Every health professional endeavouring to deliver patient care in the context of our complicated healthcare system will have wondered at some point: “Who is making these silly decisions about healthcare policies and funding? How are they made? How does one go about influencing them?”

Usually, this thinking is associated with a substitution of ‘silly’ with a favoured blasphemous term and an escalating frustration and attitude that: “If they only knew the facts. If they only asked me – they could have arrived at a much smarter decision.”

Alas, it is this experience that motivates many health professionals to volunteer their intellect and passion through leadership roles within their respective peak organisations and to strive to make a difference, through what is the ‘dark art’ of politics, lobbying and advocacy. Thank goodness for this frustration – because patients gain through this extraordinary commitment.

Advocacy: the skills and investments

The vision of the founders of Palliative Care Australia (PCA) was to generate and amplify a national voice for representation, advocacy and lobbying with decision-makers. Part of this vision was for the organisation to develop as a custodian of national policy and standards for quality care. The idea was to build a national platform to bring together all who share an interest in the palliative care endeavour.

PCA’s governance structure is based on an elected executive committee drawn from the palliative care sector, which in turn is advised by the National Council. This is the mechanism that provides national policy development, strategic direction and leadership for the development of palliative care in Australia. The day-to-day work, however, is carried out largely by the generous volunteer expertise contained in committees and working parties, supported by the national office in Canberra.

PCA and its member organisations also work collaboratively with the Commonwealth Department of Health and Ageing (DOHA) and state and territory health departments to achieve access to quality palliative care for all Australians.

The National Palliative Care Strategy is seen as a synthesis of the national effort and was developed in 2000 through collaboration between the Commonwealth, state and territory governments, PCA and stakeholders. The three main goals of this strategy are to:

1. Improve community and professional awareness and understanding of, and professional commitment to, the role of palliative care practices in supporting the care needs of people who are dying and their families of care.

2. Support continuous improvement in the quality and effectiveness of all palliative care service delivery across Australia.

3. Promote and support partnerships in the provision of care for people who are dying and their families, and the infrastructure for that care, to support delivery of high quality, effective palliative care across all settings.

The strategy recognises the importance of building health service and community capacity to support people through dying and bereavement, with acceptance that death is a natural part of life. It emphasises the need for: broad community and professional awareness of the widely varying needs of people who are dying; flexible planning and service delivery that is responsive to these needs; and high quality and accountability in the provision of services.

Abstract

It is already clear that 2007 will be a year of significant advocacy challenges for palliative care with the Federal Government election and negotiations for the next five-year Australian Health Care Agreement. Deployment of advocacy skills (as well as time, money and volunteer energy) and investments, supported by evidence and networks (numbers), must match the cycle of decision-making and opportunities.

In the lead-up to these negotiations, palliative care - its value in terms of economic and quality of life outcomes – should not be lost in the debate and weighted as a lower priority to competing health care priorities. The federal election, scheduled as a precursor to the conclusion of these negotiations, increases the scope of advocacy work to be done by the sector.

These events will provide an opportunity to strengthen recognition of palliative care as an essential and cost-effective investment in health outcomes and an opportunity to establish a robust advocacy network and make a difference.

This will be the palliative care sector’s challenge in the year ahead.

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Advocacy in Palliative Care
seeks to address palliative care across all relevant sectors, including publicly and privately funded hospitals and community services, non-government organisations and the aged care and disability sectors.

Those who are close to the nuances of government policy will recognise that it takes more than a sound strategy document to improve care. Through effective advocacy work the Australian Government has continued to provide funding through its commitment to the National Palliative Care Program through three sources.

1. Palliative Care in the Community – $62.8 million for the period 2006-10 (in addition to $52.8 million from 2002-2006).
3. Local Palliative Care Grants Program – $23.1 million over four years (2005-09) to help health-related services better support people requiring palliative care and their families.

While the initial program funding phase between 2002 and 2006 was enormously exciting for those who work in palliative care, it is fair to say that such a small sector was overburdened. An already stretched workforce was asked to deliver care while participating in research, consultation and leading change. This placed extraordinary pressure on all involved. However, the work paid off with the announcement of extended funding for this program following positive evaluation and the articulation of the new priority areas.

In 2006, there was an essential process of consolidation and focus that will see investment in major initiatives to:

1. support patients, families and carers in the community;
2. increase access to palliative care medicines in the community;
3. educate, train and support the workforce; and
4. undertake research and quality improvement for palliative care services.

The ongoing challenge for the palliative care sector is to utilise the national networks at all levels to provide feedback on the success of these investments. We must use our advocacy skills to ensure that mechanisms are in place to deliver sustainable, evidence-based improvements that deliver the national implementation of better service models and tangible change in patient care outcomes.

**Advocacy: the cycles**

Deployment of advocacy skills (as well as time, money and volunteer energy) must match the cycle of decision-making and opportunities. In 2007, PCA will expand its focus from program funding (change and service improvement) to the critical area of service funding (workforce and care costs), in particular seeking to influence the decision-makers behind the Australian Health Care Agreements. In the lead-up to these negotiations, palliative care - its value in terms of economic and quality of life outcomes – should not be lost in the debate and weighted as a lower priority to competing health care priorities. The federal election, scheduled as a precursor to the conclusion of these negotiations, increases the scope of the advocacy work to be done.

Significantly, greater activity now occurs in the area of national advocacy, with the requisite focus on influencing decision-makers to recognise the value of quality palliative care and to match this recognition with support for adequate funding, commitment to enabling the implementation of quality standards, commitment to adequate resourcing for an ageing population and greater awareness of the needs of people with a life limiting illness.

**Advocacy: the evidence**

Those involved at the receiving end of advocacy work – healthcare decision-makers at all levels - unanimously call for policy changes and funding pursuits to be underwritten by quality information and evidence.

Articulation, development and implementation of national palliative care standards is fundamental to improving access to high-quality palliative care for all Australians. An important by-product of the benchmarking and measurement of performance against these standards is the enhanced credibility of advocacy work.

The 4th Edition of the Standards for Providing Quality Palliative Care for All Australians reflected a move towards a population-based approach to the development and delivery of palliative care services. This approach is described in A Guide to Palliative Care Service Development – A Population Based Approach.

In 2007, work on the National Palliative Care Standards will take a significant step forward, with the piloting and implementation of the National Standards Assessment Program (NSAP), a national quality assurance program that streamlines self-assessment and peer-review activities while linking with existing accreditation mechanisms.

The intent of NSAP is to enable all specialist palliative care services to participate on an ongoing voluntary basis in the three stages of quality assurance: self assessment (stage 1), independent peer review (stage 2) and formal accreditation (stage 3).

Successful completion of stage 3 will result in full integration of the palliative care performance criteria with those used by the relevant national accrediting bodies. This will enable services that successfully complete NSAP stage 2 to use this status to efficiently satisfy the criteria of the accrediting body through mutual recognition.

2007 will also see the Australian Commission on Safety and Quality in Health Care complete consultation on the
proposed package of reforms to reorientate, streamline and increase the efficiency of national accreditation work. Robust linking between NSAP and this emerging work, as well as managing strong, collaborative relationships will be key success criteria for planning as well as advocacy work.

Additional work on the measurement of standards is underway through the development and collection of information against national data sets being undertaken by the Palliative Care Outcomes Collaboration (PCOC) and the Australian Institute of Health and Welfare.

This work is poised to provide, as a by-product of the provision of patient care and evaluation of service models, the evidence to support advocacy targets and specific funding requests.

**Advocacy: the numbers**

Getting the timing and influence cycle right, investing in relationships and having the compelling evidence-based arguments will set the scene for effective advocacy. But this will not have optimum impact without the essential ingredient: numbers – the bigger the constituency that is fully-aligned to pursue the change the greater the impact. Many organisations collaborate to support and co-logo each other’s initiatives: for example, the Australian Health Care Alliance with the specific aim of amplifying its impact through an increased number of constituents. The network of health professionals who share an interest in palliative care is strong and PCA aims to improve the efficiency of communication through physical and electronic networks.

Influencing health planners and funding providers through advocacy would be a much simpler task if the community possessed a level of knowledge and understanding about dying, loss and grief, and about the services available. When examining how to best increase numbers to strengthen advocacy work, it is important to consider how many people are touched by death and bereavement. Aside from those who work in the health sector, we need to consider the thousands of patients, carers and families.

Each year, more than 76,000 people die from a life-limiting illness. Assuming that each of these people have two family members, two close friends and 10 work colleagues, more than 1.2 million people are affected in some way by the death of someone with a life-limiting illness each year. This is a significant number which cannot be overlooked – the size of a few combined electorates.

Living with, caring for and working with people experiencing terminal illness, loss and grief can be a challenging and isolating life experience. Isolation from communities is not intentional, but often is a consequence of not knowing what to do and what to say when our family, friends, colleagues and other members of our community face death and grief. We need to build capacity in the community to face death and grief. The palliative care community aspires for people to encounter life-threatening illness and dying with knowledge and resources already in place, rather than have to assemble or develop them from scratch in the midst of that experience.5

A recent research report commissioned by the Commonwealth Department of Health and Ageing, **Community Attitudes Towards Palliative Care - Integrated Report**, found that while Australians typically equated palliative care with providing care and comfort for the terminally ill, few Australians spontaneously associated palliative care with support for families and carers.

During 2007, a significant national campaign will seek to foster community capacity building. One objective of the campaign is to help individuals to know what to do and what to say for their family, friends, colleagues and communities when confronted with death and loss.

While these steps are important in raising the awareness of palliative care, they can be perceived as a double-edged sword. By raising awareness of palliative care, attention is drawn to the fact that there are significant funding and workforce shortages in the sector affecting accessibility. People facing the end of life are a vulnerable group in the community and must be supported with ready access to the information they require. Unfortunately, funding levels for the development of palliative care services in Australia do not always keep pace with demand. Awareness raising becomes a topical issue when one reflects on the media bias of current euthanasia debates, with no consideration given to the significant developments in end-of-life expertise, which are of world-class standard.

Much work is also required to ensure that the term palliative care is not erroneously equated with the last few days of life and pain control. There is still evidence of reluctance among some in the medical profession to request palliative care for patients, regarding death as a medical failure. But palliative care is more than the last few days of life and can last for weeks, months, even a year or more. Palliative care is more than pain control, more than only cancer – palliative care is a whole of community affair.

Again, a by-product of awareness-raising is an increased ability to conduct advocacy through generating an increased number of people who understand the issues and through providing a mechanism for them to participate and make a difference.

**Conclusion**

This paper has described the advocacy challenges ahead for the palliative care sector. Success will rely on measured management of skills and investments, timing to correspond with funding cycles, evidence to support arguments and maintain credibility, and an ability to harness the support of others to take the argument forward to decision-makers.
References


