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Senate Standing Committees on Community Affairs
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The voice of people
affected by cancer

Dear Committee Secretary

Inquiry into Palliative Care in Australia

Cancer Voices NSW is pleased to offer a submission to the Inquiry into Palliative Care in Australia, referred to the Senate Community Affairs Committees on 23 November 2011 for inquiry and report.

Cancer Voices NSW provides the independent voice of people affected by cancer in NSW, working to improve the cancer experience of the 40,000 people who are diagnosed with our disease each year. Established in 2000, we focus on the areas of diagnosis, information, treatment, research, support, care and assistance. To achieve this we work in partnership with providers of these services, ensuring the patient perspective is heard, from planning to delivery.

Cancer Voices NSW's Palliative Care Campaign 2010-2012

Members of Cancer Voices NSW inform our views and the direction of our advocacy. Over the last few years we have heard increasing concern expressed by members regarding access to palliative care services in our state.

Our first formal activity was to develop a Position Statement based on the issues raised and recommendations reached; the most recent of these is attached as Appendix A. Due to substantial funding cuts to community palliative care services in the Northern Sydney area, coupled with our concerns about state-wide services, we decided to raise a public petition, which attracted 24,000 signatures.

Our petition was debated in NSW Parliament on 10 August 2011. The Minister for Health, the Hon Jillian Skinner MP, immediately announced that both issues would be addressed. They were:

- Immediate and direct provision of a level of funding to HammondCare sufficient to enable them to restore delivery of community palliative care in the Northern Sydney area to meet present requirements.

- Funding which actually meets the true palliative care requirements of communities throughout NSW, and which is isolated solely for this purpose and not subsumed into the general sub acute budgets of Local Health Districts.

The Minister stated in her media release:

"Mrs Skinner is committed to increasing palliative care services across the state

NSW Health will map current palliative care services against population needs; investigate population planning tools used in other jurisdictions to assist in future service planning; examine the current workforce and identify any gaps, and examine training and resources available to support volunteers, carers and health workers" Mrs Skinner said. "This is an exciting announcement because it again gives palliative care the importance it deserves in our community".

Since then Cancer Voices NSW has been represented on the NSW Ministry of Health's Palliative Care Expert Advisory Group, through Health Consumers NSW, the peak organisation for the users of health services in this state. This Group provides advice as to how the Minister's directive should be activated and its report will be delivered to the Minister shortly.

We ask the Senate Inquiry to note that NSW is now looking at a number of the matters raised by the Inquiry's current terms of reference, as a result of our advocacy efforts.

In January Cancer Voices NSW provided a detailed submission to the Policy Discussion Paper "Palliative Care in NSW" (Palliative Care NSW), which is available on request.

Regarding the **Inquiry's Terms of Reference**, Cancer Voices NSW offers the following comments.

The provision of palliative care in Australia, including:

(a) The factors influencing access to and choice of appropriate palliative care that meets the needs of the population:

A principal factor is that there is very little data about the supply of or demand for palliative care services. Obviously planning decisions cannot be made in a rational, effective and efficient way without this kind of information.

(i) Including people living in rural and regional areas

Cancer Voices NSW has identified a number of problems which are specific to people living in rural and regional areas. These are listed in Appendix B

(ii)-(v)

While recognising the importance of understanding the specific needs of these groups, Cancer Voices NSW is not in a position to gather such information.

(b) the funding arrangements for palliative care provision, including the manner in which sub-acute funding is provided and spent;

This is a problem area to which we have drawn the attention of the NSW Government through petition (see above) and through regular representations. We understand that the palliative care component of sub-acute funding is often siphoned off by hospitals and/ or Local Health Districts to other "sub acute" areas which may appear more pressing at the time. CVN recommends that palliative care funding should be quarantined to this purpose only, within health budgets and at all levels.

(c) the efficient use of palliative, health and aged care resources;

Efficient use of resources will occur when supply and demand factors are fully understood and addressed, and when gaps are identified and filled. Present lack of understanding of the community's current and future need leads to an inability to provide either effective or efficient services.

(d) the effectiveness of a range of palliative care arrangements, including hospital care, residential or community care and aged care facilities;

Palliative care services though this range should be, but are not, seamless for the patient. CVN has observed almost complete **lack of co-ordination between these services**, even where they do separately exist. This gives rise to enormous anxiety for consumers and their families and friends. It also gives rise to substantial wastage of public money, especially when palliative patients are sent to acute hospitals where beds cost ten times that of a palliative bed, and larger multiples for hospice, residential or community care at home – the latter preferred by most people needing palliative care.

(e) the composition of the palliative care workforce, including:

(i) its ability to meet the needs of the ageing population, and

(ii) the adequacy of workforce education and training arrangements;

Cancer Voices NSW recommends that a national study be undertaken to address the extremely important issue of adequacy of the workforce and what workforce will be needed to meet future demand. CVN initiated a study of the adequacy of the medical oncology workforce, as a partner with the medical Oncology Group of Australia. Overview of the results and recommendations of this study were published in the Medical Journal of Australia in January 2012. CVN recommends that a similar study be undertaken to establish the shortfalls, present and future of the various levels of palliative care workforce, so that gaps may be identified and addressed. The study should examine each state's situation as well as the national picture.

(f) the adequacy of standards that apply to the provision of palliative care and the application of the Standards for Providing Quality Care to All Australians

CVN's concern is that the standards that exist are **not** being applied; the question should be more how can we ensure that the standards developed by the states and nationally are in fact applied and their application adequately funded?

(g) advance care planning, including:

(i) avenues for individuals and carers to communicate with health care professionals about end-of-life care,

(ii) national consistency in law and policy supporting advance care plans, and

(iii) scope for including advance care plans in personal electronic health records;

(i) Cancer Voices NSW is fully supportive of the need for better, more normalised communication about end-of life care. As a health consumer group we advocate for this regularly, as do others.

However, we suggest that health professionals should be more able, and should offer, to discuss these matters openly and freely, recognising constraints in doing this resulting from some cultural positions.

(ii) CVN also concurs that there should be national consistency in law and policies supporting advance care planning. We wish the Inquiry to note that this should include a requirement that such plans should be honoured by hospital and medical staff – we are advised that this is not always the case, perhaps due to uncertainty about their standing.

(iii) CVN fully supports the idea of including advance care planning in electronic health records – there should be a prompt for inclusion.

(h) the availability and funding of research, information and data about palliative care needs in Australia.
This aspect underpins the ability of our health services to meet the needs of health consumers seeking palliation at the right time, the right place and at the right level for their specific needs.

Concluding Remarks

Through consultation with our sister Cancer Voices in other states, most specifically Cancer Voices South Australia, we are aware of similar problems for people with cancer seeking adequate palliative care in other jurisdictions. As a founding member of Health Consumers NSW, we are also aware that these problems are fully shared by those people who do not have cancer, but have a real need for palliative care. Thus the information we provide in this submission, although based on the experiences of people seeking palliative care in our own state, may be seen as a representing issues beyond our own jurisdiction and specific disease.

Yours sincerely



Sally Crossing AM
Deputy Chair
15 Feb 2012

BETTER PALLIATIVE CARE SERVICES for NSW

Cancer Voices NSW Position Statement

ISSUE:

Cancer Voices NSW is concerned about recurring reports of cuts to funding for NSW palliative care services. We believe this is serious enough to become one of our two top issues in the upcoming NSW election. Actual palliative care funding levels appear to have been eroded badly, when the opposite should be occurring.

PRESENT POSITION:

Specifically these cuts relate to:

- Reduction in palliative care beds (eg Sacred Heart Hospice)
- Loss of community palliative care funding (eg 40% cut to North Shore area)
- Further limits on time in palliative care beds
- Insufficient positions for palliative care specialists, nurses and community teams

Funding cuts are of particular concern as the demand for palliative care has and is increasing with an ageing population. There are and will be concomitant increases in the cancer burden, and a projected higher incidence of cancer (30% increase over next ten years, according to the Cancer Institute NSW). 85-90% of palliative care recipients have cancer.

Many people affected by cancer are concerned about being able to access palliative care services. Cancer Voices NSW consumer representatives across NSW, in rural, regional and metropolitan sites, report difficulty in accessing palliative care where and when they need it. This relates to palliative care beds, specialists, and community based home care teams – the full spectrum.

RECOMMENDATIONS

- Publication of data on expenditure on palliative care services by the NSW Area Health Services (individually and total) over the last three financial years – ie 2007/8, 2008/9 and 2009/10, by palliative hospital beds, community care and hospice expenditure.
- Quarantining of palliative care funding away from “sub acute” budgets, for palliative care specialists, nurses and community teams to mandate that it is spent where it should be
- NSW Health Policy Directive to ensure palliative care funding is not redirected by hospitals as they try to meet conflicting internal budget demands.
- For immediate attention and for planning purposes, a report on palliative care funding cuts over three years and their impact
- That the new Local Health Districts should have staffing levels, beds and community services to meet current palliative care needs .
- A full review of the palliative care workforce to numerically identify levels of service and current and predicted gaps, and by site.
- Publication of NSW palliative workforce levels using international benchmarks per 100,000 population, by Local Health District.
- Quarantining of palliative care funding sourced from the national government to palliative care services
- Clarification of the roles of NSW Health, the NSW Palliative Care Advisory Group and the State-wide Centre for Improvement of Palliative Care (SCIP) in developing and implementing the NSW Palliative Care Strategy.

- Publish information re distribution to NSW, and within NSW, of funding by the Australian Government's National Palliative Care Program, amounting to \$33 million for NSW through COAG.

June 2011

PROBLEMS IDENTIFIED BY RURAL CNCs and RURAL DOCTORS

1. Extinction of life: There is concern amongst primary health care providers and specialist palliative care nursing staff related to their legal standing when a palliative patient dies at home following a planned home death. This is related to the circumstance where the patient's doctors are unavailable to attend. Pending further advice and clear direction from NSW Ministry of Health Legal Branch RNs currently believe themselves to be not legally supported in NSW to pronounce life extinct after a patient dies. Clear direction and formal advice to the NSW Police and Ambulance Services is urgently required. Currently the Police consider this situation a Coroner's case and will declare the home a crime scene. NSW Ambulance service is not able to transport a deceased person except in unusual situations which don't apply to most palliative care patients. This issue is across the board, but more pronounced in rural areas due to less access to GP services.
2. Ambulance Service: When called, ambulance personnel are required to follow the resuscitation algorithms, regardless of the patient & family's wishes, or advance care plans etc.
3. Staffing: There are great difficulties maintaining rural services on a shoestring. Due to very small services, and a lack of adequately trained staff who would be suitable to backfill, Palliative Care Nurses are very seldom relieved. Few resources are available to actively and thoroughly engage in succession planning and associated training including education. Consequently when a Palliative Care Nurse takes leave a Palliative Care Nurse from a neighbouring service will often provide telephone coverage over a very large geographic area. This can lead to hospital presentations which would usually be avoided. There can be lengthy waiting times in Emergency Departments which are distressing for patients and their families. Many Palliative Care Nurses are operating at Advanced Practice level because of the paucity of medical support – both specialist Palliative Care and GPs. Most services are understaffed. As a result patients and families are not able to receive a comprehensive level of service and support. There is no funding identified to support succession planning and, with low staffing numbers, little time to train new staff. Community based nurses are often supported in the provision of palliative care via phone support due to staffing constraints within the specialist Palliative Care services.

Most rural services are only funded to provide a service from 0830 – 1700, Monday to Friday with very limited or no access to after-hours specialist Palliative Care nursing support after 5pm, over the weekend and particularly during the Christmas / New Year period. In many areas there is also inadequate general community nursing support which compounds the situation.

In many rural regions there are insufficient numbers of community nurses to provide adequate palliative care for even non-complex patients. This can lead to inappropriate presentations to Emergency Departments, premature admission and delayed discharge.

Given the limited education about palliative care which undergraduate nurses receive, Palliative Care CNCs and CNSs spend significant amounts of time teaching hospital and community based nurses a palliative approach to care including symptom management.

4. Medication: In most rural locations, the availability of adequate and appropriate medications in the home for palliative care patients is reliant on nursing staff proactively liaising with GPs and suggesting a plan of care. This relies on nursing staff (both community-based and Palliative Care) anticipating symptoms which patients may experience based on their disease. There are varying

levels of support from GPs to provide prescriptions in advance of symptoms. Local community pharmacies do not all stock the usual medications required in the palliative setting and time delays can be experienced in the supply of medications to a patient's home.

Local hospital pharmacists are not usually trained in palliative care and some do not stock the range of medications used in managing the symptoms palliative care patients experience. This can lead to the need to use substitute medications which is not best practice in Palliative Care.

A number of medications used in palliative care are not on the PBS and some patients can't afford the cost of a private prescription for medications such as Gabapentin.

ENABLE: Access to Oxygen supplies (concentrators and cylinders) is a significant issue because ENABLE demands blood gases before they will supply cylinders. (more about this later)

5. Problems with GPs: There can be difficulties in engaging with GPs to provide their patients with appropriate levels of palliative care, including home visits. PC competes with many other disciplines and geographical distances often present difficulties for GPs to attend education opportunities which are available.

There is not a good level of awareness of the Therapeutic Guidelines Palliative Care or British Gold Standards Framework model of support for GPs .
6. Telemedicine to provide specialist medical and nursing support is underutilised. Resources are required to promote its use, train users and research its effectiveness. Enticements may be required to encourage overstretched GPs and nurses to participate. It is important to note that an increase in Telehealth is not a substitute for adequate numbers of multidisciplinary Palliative Care staff in rural areas.
7. Access to Allied Health is poor with very few positions designated as palliative care but there are allied health in oncology, rehab and aged care teams. A population based approach to Palliative Care Allied Health positions is needed across the state and these positions need to provide resources and support to up-skill generalist Allied Health staff.
8. Formal Access to specialist cancer-specific CNCs in metropolitan services is needed when required - e.g. tumour stream care coordinators such as colorectal CNCs.
9. Community assistance packages: Access by palliative patients to HACC type support is grossly inadequate. Like the previous points this leads to inappropriate presentations to Emergency Departments, premature admission and delayed discharge.
10. Twining of Metropolitan with Rural Services: While many services have existing service agreements with metropolitan palliative care services to provide specialist medical support in reality staff shortages often prevent the specialists from fulfilling these agreements. This leads to a difficulty in providing reliable, consistent access to support. There is nervousness amongst both specialist nursing teams and primary care professionals, especially GPs, that the needs of complex palliative patients can be addressed. Phone support offered by metropolitan services is utilised more often when fly-in fly-out clinics are infrequent or non-existent.
15. RACFs: Many Residential Aged Care Facilities (RACF) are not staffed adequately, particularly with regard to RN's to be able to provide adequate support for palliative care patients. It is a requirement of their accreditation that RACFs provide a palliative approach to care of their residents. RN's are required to provide the full range of symptom and end of life support including

symptom assessment, ordering and administration of medication, particularly schedule 8's and to be able to provide prn medication administration. On many occasions this leads to admission into an acute care facility, often through Emergency Departments that lead to unnecessary trauma for both the patient and their family.

16. The announcement of the \$90 million Cancer Centre in Tamworth did not include anything about palliative care. What a missed opportunity! Likewise the new Cancer Centre in Orange has no palliative care funding, yet its existence generates more palliative care work for the already stretched-to-the-limit Palliative Care Service. Now with other cancer centres going in elsewhere in NSW e.g. Nowra and Royal North Shore this is an opportunity to encourage greater development of palliative care services in each area in question.
17. Doctors have been asking to have palliative care specialists in each of the regional centres for years.
18. Bereavement services, if any, are not formalised services of adequate size to be able to provide a service to families.
19. Referrals: Specialists and GPs alike can be slow to refer to palliative services. Psychosocial and symptom control needs are frequently ignored.
20. Coordination of services is a problem in rural areas as it is in the city. Palliative care is best placed to be the lead service which can direct and coordinate a collaborative team approach.

(Collated for Cancer Voices NSW by Yvonne McMaster, Jan 2012)