

E. A Public Health Oriented Palliative Care System in Australia

Overview

Similar to other developed countries, Australia’s population is ageing and there is increasing demand for equitable access to high quality end-of-life care. Life expectancy has improved over the past 20 years by 6.1 years for males and 4.2 years for females.¹⁵³ Increased longevity has brought advanced levels of frailty and higher rates of chronic diseases. Although most Australians prefer to die at home, data indicates that only 26% of people die at home or in a nursing home. Of the 144,000 people who die annually in Australia, it is estimated that between 36,000 and 72,000 people will need palliative care.¹⁵⁴ Another challenge is that there are specific groups that experience difficult access to the type of care they need and prefer, such as Aboriginal people, people from culturally and linguistically diverse backgrounds, and people living in rural and remote areas.

Australian National Palliative Care Strategy

The 2010 National Palliative Care Strategy in Australia recognized the need for a population needs-based whole systems approach to improve quality of palliative care and increase coverage of services geographically and in its reach to all groups in the community.¹⁵⁵ After consulting with the palliative care community in Australia, four strategic directions were identified: (See Table 6)

Table 6 Australia’s National Palliative Care Strategy 2010

Priority Area	Number	Goal
Awareness and Understanding	Goal 1	To significantly improve the appreciation of dying and death as a normal part of the life continuum.
	Goal 2	To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to, palliative care services.
Appropriateness and Effectiveness	Goal 3	Appropriate and effective palliative care is available to all Australians based on need.
Leadership and Governance	Goal 4	To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches.
Capacity and Capability	Goal 5	To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.

¹⁵³ Australian Bureau of Statistics (ABS) 2009, 3302.0 Deaths, Australia, 2008, Canberra.

¹⁵⁴ Palliative Care Australia. 2005 A Guide to Palliative Care Service Development: A population based approach.

¹⁵⁵ Commonwealth of Australia. 2010. National Palliative Care Strategy: Supporting Australians to Live well at The End-of-life.

National Policies and Programs funded by the Australian Government have been developed to support the State and Territorial Authorities and service providers to achieve the National Strategic Goals. (See Table 7)

Table 7 Australia’s National Palliative Care Programs Mapped to the Essential Public Health Elements

	Public Health Approach <i>Essential Elements</i>	Corresponding National Palliative Programs in Australia
1	Monitor health status	- Palliative Care Services in Australia- Data & Reports since 1999 (by Australian Institute of Health and Welfare) ¹⁵⁶
2	Diagnose and investigate health problems	
3	Inform, educate, and empower people about health issues.	- CareSearch- Australian Palliative Care Knowledge Network. ¹⁵⁷ -Palliative Care Australia ¹⁵⁸ - activities - Advance Care Planning Australia. ¹⁵⁹
4	Mobilize community partnerships and action	-Compassionate Communities Network ¹⁶⁰ -Alzheimer’s Australia ¹⁶¹
5	Develop policies/standards/regulations and community-wide plans	- Palliative Care Australia Standards ¹⁶² - Palliative Care Service Provision –A Planning Guide - Palliative Care Service Development Guide: A population-based approach - Palliative Care Guidelines in the Community Setting ¹⁶³ - Palliative Care Needs Assessment Guidelines and Tools ¹⁶⁴
6	Enforce laws and regulations that protect health and ensure safety.	- Palliative Care Australia’s Submission to the National Commission of Audit.
7	Link people to needed personal health services and Assure the provision of health care when otherwise unavailable.	-CareSearch- Australian Palliative Care Knowledge Network - Palliative Care Australia -activities -Rural Palliative Care Project ¹⁶⁵ (assuring provision of culturally appropriate care in rural/remote communities)
8	Assure competent public and personal health care workforce.	- CareSearch- Australian Palliative Care Knowledge Network

¹⁵⁶ <http://www.aihw.gov.au/publications/palliative-care/>

¹⁵⁷ <http://www.caresearch.com.au/Caresearch/Default.aspx>

¹⁵⁸ <http://www.palliativecare.org.au/AboutUs/AboutPCA.aspx>

¹⁵⁹ <http://advancecareplanning.org.au/>

¹⁶⁰ <http://compassionatecommunities.net.au/>

¹⁶¹ <https://fightdementia.org.au/>

¹⁶² <http://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow090570.pdf>

¹⁶³ <http://www.health.gov.au/internet/main/publishing.nsf/Content/palliativecare-pubs-compac-guidelines.htm>

¹⁶⁴ <http://www.caresearch.com.au/Caresearch/Portals/0/Documents/WhatisPalliativeCare/NationalProgram/PallCareNeedsAssessmentGde.pdf>

¹⁶⁵ <http://www.caresearch.com.au/Caresearch/Portals/0/Documents/whatispalliativecare/nationalprogram/rural-agpn/map.pdf>

Public Health Approach <i>Essential Elements</i>		Corresponding National Palliative Programs in Australia
		-Palliative Care Curriculum for Undergraduates ¹⁶⁶ - Palliative Care Online Training Program ¹⁶⁷ - Program of Experience in the Palliative Approach ¹⁶⁸ - Advance Care Planning Capacity Building ¹⁶⁹ - Decision Assist- Specialist Palliative and Advance Care Planning Advisory Services ¹⁷⁰ - Rural Palliative Care Project
9	Evaluate effectiveness, accessibility, and quality of personal and population-based health services.	-National Standards Assessment Program (NSAP) ¹⁷¹ -National Palliative Care Performance Indicators- Data & Reports since 2005 - Palliative Care Outcomes Collaboration (PCOC) ¹⁷² -
10	Research for new insights and innovative solutions to health problems.	-The Palliative Care Clinical Studies Collaborative ¹⁷³ -Encouraging Best Practice in Residential Aged Care (EBPRAC) program- at University of Wollongong.

National Programs Supporting Palliative Care Quality and Outcomes

National Care Standards and Service Planning and Development Guides

The Australian Government and Palliative Care Australia released documents that define the national standards for palliative care, guide the planning and development of services, and recommend guidelines for palliative care provision in the community setting. The documents provide a framework for needs-based and equitable access to quality end-of-life care:

1. Standards for Palliative Care Provision
2. Palliative Care Service Provision in Australia: A Planning Guide
3. A Guide to Palliative Care Service Development: A population based approach
4. Palliative Care Guidelines in the Community Setting

¹⁶⁶ <http://www.pcc4u.org/>

¹⁶⁷ <http://www.palliativecareonline.com.au/>

¹⁶⁸ <http://www.pepaeducation.com/>

¹⁶⁹ <http://advancecareplanning.org.au/>

¹⁷⁰ <http://www.caresearch.com.au/caresearch/tabid/2583/Default.aspx>

¹⁷¹ <http://nsap.klixhosting.com.au/>

¹⁷² <http://www.pcoc.org.au/>

¹⁷³ <http://www.caresearch.com.au/CareSearch/tabid/2476/Default.aspx>

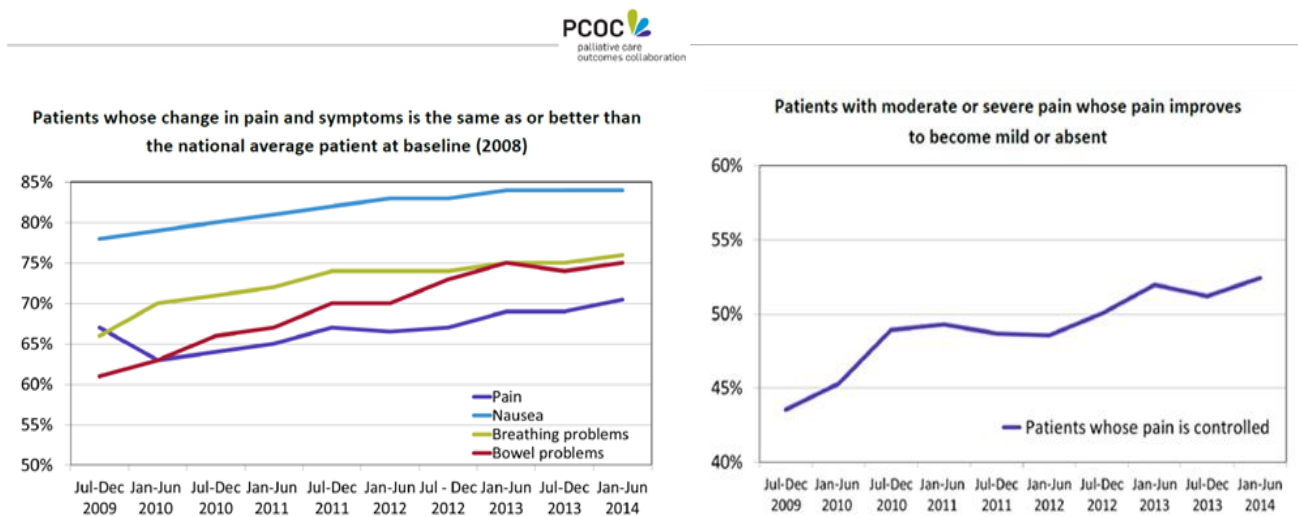
National Standards Assessment Program (NSAP)

Australia’s NSAP enables palliative care service providers to engage in improvement and accreditation cycles through self-assessment against the National Palliative Care Standards, action plan development and implementation, as well as peer mentorship, audit and survey tools. The majority of service providers across Australia have completed at least one cycle to date.

Palliative Care Outcomes Collaboration (PCOC)

PCOC is another national quality improvement program that measures and benchmarks patient outcomes between providers using data collected routinely via a standardized clinical assessment process and tools. Four outcome measures are assessed: time from referral to first contact, time in unstable phase, change in pain, and change in symptoms relative to the baseline national average. Benchmarking takes place in national and jurisdictional meetings to allow the providers to share their experiences and reflect on the success factors and challenges they face. Recent data from PCOC demonstrates systematic improvement of outcomes in the patients cared for by the providers participating in PCOC. (See Figure 17)

Figure 17 Australia data: steady improvement in the severity of pain and other symptoms in patients cared for by providers participating in the national quality improvement program



National Palliative Care Performance Indicators

The Australian Institute of Health and Welfare collects information and publishes periodical reports on the extent to which palliative care agencies are meeting the goals of the National Palliative Care Strategy.

National Programs Building Capacity of Palliative Care Providers

Palliative Care Curriculum for Undergraduates (PCC4U)

For students: The program offers medical, nursing, and allied health undergraduates learning modules including case studies and video vignettes in palliative care.

For academics: Offers a hub of teaching and learning resources to support the inclusion of palliative care in health curricula.

Palliative Care Accredited Online Training Program

The online training helps health professionals implement the Guidelines in their community-based practice. The program consists of four free, accredited, online training modules for which Continuing Professional Development points can be accrued.

Program of Experience in the Palliative Approach (PEPA)

The program offers practicing health professionals free placements in palliative care services (2-5 days duration) and free palliative approach workshops with CPD points that can be accrued. The programs also offers opportunity for palliative care specialists to travel to Aboriginal health service setting to facilitate palliative care learning.

Advance Care Planning (ACP) Australia

This is a capacity-building program based on **Respecting Choices Model**, a whole-systems integrated model that proved to increase acceptance and uptake of ACP at a community level. Through the program's website, information and educational resources are available to help Australians understand the important elements of Advance Care Planning. The website includes culturally appropriate information and resources for Aboriginal audience. The program offers health professionals a one-day practice-based workshop and online training courses.

Decision Assist

Decision Assist provides Specialist Palliative Care and Advance Care Planning Advisory Services via a national 1300 number; tele-health advice; a one-stop palliative care resource website; and training workshops. Decision Assist is funded by the Australian Government and a number of leading health, academic, and aged care organisations are contracted to deliver Decision Assist services under a consortium-style arrangement.

Rural Palliative Care Project (RPC)

The RPC Project aims to increase the capacity of primary care providers, in partnership with palliative care specialist services, to provide quality palliative care to rural and remote Australia. The Project implemented the following eight elements in 40 rural and remote sites:

1. Governance

Each RPC Project site had a local multi-disciplinary governance committee that guides the direction and focus of the project.

2. Specialist palliative care services

Generalist and specialist palliative care providers worked together in a formal partnership.

3. Sustainability

Projects were supported by sustainable quality improvement processes based on best practices. Organisation support was essential to continually drive quality improvement.

4. Data collection

Data collected to measure the impact of the project, give a clearer picture of what is happening in the region, and to ascertain how further initiatives may be more relevant.

5. Link nurses

Link nurses served as a communication and coordination conduit between all the health providers and the palliative care patients and carers.

6. Education

Generalists enrolled in the Program of Experience in a Palliative Approach (PEPA) placement to build their palliative care capacity.

7. Multi-disciplinary team meetings

The multi-disciplinary team meetings greatly benefitted the patients and their carers as it promoted coordinated holistic care.

8. Patient held records

Patient held records improved the continuity of care and communication, as well as providing families with a record of what happened towards end-of-life for their loved one.

National Programs Promoting Awareness and Understanding of Death and Dying

Palliative Care Australia (PCA) is the top national advocacy body for palliative care. PCA works to raise awareness of palliative and end-of-life care, improve the understanding and availability of services, and improve knowledge networks. In addition to its leading role in awareness, PCA produced the Palliative Care Standards and the Service Planning and Development Guides and is facilitating the National Self-assessment Program.

Examples of the PCA awareness work are:

Communication Campaigns

In 2013 PCA ran a highly successful campaign in the lead up to the Federal Election. Political candidates were provided with information about palliative care and afterwards were asked to discuss their views on palliative care priorities.

National Palliative Care Week (NPCW)

The NPCW is an annual week of awareness raising events organised by PCA during the month of May. PCA develops awareness materials and provides them at no cost to interested organizations. The theme for NPCW during 2014 was “Palliative Care is Everyone’s Business Let’s Work Together” and focussed on the palliative care workforce and included political engagement and sustained media pressure components. The campaign’s theme for 2015 is “Dying to talk; talking about dying won't kill you” aiming to normalize conversations about death, dying, and to promote Advance Care Planning.

The Australian Palliative Care Knowledge Network (CareSearch).

CareSearch is a one-stop shop of evidence-based information and practical resources for palliative care patients, carers, families, health care professionals, and researchers.

eHospice

eHospice (website/iPhone and iPad application) is a leading resource for latest news and information for families and health care professionals about hospice and palliative care sectors worldwide.

Australian Palliative Care Conference

The annual conference draws delegates from around the world and keynote speeches from renowned academics covering burning issues in palliative care and sharing their knowledge and expertise.

National Programs Supporting Research and Innovation in Palliative Care:

The Palliative Care Clinical Studies Collaborative

The world’s largest phase III clinical trial group, improving the evidence for prescribing at the end-of-life.

Encouraging Best Practice in Residential Aged Care (EBPRAC) program

This program is comprised of a number of projects aiming to improve clinical care in residential aged care by identifying and implementing evidence-based practices.

Consortia of researchers, educators, and residential care staff work together to develop standardized monitoring and impact evaluation systems for these projects.

Community Engagement and Partnerships in Palliative Care in Australia

Compassionate Communities Network

A number of like-minded Australians developed The Compassionate Communities Network after the 1st International Public Health and Palliative Care Conference in 2009. Membership is open to everyone who is interested in social approaches to end-of-life. However, no information is available on the Network's current or past activities.

Alzheimer's Australia

As the lead charitable organization for all types of dementia, Alzheimer's Australia manages a wide range of national programs to deliver services such as provision of information, a dementia help line, Dementia Awareness month, counselling, training and education to people with dementia, their families and carers as well as to professionals working in the dementia field.

Alzheimer's Australia assumes a leading role in **building dementia friendly communities** across Australia by providing technical advice and support to organizations interested in following the **Alzheimer's Australia's Guidelines and Toolkit** to become dementia friendly.¹⁷⁴ A number of cities and towns in Australia are currently working with Alzheimer's Australia to become Dementia Friendly.

Kiama Town in New South Wales is Dementia Friendly

Alzheimer's Australia, Kiama Municipal Council and the University of Wollongong are working together to make Kiama dementia friendly by:

1. Listening to what is important for people living with dementia
2. Establishing a Local Dementia Alliance
3. Supporting local businesses follow the Guidelines for Dementia friendly organisations
4. Raising awareness about dementia across the community
5. Promoting volunteering, employment and social engagement opportunities for people with dementia

¹⁷⁴ https://fightdementia.org.au/sites/default/files/NATIONAL/documents/Business%20Toolkit_guidelines.pdf

Conclusion

Palliative care in Australia is highly regulated and well supported by government-funded national policies and programs. Australia's approach to improve and drive quality of end-of-life care focuses mainly on strengthening the governance of palliative service provision; building palliative care knowledge and capacity of the workforce; integrating of specialist services into all levels of care; reorientating and systematizing clinical practice based on evidence; and establishing monitoring, evaluation, and quality improvement systems. The wealth of palliative care data that is being collected and goes back to 1999 provided evidence for the effectiveness of this approach in terms of place of death and improved patient outcomes. Four out of five unstable patients now have their problem managed within 3 days. The proportion of patients with moderate pain whose pain improves to become mild or absent increased from 44% in 2009 to 53% in 2014. The proportion of deaths that occurred in the hospital decreased from 54% to 51% over a 10-year period (from 2002-2012).¹⁷⁵ In addition to quality of care, Australia provided exemplary model of care to effectively address the access and holistic issues of care in remote and rural areas (Rural Palliative Care Project).

The palliative care awareness and promotion activities in Australia employ innovative multifaceted ways to reach out to all sectors, population groups, and influential groups in the society. The awareness campaigns and activities are planned and led by national programs and for the most part are funded by the Federal Government. It is noted that the community engagement and partnerships component of the public health approach to palliative care in Australia is still in the early development stage. However, the methodology to engage the society in building compassionate communities is clearly defined and available in the form of guidelines and toolkits to enable a national, systematic implementation process.

¹⁷⁵ <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129548892>