Palliative
Care
Australia

Submission to the Australian Senate

on

Implementation of the National Health Reform Agreement

on behalf of

Palliative Care Australia

Contact:

Dr Yvonne Luxford
Chief Executive Officer
Palliative Care Australia
PO Box 24
Deakin West ACT 2600

Ph: 02 6232 4433
M: 0420 537 211

yvonne@palliativecare.org.au

February 2013

The Issue

Palliative Care Australia is deeply concerned that the use of retrospective adjustment to funding levels announced through the *National Health Reform Agreement* is creating immediate funding crises resulting in patients assessed as needing palliative care, particularly as they approach the end of their life, not being able to access services that were previously available.

PCA is deeply concerned that the lack of planning for the cessation of funding through the *National Partnership Agreement on Hospital and Health Workforce* will further reduce service delivery.

PCA is deeply concerned at the impact of these combined funding reductions on the palliative care workforce. At a time when demands for palliative care services are growing, the palliative care workforce may be decimated.

The likely outcome is that Australians will die without their needs being met.

Palliative care

Palliative Care Australia (PCA) is the peak national organisation representing all state and territory palliative care organisations, the Australian and New Zealand Society of Palliative Medicine, and the interests and aspirations of all who share the ideal of quality care at the end of life.

Palliative care[1] will affect all of us at some stage in our lives whether as a patient, carer, family member, neighbour or friend. When an illness cannot be cured, the focus of care changes to supporting and assisting patients to have the best quality of life possible while managing their symptoms. Palliative care maintains quality of life by addressing physical symptoms, such as pain or nausea, as well as helping with emotional, spiritual and social needs. A person receiving palliative care will have an active, progressive and far advanced disease, with little or no prospect of cure. The

---

[1] The World Health Organization (WHO) defines palliative care as:

> …an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and
- Includes those investigations needed to better understand and manage distressing clinical complications.

World Health Organisation, *WHO definition of Palliative Care*, 2008.
http://www.who.int/cancer/palliative/definition/en/

aim of palliative care is to achieve the best possible quality of life for the individual patient, their carers and families.

Access to palliative care and appropriate treatment of pain is a human right in accordance with various international declarations and protocols. Yet access to palliative care in Australia is a lottery – with access determined by diagnosis, age, cultural background and the knowledge of the treating health professional.

PCA welcomes the opportunity to comment on the level of Commonwealth funding provided to the states and territories through the National Health Reform Agreement.

Palliative care is delivered in both community and hospital settings, and changes in the level of funding to jurisdictions has a direct impact on the level of palliative care that can be delivered nationally in both settings.

Funding formulae

PCA supports public health funding that is derived from funding formulae that recognise the population, its geographical and age distribution and the additional costs of delivering services outside the major metropolitan centres.

PCA recognises that dispersal of funding between the states and territories will always be complex and contentious.

Palliative care in a rapidly ageing society

With a rapidly ageing society, particularly in regional, rural and remote Australia, the demand for palliative care services is increasing in all settings.

This submission concentrates on the funding that has been dispersed under a Council of Australian Governments (COAG) *National Partnership Agreement on Hospital and Health Workforce Reform*, which included enhancing the provision of subacute care services – and two key issues:

- Reductions in the level of funding available for this financial year; and
- Potential closure of palliative care services on 30 June 2013.

Palliative care services

The recent change in funding for public hospital services, which was advised to jurisdictions in December 2012, is bringing significant challenges for palliative care services. What is particularly difficult is that the reductions are being applied to current year services – effectively being implemented retrospectively. Services that have planned on a budget of *X* in 2012-13 are now being told that their budget is *X-Y*. For many services, the only way to meet the sudden reduction will be to cease services immediately, or cease admitting new persons into the service. The rationing of services that will result will mean patients will not be able to access the palliative care services they need, and would be assessed as requiring. It will also significantly compromise the palliative care workforce.

In addition, the COAG *National Partnership Agreement on Hospital and Health Workforce Reform*, which also supports the delivery of a range of palliative care services, is scheduled to conclude on 30 June 2013.

The combination of these two funding issues has the potential to decimate the level of palliative care services provided throughout Australia.

The potential conclusion of the COAG *National Partnership Agreement on Hospital and Health Workforce Reform* and lack of transitional arrangements is resulting in palliative care services in each state and territory potentially facing closure on 30 June 2013. Staff in these services are looking at options to guarantee their future, which may result in a loss of many staff to overseas services or to staff leaving palliative care altogether. Should either option occur, the result on the palliative care workforce will take decades to remedy.

The impact of such closures will be catastrophic nationally. For example:

- In New South Wales, it is estimated that at least 53.95 full time equivalent (FTE) positions will cease on 30 June 2013.

- In South Australia, indications are that in excess of 30 FTE positions will cease on 30 June 2013.

In addition, the reduction in public hospital funding through changes to the *National Health Reform Agreement* is leading to immediate closures, both permanent and temporary, in the jurisdictions. For example, in Victoria an outpatient clinic has closed permanently and five palliative care beds have closed temporarily with more closures, temporary or permanent possible as health services look at how to address the sudden cut in current year funding.

From 2008-09 to 2012-13, the COAG *National Partnership Agreement on Hospital and Health Workforce Reform* has seen the appointment of new or increased palliative care social work and occupational therapy, palliative care Aboriginal health workers, palliative care support for residential aged care facilities, medical consultations in the community, advanced trainee positions in Palliative Medicine, bereavement coordinators for paediatric palliative care, plus many in hospital and community palliative care nursing positions across Australia.

This has enabled greater support for palliative care in all settings and particularly for palliative care delivered in residential aged care services.

Examples of the impact on palliative care services

In NSW, the positions at risk cover Medical, Nursing and Allied Health service provision across Metropolitan, Regional and Rural NSW. The specific Local Health Districts impacted are Central Coast, Illawarra / Shoalhaven, Northern Sydney, Sydney, South Eastern Sydney, South Western Sydney, Western Sydney, Hunter New England, Northern NSW, Western NSW plus the St Vincent’s Network.

In SA, the positions at risk cover Medical, Nursing and Allied Health service providers across metropolitan, regional and country SA including Mount Gambier, Adelaide Hills, Barossa / Gawler and Southern Fleurieu (Victor Harbour) area.

Particularly at risk in SA is the highly successful End of Life Choices program. This program entails four different types of funded packages of individually planned care options for people in the palliative phase requiring extra support to remain at home.

The intention of these packages is to provide end of life care in the community (instead of in hospital) and support people to enable them to die at home (should they so choose) or spend as much time at home as possible.

The suite of alternatives currently supported through the End of Life Choices program include:

- Terminal Phase of Care – for use in the last week of life
- Stabilisation Care – used as a short-term strategy in response to a rapid escalation of an existing or new symptom
- Respite Care – for short periods of both planned and unplanned caregiver respite
- Complex Continuing Care – the continuing care of a person at end of life at home who would otherwise require admitted care in a hospice or hospital.

On the basis of need, these choices are also accessible to support home based care at the end of life provided by generalist providers. A critical enabler is the availability of the right mix of Registered Nurses and personal care workers required for this work, particularly at short notice, after hours and overnight.

The types of support End of Life Choices may provide include:

- Nursing management / care;
- Personal care (Activities of Daily Living);
- Allied health assessment and therapy depending on client need;
- Carer respite;
- Short term supply of equipment;
- Overnight support if required; and
- Other services as negotiated.

Neither medication nor transport is covered by the program.

The general eligibility criteria for the program include:

- A life limiting illness – malignancy, end stage chronic illness (renal, cardiac etc) – with an expected prognosis of 6 months. The prognosis is made on clinical indication.
- The client and their carer / family (if available) agree with the preferred place of care / death being in the home setting and consent to end of life care at home.
- The client requires end of life services in metropolitan or country South Australia and is admitted to, or is at risk of admission to, a metropolitan or country hospital, and could be safely managed at home if appropriate short term home based supports are made available.
- It can be clearly demonstrated that the provision of an End of Life Choices care option will enable the client to immediately avoid an emergency department presentation, or hospital admission or that the client is able to be discharged earlier than otherwise possible, resulting in saving of hospital bed days.
- The client requires a level of care that can be safely provided within the home or other alternative accommodation environment.
- The client is clinically assessed as being appropriate to manage at home.
- The client has access to a medical practitioner who is available and willing to accept medical management of the client.
- Request for services / care is within the scope of the program to achieve safe and effective home care.
- Services are not expected to exceed seven days (for terminal and stabilisation options).

End of Life Choices also offers options of care for clients living in residential care facilities. The options must reflect the need for advanced clinical and / or technical professional care or support care that is outside the capacity and scope of practice for that residential care facility, both in frequency and intensity on a daily basis.

Where the End of Life Choices coordinator or service provider identifies the availability of an alternative funding stream to support client care, the service provider is obliged to access this funding (eg private health insurance, Department of Veterans Affairs or Workcover) and able to access home support through this means. The End of Life Choices options of care are designed to supplement or top up existing community supports, not replace them.

The impact of cessation of the funding
Funding through the *National Partnership Agreement on Hospital and Health Workforce Reform* has resulted in a range of highly successful palliative care programs, such as the program above from SA.

Should the funding through this Agreement cease these palliative care services, including those working with residential aged care facilities, will cease operation. This will leave many staff unemployed and likely to move out of palliative care. However, the impact will be significantly broader than the cessation of services.

Combined with the reduction in funding announced through the *National Health Reform Agreement,* the result of such cuts will affect clinics and education programs conducted with universities planned for 2013-14, compromising training of future palliative care professionals.

Rapid response to get patients home or to support them to stay at home will not be available, resulting in significant increases in hospitalisations. Further, the lack of staff to plan and provide complex case management will result in longer hospitalisations for palliative patients. Transfer of hospital patients to hospice will also be affected.

Social work services which support both patients and their families and carers will be reduced and other services, such as pharmacists for example, would no longer be available to assist with education and support for nurses and doctors. In addition, palliative care research and trials will be at risk.

Paediatric palliative care services, which have also expanded under the current subacute funding, will also be compromised, and will not be able to retain the current level of support to families caring for children with life limiting conditions.

PCA is aware that in Victoria five inpatient palliative care beds have been closed temporarily by one health service and one palliative care outpatient clinic has been closed permanently. However, decisions about how to manage the cuts are being made by each health service, so it is difficult to know the true impact in Victoria at this stage.

There are also flow-on consequences. Palliative care services have reported that inpatient cuts are impacting on the timing of adequate planning of discharges of patients who require community palliative care services. This is likely to result in higher rates of hospitalisation for palliative care patients.

PCA is deeply concerned that the use of retrospective adjustment to funding levels announced through the *National Health Reform Agreement* has the potential to create immediate funding crises resulting in patients assessed as needing palliative care, particularly as they approach the end of their life, not being able to access services that were previously available.

PCA is deeply concerned that the lack of planning for the cessation of funding through the *National Partnership Agreement on Hospital and Health Workforce* will further reduce service delivery.

PCA is deeply concerned at the impact of these combined funding reductions on the palliative care workforce. At a time when demands for palliative care services are growing, the palliative care workforce may be decimated. Staff facing the end of their contracts will have no choice but to make employment plans overseas or in other specialties.

The outcome will be a sudden and significant increase in hospitalisations throughout Australia – hospitalisations that public health systems already under pressure will struggle to support appropriately. As many will enter through Emergency Department (ED) presentations, this will also result in additional pressure on EDs.

In regional, rural and remote communities, the lack of community services will place additional strain on local hospitals and may result in patients nearing the end of life being transferred if beds are not available, placing significant strain on families and carers.

Recommendations

PCA calls for an immediate clarification of the level of funding to support palliative care services to ensure continuation of vitally needed services.

PCA calls for immediate confirmation that services currently funded and staffed through the *National Partnership Agreement on Hospital and Health Workforce* will not be reduced.

Should the current situation continue, palliative care services and the long term future of the palliative care workforce will be at risk. Should services cease, the impact on patients, families and carers, hospitals and the workforce will be significant.

PCA believes this situation is unacceptable and seeks immediate steps to ensure the future of palliative care services and the palliative care workforce.