of nurses and, to a lesser extent, that of primary care providers. Recent evidence demonstrating the benefits of nurse coordinators and case managers in cancer care include:
    - The Clinical Practice Guidelines for Psychosocial Care of Adults with Cancer reports Level 2 evidence (at least one randomised trial) that specialist breast nurses improve understanding and provide continuity of care throughout the treatment process for women with breast cancer[6]
    - A US based study[7] evaluated a nurse case management intervention in a randomised controlled trial involving 335 women over 65 years of age newly diagnosed with breast cancer. Findings demonstrated that women who received the support of a nurse case manager were more likely to be seen by a radiation oncologist and receive radiotherapy after breast conserving surgery, and that they were more likely to have normal arm functioning in the recovery period than women who did not receive case management support.
    - A three year demonstration project in the US involving patients with advanced lung cancer found that where nurse case managers were employed, higher rates of advance care planning and referral to hospice programs, and improved symptom management was achieved[8].
- The actual processes of care coordination or case management that contribute to improved patient outcomes are not always clearly described. Qualitative studies involving patients with cancer who have received nurse case management interventions identify that patients felt they had been helped through practices including managing co-existing problems, providing informational and emotional support, providing education about procedures and self care, assisting with activities of daily living, navigating the health system through making appointments, explaining procedures, reinforcing information from other health care providers and ensuring comprehensive recording of patient information in health records[9,10]. These studies also suggest families of patients with cancer report the nurse case managers help by providing advocacy, support, education and monitoring of their relative's progress[9].
- Addressing key questions about role definition will be crucial for developing evidence based models of care coordination that are appropriate for the populations being served. Such clarity will assist consumers and other health professionals to better understand their relationship with care coordinators, as well as minimise role confusion and the perception that care coordinators can be 'all things to all people'[5].
- Studies that have evaluated case management interventions have tended to involve patients with complex health or social needs[7,8,10]. Furthermore, while studies demonstrate the potential benefits of care coordination interventions in both the treatment phase[7] as well as palliative phase of illness[8], the best timing and length for care coordination interventions is not well defined. Few studies

have reported on coordination activities in post-treatment or follow up stages of the patient's journey[5].

- The interface between the care coordinator functions and those of other members of the health team need to be clarified. A review of the type of activities that are suggested to be within the scope of practice for care coordinators highlights the potential for role overlap, role conflict, and duplicated and fragmented efforts[5].

(iii) Differing models and best practice for addressing psychosocial factors in patient care

- The recently published Clinical practice guidelines for Psychosocial Care of Adults with Cancer[6] provides an important resource for all health care professionals in understanding the support needs of people with cancer and how to respond to these needs. However, efforts at implementing these guidelines in practice require considerable attention to achieved desired improvements.
- All patients with cancer require attention to psychosocial needs. The Clinical Practice Guidelines emphasise that all health professionals have role in psychosocial care. This should not be delegated to an individual.
- While all health professionals require some skills in the providing psychosocial care, some patients require more advanced level support and intervention. Models of care which are centred around responding to the intensity and nature of each individual patient's need are therefore likely to be most effective. This requires health professionals, especially nurses who are at the 'front line' of supportive cancer care to be adequately skilled in assessing psychosocial need, and collaborating with other members of the team to ensure appropriate levels of psychosocial care are implemented.
- Anecdotal reports suggest that there appears to be considerable divergence in practice from ideal models and evidence based guidelines for psychosocial care, with psychosocial assessment tending to be more ad-hoc than systematic. The consequence of this is that patient needs are often not adequately identified or addressed.
- Reports suggest that health care professionals require development of skills in psychosocial assessment and care. Nurses like other health professionals require development of competency in this area[11].
- A model has recently been developed and trialed by the Department of Human Services in Victoria to improve the skills of breast care nurses in psychosocial assessment. The "C-Care" model included:
    - A practice model emphasising early assessment of distress and risk factors
    - Draft assessment forms
    - A training package developing BCN role

  Breast care nurses participating in the trial reported that the model facilitated the implementation of psychosocial assessment and early intervention support for study participants, and that it appeared acceptable to the majority of consumers surveyed during the study. The report makes some important recommendations for further improvements to the model, including the establishment of consultative networks and referral processes for psychosocial care, reinforcement that psychosocial care is a team effort, and continuing development breast care nurse competencies[12]. Action on these

recommendations, as well as further trials and implementation of similar projects are needed.

(iv) Differing models and best practice for delivering services and treatment options to regional Australia and indigenous Australians

- There is a tension between the desire to provide local services close to where people live, and the need to ensure that the services provided are equipped to achieve best possible clinical outcomes.
- To achieve best clinical outcomes, patients may be required to travel to specialist centres where the expertise and experience and concentrated services can be employed. This can create considerable burden to patients and their families. Current mechanisms for supporting patients in these circumstances are sometimes inadequate.
- Nurses and GPs are key service providers in rural areas. However, a recent qualitative study involving nurses in rural settings identified a number of issues which nurses perceived impacted on their ability to provide optimal care to people undergoing chemotherapy in rural settings, including a lack of understanding and support from colleagues in metropolitan settings, lack of professional supports, and a lack of understanding of health service managers about critically important minimum standards for practice in cancer care[3].
- Limitations in the training of nurses delivering chemotherapy in rural settings has also been identified in recent studies[13].

(iv) Current barriers to the implementation of best practice in the above fields

- Several barriers to implementation of best practice have been noted in the above discussion. For nurses working in cancer settings, the most significant barriers to achieving best possible cancer care include
    - Workforce shortages: The 2004 assessment of national and state skill shortages identifies oncology and palliative care registered nurses as being professional groups in shortage in all states and territories of Australia except the Northern Territory.[4]
    - Lack of minimum standards, and methods for monitoring compliance with standards
    - Workload pressures: A number of recent studies suggest nurses are becoming increasingly distressed that they can no longer provide quality care as they do not have the time due to workload pressures[14, 15]. A recent Queensland study of oncology / haematology nurses indicated that workload issues were a major dissatisfier for them, with nearly 50% reporting that they did not have the time to get through their work, and that overall staffing levels were a concern for them.[16] The Queensland study further identified that cancer nurses are at high risk of burnout, with 70% of the sample categorised as experiencing moderate to high levels of emotional exhaustion on the standard burnout measures.[16]
    - Education: Two recent Commonwealth reports have clearly summarised the challenges faced by nursing education today. Many of the recommendations in these reports relating to Specialist Nursing Education are yet to be implemented. Some of the challenges facing education of nurses in specialties such as cancer nursing include: the

poor link between education and career pathways; the costs of higher education; high workloads and competing demands that impact on nurses' ability to undertake courses[17]. The Howard Governments commitment of funds to cancer nursing education outlined in the *Strengthening Cancer Care Policy* document is a timely and welcome beginning to developing the cancer nursing workforce. The success of such initiatives will, however, require collaboration between a wide range of stakeholders in nursing education, as well as accompanying structural reforms to enable nurses to participate in and achieve the best educational outcomes.

Terms of Reference

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

(i) The extent to which less conventional and complementary treatments are researched or are supported by research

(ii) The efficacy of common but less conventional approaches either as primary treatments or as adjuvant/complementary therapies

(iii) The legitimate role of government in the field of less conventional cancer treatment

Issues

- Definitions of conventional and complementary cancer treatment vary considerably, and have changed over time. Important distinctions need to be made according to the evidence to support various therapies, as well as the reasons patients choose to use such therapies.
- Some less conventional approaches may have adverse effects, and government regulation to avoid the risk of such harm is essential.
- Research suggests that patients may choose to use alternative and complementary treatments for a wide range of reasons, including:
    - Beliefs that such therapies have benefits in terms of survival or quality of life that are not offered by or that may enhance standard medical treatments
    - Belief in the approach or philosophy underlying the treatment
    - Dissatisfaction with conventional medical care
    - Poor response or adverse effects experienced from conventional medical care[18]
- Some patients report considerable satisfaction with and benefit from use of complementary therapies[18]
- To provide person-centred care, the reasons patients choose such therapies need to be understood. In addition to important clinical outcomes, patient's perception of treatments and their outcomes need to be understood and considered in health professional responses.
- Health professionals require skills to enable them to understand the patient's perspective of their illness and treatment, to respond appropriately when the patient's perspective may be different to that of the treating team, and to advise and support them appropriately in treatment choices.
- Research into the efficacy of complementary therapies is needed, however the investment in such research needs to be balanced with the urgent need for research in many different areas of cancer care.

Summary and Recommendations

Two major government reports published in the last two years "*The Patient Profession*"[19] and "*National Review of Nursing Education in Australia*"[20] clearly place the spotlight on nursing as a key component of the health system that requires attention if Australia is to maintain its high quality health service. This is especially so in cancer care, as nurses' contribution to patient safety support is critical. Some key points highlighted in the two Commonwealth reports include:

- that Australian nurses should be proud of the contribution they have made, often with limited acknowledgement other than the community's trust
- that many of the current problems experienced by nurses are brought about by the fragmentation of different policy and funding responsibilities.
- that considering the size of the nursing profession, it has received relatively little attention, being largely invisible in the policy debate, and research priority agendas.

More specifically,

> *"We have a growing body of evidence about what patients need and want from our cancer system, and about the models of care that might best address these needs. Such evidence continues to suggest that nurses will be integral to achieving a more patient-centred service"*[21].

Recommendations:
CNSA is the peak national body for cancer nursing in Australia. It is also the nursing group of the Clinical Oncological Society of Australia (COSA). As the nursing group of COSA, CNSA endorses the recommendations included in the joint submission to the Senate Inquiry submitted by the Clinical Oncological Society of Australia, the Cancer Council Australia, National Cancer Control Initiative, and the National Aboriginal Community Controlled Health Organisation. The recommendations outlined in the Joint Submission from these organisations address critical areas of cancer service planning and delivery that require action.

This submission, presented on behalf of the Cancer Nurses Society of Australia, presents issues and recommendations which focus primarily on *nursing related issues and perspectives*, and the *nursing contribution* to achieving optimal services and outcomes for people with cancer in Australia. It is intended to complement the Joint Submission presented by the Clinical Oncological Society of Australia, the Cancer Council Australia, National Cancer Control Initiative, and the National Aboriginal Community Controlled Health Organisation.

To achieve optimal cancer services and treatment for people with cancer, it is recommended:

- That research and local demonstration projects or trials to determine the key principles for achieving optimal outcomes from multidisciplinary models of care be supported. These trials need to be based on definitions of multidisciplinary care that reflect the contribution of all health professionals to team functioning and care outcomes.
- That standards for multidisciplinary care in the context of cancer be defined, and that these standards be linked with relevant service capability/role delineation frameworks, accreditation standards, and appropriate service reform and supports for their implementation.
- That training programs focused specifically on developing competencies in multidisciplinary approaches to care be developed and implemented, incorporating the perspectives and issues for consumers and all health professionals involved in the team
- That appropriate methods for providing professional support and clinical networks for cancer nurses working outside metropolitan areas be identified, developed and supported
- That evidence based frameworks that clarify scope of practice, competency standards and related training requirements for care coordinators be undertaken.
- That appropriate principles and supporting clinical tools for care coordination in the context of cancer be developed. While it is likely that there is no one model for care coordination, ensuring equity of access and appropriate use of resources for care coordination will remain critical policy considerations[5]. As such, models of care coordination should provide supporting tools and guidance for issues which include:
    - When and under what circumstances patients require services provided by a care coordinator
    - What is an appropriate casemix and caseload for care coordinators
    - Which practice setting/s the cancer nurse coordinator may work within to achieve optimal outcomes
- That models for improving nursing competence in psychosocial care, such as the C-CARE project to be widely implemented, given the central role that nurses play in providing supportive care for people with cancer,
- That recommendations for further improvements to psychosocial care proposed in the C-CARE report be supported, including the establishment of consultative networks and referral processes for psychosocial care, reinforcement that psychosocial care is a team effort, and continuing to development breast care nurse competencies[12]
- That implementation of the cancer nursing education initiative identified in the Howard Government's Strengthening Cancer Care Policy be considered a priority, and that such implementation be based on a national collaborative approach to ensure benefit for cancer nurses across all areas of Australia
- That the vision provided in the National Health Workforce Strategic Framework for the health workforce over the next decade, and the

blueprint for action to achieve a sustainable health workforce be considered a priority for the Australian Government. Within these responses, specific attention should be given to the unique workforce issues for cancer nurses identified by the Cancer Nurses Society of Australia in their 2002 position statement on Cancer Nursing Workforce Issues. Actions may include:

  - Development of cancer nurse staffing models in inpatient, outpatient and community settings
  - Financial support to enable nurses to pursue further studies
  - The establishment of more joint academic-clinical appointments in cancer nursing
  - Research to develop and evaluate innovative models of cancer care involving specialist cancer nurses

- That initiatives which enable the nursing profession to achieve the requirements outlined by the International Council for Nurses for ensuring the orderly development of specialistions in nursing be actively supported through
  - the adoption of a systematic means of determining and designating nursing specialities combined with minimum standards in regard to education, experience, performance and the maintenance of competence;
  - the establishment of regulatory mechanisms for nursing specialists to ensure a certain level for competence; and
  - nursing resource planning with coordination of nursing education and workforce planning as an integral part of health system development.

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