



MEDICAL ONCOLOGY GROUP OF AUSTRALIA INCORPORATED

A.B.N 94 601 175 669

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Senator Rachel Siewart  
Inquiry Chair  
Committee Secretary  
Senate Standing Committee on Community Affairs  
PO BOX 6100  
Parliament House  
Canberra ACT 2600

community.affairs.sen@aph.gov.au

Dear Senator Siewart,

### **SENATE INQUIRY ON AUSTRALIA'S PALLIATIVE CARE-SUBMISSION**

The Medical Oncology Group of Australia Incorporated (MOGA) welcomes the Australian Senate's decision to undertake the first, comprehensive inquiry into Australia's palliative care system. This Inquiry provides an opportunity for our Association, on behalf of the Australian medical oncology profession, to present a submission that can contribute to the development of an efficient, effective and world class palliative care system for Australia.

We commend the Inquiry's very broad scope as reflected in the terms of reference which span all facets of palliative care nationally from service provision, access and choice, funding through to the interaction with various sectors, including aged care. The scope of the Inquiry correctly reflects the complexity and timeliness of this examination of palliative care in Australia.

Australian medical oncologists are major stakeholders in the Australian palliative care system, with a high level of specialist medical and clinical knowledge as well as experience and skills in managing cancer patients who require palliative care at all stages in their treatment continuum.

There is an important opportunity for Australia to benefit from a review of the international developments with regard to national palliative care systems and approaches. It is recommended that international experience, processes and information serve as valuable learning models to be adapted for the Australian context, including both positive and negative information.

#### **We submit our comments for your consideration:**

##### **ACCESS TO/CHOICE OF APPROPRIATE PALLIATIVE CARE THAT MEETS POPULATION NEEDS**

It is the view of our Association that while myriad factors influence access to and choice of appropriate palliative care to meet the needs of the population, as a nation we should ensure the provision of best possible quality of life for individual Australian patients, their carers and families. This requires the development, funding and implementation of a highly flexible, adaptable and progressive national palliative care system. It is recommended that the immediate challenge is for government at all levels to pull these many strands together and invest in improved co-ordination and an expansion of existing resources to deliver much needed improvements in palliative care services.

For instance, families and carers in addition to patients receive support from palliative care services. Families provide much of the care for people who are dying thus practical and emotional support for them in this role is critical. Palliative care services can be provided in the home, in community-based

settings like nursing homes, palliative care units and in hospitals. People who are dying need to be able to move freely in response to their medical care and support needs. The pattern of care will be different for every individual and may depend on any number of issues such as geography, services in an area, and the needs and desires of a patient family members and friends.

### **PEOPLE LIVING IN RURAL AND REGIONAL AREAS**

It is the view of our Association that Australian patients and medical oncology clinicians should have the right to access high quality health care services and support regardless of their geographic location. Like all oncology treatments, palliative care is best provided within close proximity to a patient's local environment and community. However, patients living in rural, remote and regional areas of Australia and their clinicians have limited access to oncology and cancer management services including palliative care, in comparison with their counterparts based in metropolitan centres.

This is highlighted by a recent qualitative study of the needs of Australian Rural and Regional Cancer Patients and Health Professionals in Dubbo, Tamworth, Albury and Bega that was presented in 2011 and is soon to be published: "Access to palliative care services was limited. Some palliative care drugs were not routinely carried by small rural pharmacies and others such as methadone could not be legally prescribed if there was lack of access to a specialist palliative care physician. There was also limited access to hospice care. It was harder for patients to fulfil a wish to die at home, due to the limited availability of palliative care staff to visit and administer medications. It was felt that limited access to palliative care services often led to futile treatments being offered for longer."

The authors recommend, "Improved access to specialist palliative care physicians through greater use of telemedicine and outreach services.....to address current limitations in hospice care, delivery of specialist palliative care drugs, and planned dying within the home." P. N. Butow, F. Phillips, K. White, C. Underhill, P. Grimison, D. Yip, D. Goldstein. Improving the Cancer Journey in Rural and Regional Australia. Asia Pacific Journal of Clinical Oncology, Clinical Oncological Society of Australia Annual Scientific Meeting Proceedings 2011; 7(S4):173 (Abstract 387).

### **INDIGENOUS PEOPLE; PEOPLE FROM CULTURALLY AND LINGUISTICALLY DIVERSE BACKGROUNDS; PEOPLE WITH DISABILITIES; CHILDREN AND ADOLESCENTS; THE ELDERLY**

Our Association recognises that each of these patient groups presents a range of specialised palliative care needs to be addressed by our national system. The current system for palliative care provision and funding fails to address the different care priorities, facilities and professional skills that are required to effectively and efficiently address the palliative care needs of each of these groups.

### **FUNDING ARRANGEMENTS FOR PALLIATIVE CARE PROVISION; EFFICIENT USE OF PALLIATIVE, HEALTH AND AGED CARE RESOURCES; EFFECTIVENESS OF PALLIATIVE CARE ARRANGEMENTS, INCLUDING HOSPITAL CARE, RESIDENTIAL OR COMMUNITY CARE AND AGED CARE FACILITIES**

Our Association believes that the current system for palliative care provision and funding is fragmented and there is little integration between the many service providers during transition from different care settings: viz., the transition of patients from hospital back to the community or to an aged care facility. This results in reduced efficiencies and effectiveness of resources.

Currently, a patient with terminal illness being discharged from hospital back to the community would be referred from a hospital-based palliative care team to the community palliative care service. The community palliative care service, being a separately funded organisation, would perform a reassessment of the patient and there may be a delay until that initial assessment can be performed. In the interim, there is a lack of appropriate formal arrangements for hospitals to bridge this gap as hospital-based palliative care teams are not funded to provide community support. It is recommended that hospitals be funded to provide community support.

Aged care facilities on their own do not have adequate resources to provide palliative care (such as the availability of palliative care consultants and access to syringe drivers). However, this additional resource may be provided via a community palliative care service in some areas. In other areas, a

hospital-based aged care service (e.g. the RECIPE program at Northern Hospital) may have the funding and resources to provide the palliative care service at a nursing home. It is recommended that funding be improved to provide end-of-life care in aged care facilities, which would in turn reduce the load on the acute hospital system. This would be particularly beneficial because length of life is difficult to accurately estimate and patients may live longer than expected, thus rather than holding a hospital/hospice bed, they could be treated in a community aged care facility.

An area of concern to medical oncologists is the co-ordination of palliative care services across the wide range of skills and disciplines of many service providers. The number of different service providers involved with palliative care in Australia significantly reduces the efficiency of the system. The integration of palliative, health and aged care resources under the umbrella of hospital-based ambulatory care service, with consideration made to provide hospital-based outreach palliative care service to aged care facilities (via combined palliative care / aged care units) if funding and resources were available, is a viable model. The integration of hospital-based and community-based palliative care teams is also a viable model.

### **THE COMPOSITION OF THE PALLIATIVE CARE WORKFORCE**

The Australian palliative care workforce encompasses many skills, disciplines and service providers. It is anticipated that the complexity and scope of this workforce will increase given growing and emergent areas of specialisation within palliative care and increasing patient demand. Major concerns are will the national palliative care workforce supply and the number of funded employment positions meet not only short but long-term demands.

As the medical oncology profession continues to grow and expand an increasing number of medical oncologists in Australia and overseas are working across medical oncology, the growing field of geriatric medicine and palliative care. Additionally, current medical oncology clinical practice globally is distinguished by significant changes with an increased emphasis on palliative care in the provision of oncology support to patients and the use of palliative care over extended treatment times. Service integration is vital to increase the effective delivery of these expanded palliative care activities in medical oncology and would result in substantial productivity.

### **ABILITY TO MEET THE NEEDS OF THE AGEING POPULATION**

There is irrefutable evidence that Australia's population is ageing. The 2010 Federal Government's Intergenerational Report estimated that, "Between now and 2050 the number of older people (65 to 84 years) is expected to more than double; very old people (85 and over) is expected to more than quadruple, from 0.4 million people today to 1.8 million in 2050: the number of children is expected to increase by 45 per cent. This means that, the proportion of people aged 65 years or over is projected to increase from 13 per cent in 2010 to 23 per cent by June 2050." ; [www.treasury.gov.au](http://www.treasury.gov.au). This ageing population will place substantial demands on the Australia Health sector and in particular areas such as aged care, palliative care and cancer service. Indeed, the number of new cases of cancer continues to increase by about 3% per annum due to increased population, improved longevity and increased detection rates. Over a decade, this increase amounts to nearly 40%.

The Australian Medical Oncology Workforce conducted by MOGA in 2009 showed that the 2009 and projected (2014) supply, demand and shortfall of full-time equivalent (FTE) medical oncologists was estimated at 92 to 157 in 2009 and 84 to 156 in 2014. The study also concluded that the current shortage is expected to persist in the future: See B. Koczwara, M. B. Barton, E. T. Walpole, P. Grimison, P. L. Blinman, S. Crossing, K. Francis. Workforce shortages in medical oncology: a looming threat to quality cancer care. *Medical Journal of Australia*; 196 (1): 32-33: P. L. Blinman, M. B. Barton, S. Crossing, E. T. Walpole, N. Wong, K. Francis, B. Koczwara. The shortage of medical oncologists: the Australian Medical Oncologist Workforce Study. *Medical Journal of Australia*; 196 (1): 58-61

Extensive national strategies are needed to increase the capacity of the medical oncology and palliative care workforce and address the current and future shortages by increasing recruitment, training and participation rates, improving clinical practice efficiency and the introduction of innovative methods of service delivery. Tailored national strategies will be necessary to ensure an adequate medical oncology

and palliative workforce in the future, and ongoing monitoring will be needed to guide and promote the strategies.

### **ADEQUACY OF WORKFORCE EDUCATION AND TRAINING ARRANGEMENTS**

The Association is of the view that training in palliative care principles should be an important part of training for general practitioners and rural physicians to assist them in providing support to patients, families and carers. To assist with this task, MOGA has launched two free, national e-learning programs for general practitioners and health care workers, 'Enhancing Palliation in Patients with Advanced Cancer in Rural Areas of Australia', funded by the Department of Health & Ageing and the 'Education Program in Cancer Care', funded by Cancer Australia. These programs, developed by a committee of experts, include didactic modules relating to palliative cancer treatment modalities, making decisions about palliative cancer treatments and multidisciplinary care. As viable funding options expired, these programs are currently unavailable however do represent valuable educational initiatives that could be developed further and/or made available if funding was made available.

### **ADEQUACY AND APPLICATION OF STANDARDS FOR THE PROVISION OF PALLIATIVE CARE AND FOR PROVIDING QUALITY CARE TO ALL AUSTRALIANS**

It is the view of our Association that there is a demonstrable requirement for formal recognition of the need for, and a collaborative government response to, the development of a comprehensive palliative care system. The establishment or development of metropolitan and regional palliative care centres of excellence some in conjunction with the twenty regional cancer centres provides a viable starting point. The Association also recommends the establishment of a national palliative care quality assurance framework, clinical guidelines and short-term capacity-building measures be developed in the interim.

### **ADVANCE CARE PLANNING**

#### **AVENUES FOR INDIVIDUALS AND CARERS TO COMMUNICATE WITH HEALTH CARE PROFESSIONALS ABOUT END-OF-LIFE CARE**

It is the view of our Association that there is a demonstrable need for the introduction and development of opportunities to improve patient and carer access to palliative care information including direct and on-going communication with health care professionals about end of life care and throughout the end of life palliative care cycle. It is recommended that this can be achieved by a national communications strategy and the development of information service facilities, including the introduction of web-based online services and other dissemination mechanisms such as direct online/phone consultation with health care professionals. It is recommended that accurate, regular and timely e-communications, alerts and advice be posted on an updated national Palliative Care website and circulated to stakeholders.

### **NATIONAL CONSISTENCY IN LAW AND POLICY SUPPORTING ADVANCE CARE PLANS**

It is the view of our Association that national advance care plans for the palliative care system should be underpinned by co-ordinated and consistent legislation and policy at all governmental levels in Australia.

### **SCOPE FOR ADVANCE CARE PLANS IN PERSONAL ELECTRONIC HEALTH RECORDS**

It is the view of our Association, in keeping with national Health Reform and the focus on eHealth strategies, that there is scope for the inclusion of advance care plans in personal electronic health records. However, given privacy and confidentiality concerns, we acknowledge that this decision will rest with each patient and their clinician.

### **THE AVAILABILITY AND FUNDING OF RESEARCH, INFORMATION AND DATA ABOUT PALLIATIVE CARE NEEDS IN AUSTRALIA**

It is the view of our Association that there is a demonstrable need to substantially increase the available funding to support and foster extensive research on palliative care in Australia across a wide spectrum of issues, including national palliative care needs and best practice international models of excellence. Effective facility, services and workforce planning for Australia's palliative care system can only be undertaken from an informed perspective based on current data and learning through the experience of other countries, above all to address current and short-term shortages.

### **CURRENT CLINICAL PERSPECTIVE**

MOGA is of the view that palliative care is often incorrectly classified as end of life care. Palliative care alleviates all forms of pain and distress throughout the entire cycle of a patient's illness and treatment therefore its significance to medical oncologists is increasing as it potentially improves quality of life and survival rates, alongside implications on the cost of care.

Survivorship research and the increased number of cancer survivors (due to advances in early detection, treatment and population ageing) highlight additional palliative care requirements for cancer survivors coping with life during and beyond acute treatment. The resultant blurring of the once clear distinction between cancer patient and survivor has substantial demand implications for medical oncology practice and palliative care in Australia and overseas with cancer survivors more frequently requiring on-going treatment and care for extended periods of time: Victorian Cancer Survivorship Program, Department of Health Victoria, [www.health.vic.gov.au](http://www.health.vic.gov.au)

A recent ASCO Provisional Opinion explores the integration of palliative care services into standard oncology practice at the diagnosis stage for patients with metastatic or advanced cancer; See T. J. Smith, S. Temin, E. R. Alesi, A. P. Abernethy, T. A. Balboni, E. M. Basch, B. R. Ferrell, M. Loscalzo, D. E. Meier, J. A. Paice, J. M. Peppercorn, M. Somerfield, E. Stovall, J. H. Von Roenn. American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care; posted ahead of print on [www.jco.org](http://www.jco.org), February 6, 2012. This study, based on phase III trial data, contends metastatic non-small-cell lung cancer patients should be presented with synchronised palliative and oncology care at the point of diagnosis and this approach should also be considered early in the treatment cycle for any patients experiencing high symptom burdens.

The Association believes strategies to advance these concurrent care models should form the focus of future in-depth research as evidence demonstrates palliative care combined with standard care, or as the main focus of care, offers improvement to patient outcomes, including symptoms, and reducing the burden on the caregiver. Further, whilst patients are increasingly able to access hospice and other care services, the benefits derived from these services are still limited as most are only admitted in the last weeks of their lives. Palliative care during early stages of diagnosis and treatment leads to more effective and efficient uses of hospices, reducing the burden on intensive care. Additionally, consideration should be given to the cost and resource savings, in financial and emotional terms, from futile end of life care and medication.

### **COMPLEMENTARY MEDICINES**

There are a number of issues pertaining to complementary medicines and treatments that impact on the delivery of the Australian health care system, including palliative care. There is a clear lack of appropriate legislation and monitoring regarding complementary medicines and treatments in Australia, complicated further by substantial misinformation as well as misunderstanding in the marketplace. There is also an urgent need to address emerging issues caused by the increasing number of unregulated medicines, technologies, tests and treatments in the Australian marketplace, many of which are bogus.

The current arrangements for disclosure of information in relation to complementary medicines and treatments in the market are not appropriate and there is a need for promoting awareness of this information and increasing the amount of information that is available; See L. Braun, E. Tiralongo, J. M. Wilkenson, et al. Adverse Reactions to complementary medicines: the Australian Pharmacy experience. *International Journal of Pharmacy Practice* 2010; 18: 242-24. There is no suitable regulatory organisation that deals with complementary medicines and treatments at a national level. The Therapeutics Goods Administration's (TGA) role with regard to complementary medicines and treatments is unclear and it is recommended that this be examined with a view to being expanded to take on this national role, including an active media and communications function that will provide stakeholders with responsive, up to date information on key issues, especially core media issues that impact on the public interest. This will also ensure that the stakeholders who are most impacted viz., health practitioners and patients, are fully advised regarding the benefits and limitations of complementary medicines and alternate treatment options.

Complementary medicines and treatments are considered to be inherently low risk medicines but this is not always the case and issues of combinatory use with regard to oncology drugs and treatments, toxicology, stability and manufacturing need to be evaluated by the regulator and this information made available. For instance, the “generic” concept for conventional medicines is invalid for complementary medicines and the current listing system has allowed the misconception that all complementary medicines containing the same ingredients are equally effective. It is recommended that all therapeutic goods not assessed for efficacy by the TGA must contain an appropriate warning on their public summary document, the product label and marketing material. This submission supports and recommends full disclosure of product information in relation to ingredients/formulas, toxicology, stability and manufacturing for complementary medicines and treatments but recognises that this would breach a range of commercial considerations.

### **PALLIATIVE CARE ONCOLOGY DRUGS AND TREATMENTS**

Timely and affordable access to oncology drugs and treatments is an important part of palliative care, that is of direct and immediate concern to Australian medical oncologists as the consulting specialist and chief prescriber. Many medicines used in oncology and palliative care are available in Australia, most under the Pharmaceutical Benefits Scheme (PBS) or through special access programs. However, Australia continues to lag behind other advanced nations in providing timely and cost effective access to proven oncology drugs and treatments that are available overseas. Additional issues including drug shortages, access to generic drugs and drugs going off patent also have an ongoing negative impact on the capacity of medical oncologists to effectively provide Australian cancer patients with appropriate medical and palliative care. A national application process needs to be developed to allow professional organisations representing clinicians to make no-cost applications for the listing of drugs for other indications based on recent phase III trials or small trials for very rare tumours, in instances where there are no incentives for generic and originator pharmaceutical companies.

Our Association is of the view that the need for palliative care does not depend on any specific medical diagnosis but on a patient's needs. Further, we are of the view that the aim of palliative care is to achieve the best possible quality of life for the individual patient, their carers and family. This submission recognises the need for all Australian's to have appropriate and timely access to medicines, treatments and palliative care of the highest quality, that are safe, effective and caring.

MOGA would like to invite the Inquiry Committee to seek our assistance on any relevant issues that may require expert oncology and clinical advice of international best practice standard. MOGA has substantial expertise regarding oncology drugs and treatments, and have been highly proactive in working closely with the Pharmaceutical Industry, Department of Health and Ageing, regulatory bodies and other stakeholder organisations to benefit the Australian Health system.

We trust that the matters detailed in this submission will be of assistance and would be pleased to provide further advice should this be required. We look forward to the Inquiry's September 12 Report and working with the Senate Review Committee in the future.

Yours Sincerely,

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Associate Professor Gary Richardson  
Chairman  
Medical Oncology Group of Australia