



Geoffrey Mitchell

End-of-life care for patients with cancer

Background

End-of-life care is a core role of general practice. Patients with disseminated cancer have rapidly escalating needs at the end of life that are usually predictable and, therefore, planning for future needs is possible. Care planning and working with specialist palliative care colleagues improves patient outcomes.

Objective

The aim of this article is to provide an overview of end-of-life care for patients with cancer, including evidence supporting the involvement of general practitioners (GPs).

Discussion

Care planning is predicated on understanding the patient's wishes about how care should be conducted and ensuring the plan conforms to these wishes. Not all GPs are willing to undertake palliative care, often because of a sense of inadequate knowledge, confidence and support. The more palliative care is undertaken, however, the more confident practitioners feel. Therefore, starting to treat end-of-life patients early in a GP's career is important, and making use of the considerable resources available will assist in building knowledge and confidence. Systematically caring for carers might be a way of introducing GPs to the care of patients with cancer at the end of life.

Keywords

cancer; palliative care; health services; doctor–patient relations

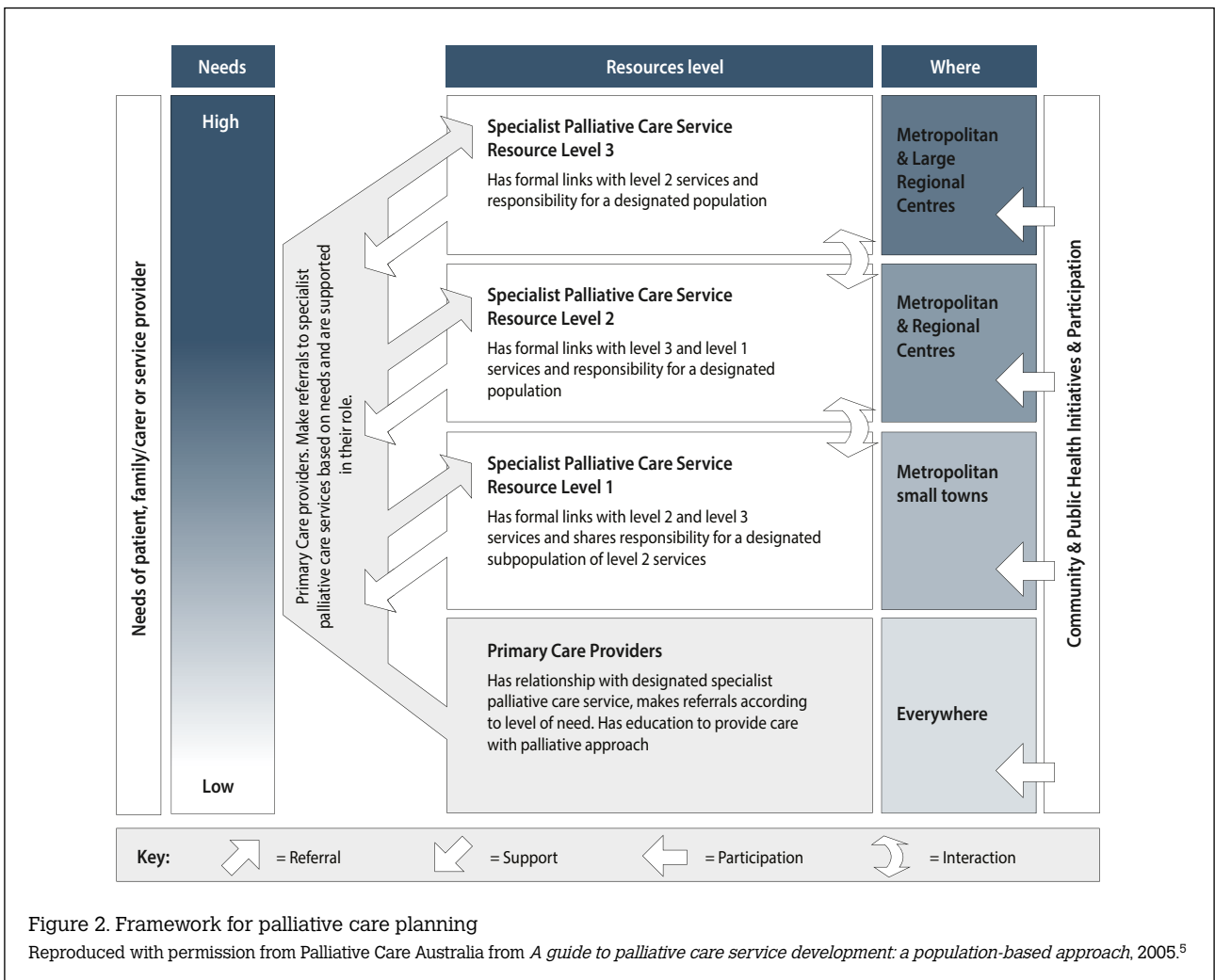
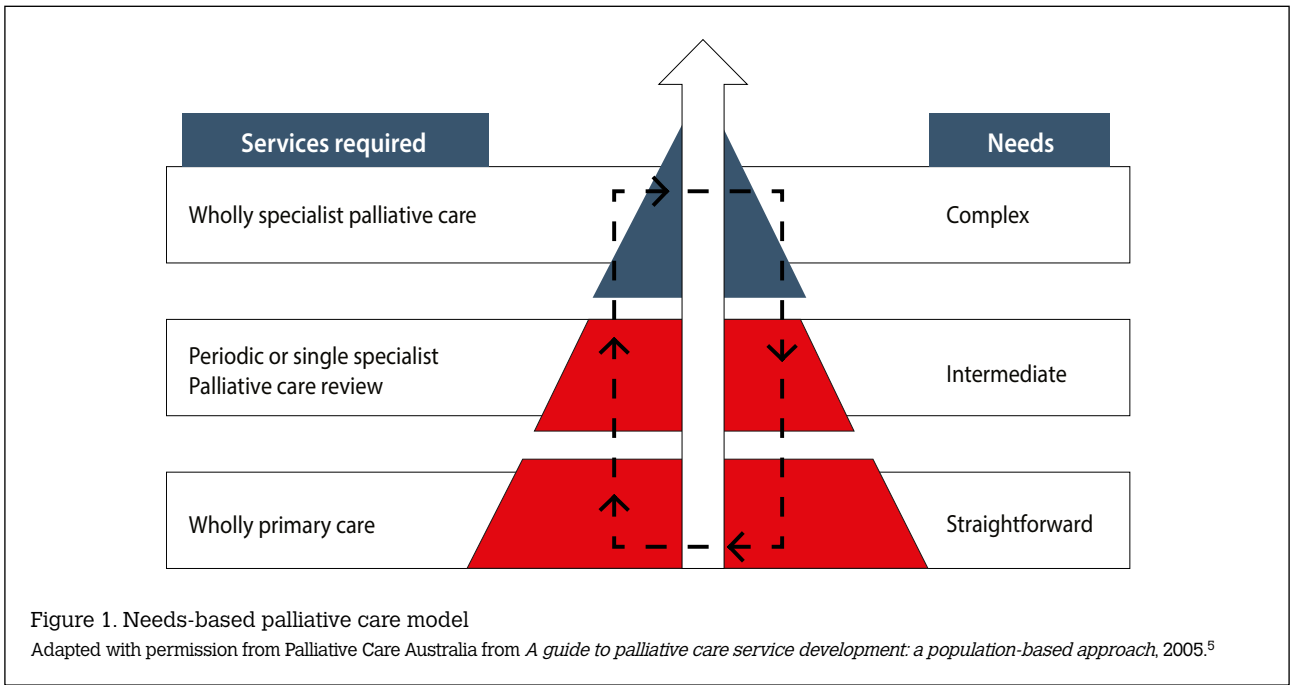


General practice has a clear part to play at the end of life in patients with advanced cancer. The close similarities between the definitions of general practice¹ and palliative care² support the notion that good general practice should encompass good end-of-life care as a matter of course. End-of-life care brings all of the skills of general practice into play. These include high-quality physical care, understanding the impact of the disease on the illness, validating the impacts of being unwell and paying attention to the context of the person – their immediate circle of family and loved ones, the community in which they live and the beliefs that sustain them.³

In marked contrast to the trajectories of non-malignant diseases, the burden of disease and the time course of disseminated cancer are relatively predictable. This makes care planning for these patients relatively straightforward. Comprehensive care is made more possible by the fact that specialist palliative care is largely built around the care of people with cancer,⁴ so GP-based coordinated care is possible.

Palliative Care Australia service planning documents assume a hierarchy of need⁵ (*Figure 1*). Many patients have uncomplicated problems at the end of life, well within the skill of most GPs. Some will require advice from a palliative care team only. A small proportion of patients will have such complex needs that they require the full suite of services offered by specialist teams. At all levels, specialist care should link with the patient's GP (*Figure 2*). The presence of a GP actively involved in care increases the likelihood of dying at home, compared with low GP involvement.⁶ Low continuity of care increases the likelihood of visits to the emergency department in the last 6 months of life by 2–4 times.⁷

This article focuses on the process of care and presents evidence supporting GP involvement in end-of-life care. In particular, it discusses care planning, advance health directives and the care of carers. Finally, it discusses barriers to good care, and resources to assist in providing high-quality end-of-life clinical care.





Advance care planning and clinical care planning

At the heart of good end-of-life care is advance care planning. This planning is defined as the opportunity for people to think, discuss and plan for the medical treatment they would prefer if they became too ill in the future to express their wishes.^{8,9} Advance care planning usually involves completing a legally binding document called an advance health directive (AHD) or living will, which seeks to capture the patient's intentions for their future healthcare. A randomised controlled trial (RCT) of advance care planning versus normal care (in a specialist hospital)¹⁰ showed that developing an AHD leads to the patients wishes being known and followed. Furthermore, it leads to more satisfied bereaved carers, who experience less anxiety and depression.

The relationship between personal advance care planning and clinical care planning is shown in *Figure 3*. In addition to recording the wishes of the patient, it is also important to consider the nature and clinical course of the cancer and to do a comprehensive review of the whole person's needs from many perspectives. This makes it possible to anticipate problems and prepare for them.¹¹ This process can also assist people who are ill to consider their wishes across a much broader spectrum that is not limited to whether they want resuscitation or other life-sustaining processes. Each element of care planning supports the other.

Facilitating care planning within primary care is well developed in the UK and Europe.^{11,12} In the UK, the Gold Standards Framework program of end-of-life care¹¹ developed by Thomas offers a conceptual framework to end-of-life care (*Table 1*). By considering all of the elements of the PEPSI COLA framework, a GP can be reasonably confident of anticipating and preparing for most potential problems.

Multidisciplinary teamwork

The complexity and intensity of the problems at the end of life, and the short time frames inevitably lead to a team forming around the

patient. It is essential that the team has a coordinator, and this role often falls to the GP. However, this is not inevitable – it could be a palliative care or domiciliary nurse that bears this responsibility.

Involvement of a palliative care team is important and effective. Temel's landmark study¹³ in a USA oncology service showed the early addition of palliative care to specialist oncology in disseminated lung cancer improved quality of life, reduced service utilisation and, most significantly, improved survival.

Further, coordination between specialist palliative care and the GP also confers patient benefit. Two RCTs of a single case conference (and subsequent care planning) between GPs and specialist palliative care teams showed improved quality of life in the last month of life,¹⁴ persistent improvements in functional ability of patients¹⁴ and a 30% reduction in hospital admissions,¹⁵ compared with normal care.

How well are we doing?

In spite of clear evidence that GP involvement in end-of-life care is beneficial to patients and carers, there is also evidence that about 25% of GPs do not accept this role and are particularly reluctant to do home visits and out-of-hours calls.^{16,17} Other reasons for this were having family or personal commitments, and a sense of inadequate knowledge or support. One-third of this group stated they had no interest in end-of-life care.¹⁷ More disturbingly still, the demographics of those who did not do palliative care were similar to the demographics of the emerging GP workforce¹⁷ (*Table 2*). This problem is compounded by an increasingly ageing population,¹⁸ where more patients will die of cancer and more palliative care will be required.

There is also a problem in recognising when patients are approaching the end of life. Doctors routinely overestimate patient prognosis¹⁹ and, as a result, are likely to undertake palliative care planning too late. Even with cancer, this leads to people being considered as approaching the end of life far later than is ideal and to late referrals to palliative care.²⁰

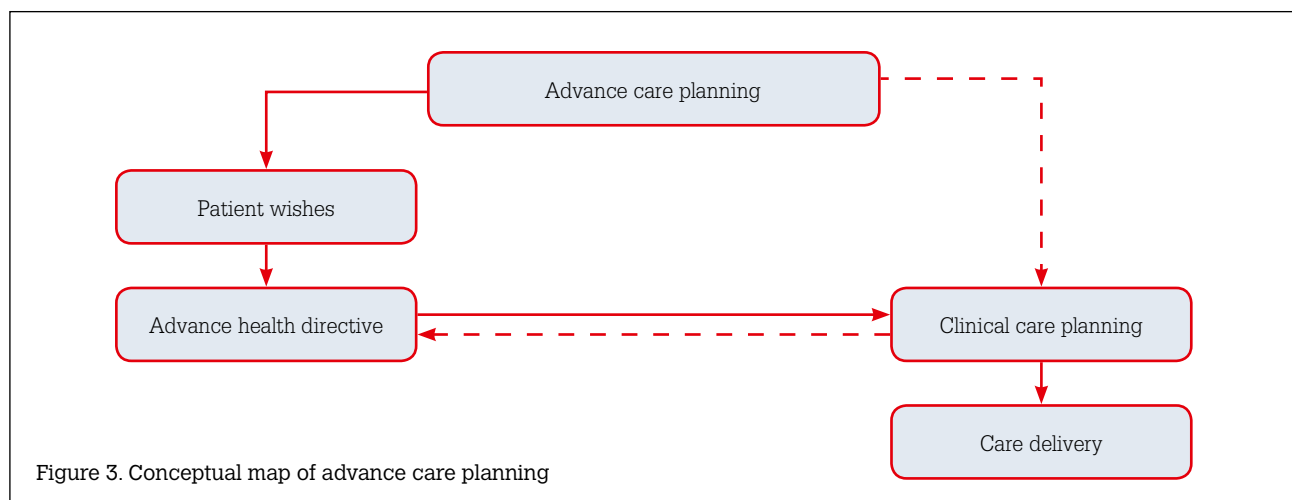


Figure 3. Conceptual map of advance care planning



The self-perceived role of GPs in advanced cancer care is also dependent on location.²¹ Urban GPs are not sure where they fit, particularly where some oncology services refer directly to specialist palliative care services. What is expected of them? Who brings the GP into this picture? The role is much clearer in regional and rural settings, and much more accepted: the GP may often be the only medical resource available. Involving younger GPs in end-of-life care is a very important task. The more GPs perform palliative care, the more comfortable they become with it.²² Not starting early will lead to more difficulty in engaging in end-of-life care later.

Table 1. The PEPSI COLA structure for palliative care clinical planning¹¹

Domain	Issues to consider
Physical	Symptom control Medication – regular and as needed Compliance/stopping non-essentials Complementary therapies
Emotional	Understanding expectations Depression and adjustment Fears/security Relationships
Personal	Spiritual/religious needs Inner journey Quality of life Patient/carer agenda
Social Support	Benefits/financial Care for carers Practical support
Information/communication	Within team Between professionals To and from patient To and from carers
Control	Choice, dignity Treatment options/management plan Advance directive Place of death
Out of hours/emergency	Continuity Provision of out-of-hours care to patients/carers Carer support Medical support Drugs and equipment
Late	End-of-life/terminal care Stopped non-urgent treatment Patient and family aware Comfort measures/spiritual care Rattle, agitation
Afterwards	Bereavement follow-up/others informed Family support Assessment/audit Support team

Solutions

Advance care planning

Scott et al²³ offer suggestions for GPs to facilitate having the difficult but necessary conversations about end-of-life care. These include computer-generated prompts, mailouts to eligible patients, incorporating advance care planning discussions into regular health checks and chronic disease management plans, and training practice nurses to participate in advance care planning case management. The Personally Controlled eHealth Record²⁴ contains provision for recording the contact details of the substitute decision maker, as well as for storage of medical documents such as the AHD. This will make the AHD available to all healthcare providers.

Support for providing patient care

Most specialist palliative care services are more than happy to support GPs caring for patients. They will usually take phone calls from GPs to discuss clinical problems. GP–specialist case conferences improve patient outcomes.^{14,15} While GPs can initiate a case conference, it is more likely that the initiation will come from specialists or aged care facilities. They will attract a rebate even if conducted by distance technology and this may make them more feasible. There is a wide array of online resources aimed at providing general and clinical information. Some of these are presented in *Table 3*.

Accessibility

A key part of providing palliative care is to be available. Issues of personal safety are legitimate and concern some doctors. However, this service does not have to be made available to all – it can be applied to well known patients only. If this is not feasible, offering patients and their carers a telephone contact number is enormously reassuring. Given the small number of palliative care patients a GP sees annually,²⁵ the number of calls is very small and patients almost never abuse this privilege. If neither of these options is possible, it is important that patients know what the practice after hours arrangements are, and that a written health summary including an up-to-date medicines list, is at the home to assist locum services provide appropriate care. Consider informing the locum services of the patient's palliative status – they may hold a register.

Carers

A good way of introducing GPs into palliative care is to care for the carers. Their needs are very substantial²⁶ and often overlooked because they are not the ill person. The Needs Assessment Tool for Carers (NAT-C)²⁷ is a self-completed checklist for carers, which allows them to identify their own major concerns and is available online (*Table 3*). This can guide such a consultation. NAT-C improves outcomes for carers, particularly those with anxiety or depression.



Table 2. Characteristics of GPs willing to and unwilling to treat palliative care patients¹⁷

	Performs palliative care		
	Yes (74.8% of total)	No (25.2% of total)	P value
Female (%)	38.7	52.2	0.052
Mean age (years)	52.1	48.0	0.004
Years in general practice	22.7	18.2	0.001
>40 hours per week (%)	48.7	25.8	0.001
Overseas medical degree (%)	25.3	40.3	0.019
Employment status – employee (vs practice owner or associate) (%)	13.2	50.8	0.001

Table 3. Useful resources for GPs when providing palliative care

Clinical resources	Therapeutic Guidelines: Palliative Care. 3rd edn. www.tg.org.au	National consensus-based palliative care guidelines
	EviQ. Cancer Treatments online. Cancer Institute of NSW. www.eviq.org.au/ GP pain help. (PDA device app) Australian College of Rural and Remote Medicine https://itunes.apple.com/au/app/gp-pain-help/id722694198?mt=8	Web-based resources in palliative care and primary care. Includes an opioid conversion page Comprehensive assistance in managing severe pain. Includes an opioid conversion function
	Flinders University. Caresearch. GP Hub. www.caresearch.com.au/caresearch/ tabid/901/Default.aspx	National palliative care information hub. Has a dedicated hub for GPs, with comprehensive information on clinical palliative care
Advance care planning	Advance Care Planning Australia http://advancecareplanning.org.au/	National web page for advance care planning that provides state-by-state information on legally binding advance care documents, as well as information and a how-to process for the community
Care for carers	University of Queensland. Needs assessment tool – carers. www.caresearch.com.au/caresearch/ tabid/1643/Default.aspx	Self completed form for carers to systematically identify care needs. For use in guiding GP consultations about caring for people with advanced cancer

Conclusion

Quality general practice necessarily includes quality end-of-life care, regardless of the type of illness involved. Caring for cancer patients has distinct advantages over other forms of cancer in that planning is possible. Planned care improves outcomes for patients and should be the norm in modern general practice.

Author

Geoffrey Mitchell MBBS, PhD, FRACGP, FACHPM, Professor, Discipline of General Practice, University of Queensland, Herston, QLD; Limestone Medical Centre, Ipswich, QLD. g.mitchell@uq.edu.au
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References

- Royal Australian College of General Practitioners. What is general practice? Available at www.racgp.org.au/becomingagp/what-is-a-gp/what-is-general-practice/ [Accessed 25 June 2014].
- World Health Organization. WHO definition of palliative care. Geneva: WHO; 2014. Available at www.who.int/cancer/palliative/definition/en/ [Accessed 10 May 2014].
- Stewart M, Brown JB, Weston WW, McWhinney IR, McWilliam C, Freeman TR. Patient-centered medicine: transforming the clinical method. 3rd edn. London: Radcliffe, 2014.
- Christakis NA, Escarce JJ. Survival of Medicare patients after enrolment in hospice programs. N Engl J Med 1996;335:172–78.
- Palliative Care Australia. A guide to palliative care service development: a population-based approach. Canberra: Palliative Care Australia, 2005. Available at www.palliativecare.org.au/portals/46/resources/palliativeca-reservedevelopment.pdf [Accessed 9 July 2014].



6. Burge F, Lawson B, Johnston G, Cummings I. Primary care continuity and location of death for those with cancer. *J Palliat Med* 2003;6:911–18.
7. Burge F, Lawson B, Johnston G. Family physician continuity of care and emergency department use in end-of-life cancer care. *Med Care* 2003;41:992–1001.
8. Advance Care Planning Australia. Advance Care Planning. Melbourne: Advance Care Planning Australia, 2014. Available at <http://advancecare-planning.org.au/> [Accessed 9 May 2014].
9. Scottish Partnership for Palliative Care. Good life, good death, good grief. Edinburgh: Scottish Partnership for Palliative Care, 2013. Available at www.goodlifedeathgrief.org.uk [Accessed 11 May 2014].
10. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end-of-life care in elderly patients: randomised controlled trial. *BMJ* 2010;340:c1345.
11. The National Gold Standards Framework (GSF) Centre in End of Life Care. Shrewsbury: The Gold Standards Framework. Available at www.goldstandardsframework.org.uk [Accessed 10 May 2014].
12. Murray S, Firth A, Schneider N, et al. Promoting palliative care in the community: producing a toolkit to improve and develop primary palliative care in different countries internationally. Report of the European Association of Palliative Care (EAPC) Taskforce in Primary Palliative Care. Milan: EAPC. Available at www.eapcnet.eu/Portals/0/Organization/Primary%20care/EAPC_PrimaryCareReport2014.pdf [Accessed 25 June 2014].
13. Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. *N Engl J Med* 2010;363:733–42.
14. Mitchell GK, Del Mar CB, O'Rourke PK, Clavarino AM. Do case conferences between general practitioners and specialist palliative care services improve quality of life? A randomised controlled trial (ISRCTN 52269003). *Palliat Med* 2008;22:904–12.
15. Abernethy AP CD, Shelby-James T, Rowett D, et al. Delivery strategies to optimize resource utilization and performance status for patients with advanced life-limiting illness: results from the 'palliative care trial' [ISRCTN81117481]. *J Pain Symptom Manage* 2013;45:488–505.
16. Tan HM, O'Connor MM, Miles G, Klein B, Schattner P. GP and nurses' perceptions of how after hours care for people receiving palliative care at home could be improved: a mixed methods study. *BMC Palliat Care* 2009;8:13.
17. Rhee J, Zwar N, Vagholkar S, Dennis S, Broadbent A, Mitchell G. Attitudes and barriers to involvement in palliative care by Australian urban general practitioners. *J Palliat Med* 2007;11:980–85.
18. Australian Institute of Health and Welfare. Older Australia at a glance: 4th edn. Cat. no. AGE 52. Canberra: AIHW, 2007.
19. Glare P, Virik K, Jones M, et al. A systematic review of physicians' survival predictions in terminally ill cancer patients. *BMJ* 2003;327:195–98.
20. Zheng L, Finucane A, Oxenham D, McLoughlin P, McCutcheon H, Murray S. How good is primary care at identifying patients who need palliative care? A mixed methods study. *Eur J Palliat Care* 2013;20:216–22.
21. Mitchell GK, Burridge LH, Colquist SP, Love A. General Practitioners' perceptions of their role in cancer care and factors which influence this role. *Health & social care in the community*. 2012;20:607–16.
22. Lopez de Maturana A, Morago V, San Emeterio E, Gorostiza J, Arrate AO. Attitudes of general practitioners in Bizkaia, Spain, towards the terminally ill patient. *Palliat Med* 1993;7:39–45.
23. Scott IA, Mitchell GK, Reymond EJ, Daly MP. Difficult but necessary conversations--the case for advance care planning. *Med J Aust* 2013;199:662–66.
24. National E-health Transition Authority. The personally controlled ehealth record system. Canberra: NEHTA. Available at www.nehta.gov.au/our-work/pcehr [Accessed 11 May 2014].
25. Higginson I. Health needs assessment: palliative and terminal care. In: Stevens A, Raftery J, editors. *Health care needs assessment*. Oxford: Radcliffe Medical Press; 1997;183–260.
26. Grunfeld E, Coyle D, Whelan T, et al. Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *CMAJ* 2004;170:1795–801.
27. Mitchell GK, Girgis A, Jiwa M, Sibbritt D, Burridge LH, Senior HE. Providing general practice needs-based care for carers of people with advanced cancer: a randomised controlled trial. *Br J Gen Pract* 2013;63:e683–90.

correspondence afp@racgp.org.au