

The Committee Secretary
Senate Standing Committees on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600
Australia

9/2/2012

Dear Sir/Madam,

Please accept this as an individual submission to the Senate Community Affairs Committee Inquiry into Palliative Care in Australia.

I submit this as a GP working in an urban practice for 20 years who frequently cares for patients requiring palliative care in their homes or in residential aged care facilities. I am also a member of the SA (Department of) Health End of Life Decision Making Working Group, and a member of the Clinical Advisory Committee of the Palliative Care Council of SA Inc.

I would like to provide my two key recommendations at the outset, followed by an informal analysis of the normal workflow for a GP looking after a palliative care patient in the community- which I hope will allow you to understand the barriers to providing comprehensive palliative care for my patients in their homes.

In regard to my two main recommendations, I feel that the following two changes would facilitate the provision of palliative care for patients in the community:

- 1) A single entry point for all referrals to palliative care services- ie one national or statewide phone number and fax number (e.g. 1800 PA CARE)- with diversion to the palliative care service of the relevant Local Hospital Network
- 2) After referral of patients to palliative care services via this streamlined referral system, better coordination of all of the palliative care and community services required to care for individual palliative care patients in the community- ideally by community palliative care nurses who either work with or from local general practices, or, who make concrete steps to build partnerships with local general practices.

To put these suggestions in perspective then, I think it might be worthwhile going through the normal workflow of caring for patient requiring palliative care at home:

- 1) Often, my first notification about a patient requiring palliative care at home will be a District Nurse calling me, without prior warning, to tell me that my patient, who has been in hospital for months having treatment, has returned home for palliative care and requires me to urgently complete a medication authorisation form. This will often be in the middle of an already busy day. The issues here are that GPs often find this sort of initial contact to be totally unsatisfactory:
 - as they have not been involved or notified about care decisions and the patient's impending return to their home. In this regard- hospital services need to more adequately prepare the ground and communicate to GPs about an impending handover of such a patient.
 - the calls by the nurse- who the GP may never have met- are often perceived as rude and demanding. This is why I believe that any community nurse palliative care coordinators should build prior relationships with local GPs so that interactions can be more constructive when they are needed.
 - they require significant time for paperwork which is not remunerated. And remember- GPs are paid on a fee for service basis while other services are paid on a salaried basis- so the not

inconsequential time for this work is really charity or service to the community- and this is often not recognised.

2) In other situations, my first notification might be a call about the deterioration of the patient at home. This will again usually occur in the middle of a busy session near the end of the day. The issues here are:

- the GP will often need to attend after hours and, as the consultations are extremely complex (encompassing medical, logistical and emotional issues) and prolonged- often 60-90 minutes. Given that the Medicare rebate is around \$100 for this visit- with usually half going to practice costs- the issue of adequate remuneration for these consultations needs to be a key consideration- especially when one compares this to the usual call out fee for a plumber, for example.

- in addition, given the other key requirements in providing adequate palliative care such as paperwork, phone calls, being on call 24 hours a day, there needs to be a realisation of the totally inadequate way that GPs are remunerated for providing palliative care.

3) Then, when faced with trying to put the key elements of a package of care which can help the patient stay at home as they die, the GP often faces more hurdles:

- the issues of caring for a patient at home go far beyond issues of medication and emotional issues. Patients and their families usually need nursing and carer support, equipment (toileting equipment, mobility aids, beds), social work support and access to respite and emergency hospice beds when things do not allow them to cope at home. These services are provided by an often disparate and poorly coordinated mix of public and private community and hospital based organisations which are sometimes even in competition. These organisations are often only accessed via an array of different phone and fax numbers- with differing and duplicated referral forms- and only if the patient passes a confusing maze of different referral criteria (e.g. nursing only if the patient is likely to die in the next 5 days) which the GP has no hope of knowing beforehand. Community Palliative Care nurses - who know and understand local services- are in the best position to navigate and set up these other services- which are often the main determinant of whether the patient can be maintained in their home. This gets back to my suggestions regarding coordination by community palliative care nurses- who either work with or from local general practices, or, who make concrete steps to build partnerships with local general practices- who can be accessed via a single entry point or phone/fax number. These two suggestions would greatly streamline the provision of palliative care in the community, and minimise the gaps in care provision which often lead to unnecessary and unwanted admissions to acute hospitals. GPs can then get on with providing the medical advice- and let the community nurse organise the implementation of the other critical elements needed to keep the patient at home (e.g. organising nursing, equipment). This is the true essence of holistic and multidisciplinary care.

- some GPs have little experience in both the philosophical and practical aspects of palliative care provision. In particular, some GPs have little experience in medication management- and because of this they may shy away from providing palliative care for their patients. In this regard- GPs need a single entry point, coordination of services by a community palliative care nurse, better education regarding a streamlined palliative care medication and care protocol, and, most importantly, easy access to specialist palliative care phone support so that they can seek advice via a single phone number.

- finally, the patient cannot always be maintained at home- and it is here that a GP needs adequate access to respite or hospice beds- again in a streamlined fashion. This is clearly a gap in care at the present time.

In regard to my main points, I believe that having a single point of entry to palliative care would

be positive for quite a number of reasons:

- it would make referral easier- especially for occasional referrers or those unfamiliar with services that are available
- it would greatly reduce the time required for coordination and red tape which is such a part of organising the care for these patients
- it would increase the profile and visibility of palliative care as an specific entity- something that is desperately needed
- it would force the currently disparate and poorly coordinated community and hospital services to develop and act more coherently- and hopefully evolve into a more effective and flexible system
- it would allow better monitoring of palliative care service requirements over population- by allowing the logging of service requirements against current provision of services.

I express my concerns about these issues in the context of being experienced in this area- I could understand the reluctance of inexperienced GPs to be involved as that they may find it all too hard and complicated. It's hard enough to get GPs to do home visits- palliative care is often a bridge too far.

And I realise that my comments are very centred on the issues of GPs- but it must be clear that it is GPs who have the longest ongoing relationships with their patients- and the trust inherent in this is such a valuable commodity in caring for patients at such an upsetting and frightening time.

GPs are often spoken of in rather disparaging terms in palliative care circles- and it is often the hurdles which I have identified above which create the barriers to their involvement. But, if one really thinks about it, GPs are often missing link in the palliative care landscape.

I thank you for the opportunity to submit my thoughts.

Dr Chris Moy