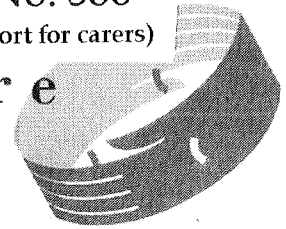


A.o.e. 7/7/08

Submission No. 580

(Inq into better support for carers)

eastern palliative care



Thursday, 3 July 2008

Committee Secretary  
Standing Committee on Family, Community, Housing and Youth  
PO Box 6021  
House of Representatives  
Parliament House  
CANBERRA ACT 2600

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Dear Sir/Madam

**Re: Inquiry into better support for carers**

Thank you for the opportunity for Eastern Palliative Care participating in the enquiry into carers.

Eastern Palliative Care (EPC) is a not-for-profit home-based palliative care service which offers a full range of support programs with the aim of improving the quality of life of individuals, carers and families of those suffering life-limiting or terminal illnesses. Clients can be referred by treating doctors, local hospitals, treating specialists, allied health professionals, by self or by family members and friends. We work with people in their own homes providing support and expert advice through a holistic model of care.

Through supporting people to die in their own homes a great deal of pressure is taken off the public hospital system; however it can mean extra pressure and resources required in people's homes.

This submission represents the issues of those people undergoing palliative care and their carers and also the experiences of staff who work for Eastern Palliative Care but who are also carers in their own right.



A partnership  
between  
St. Vincent's  
Health Service,  
the Order of Malta,  
Melbourne Eastern  
Palliative Care  
Association and the  
Outer Eastern  
Palliative  
Care Service

There are many problems often insurmountable but restricted to a single situation or family e.g. a woman is the carer of a 17 year old disabled child. She is diagnosed with a life threatening illness. When her child is 18 she will not be able to attend the special school any longer. The woman is undergoing treatment for her condition, is tired and stressed under her caring role and knows that she cannot continue but has no social supports to assist.

The following list of issues indicates the complexity for carers and those they care for:

- Palliative care is required for varying lengths of time. It may be a short journey of only weeks but may extend for some years not just 3 months. In order to receive disability benefits it needs to identify that the person will probably not live longer than 3 months. This is very disrespectful for the person. All people live in hope that a cure may occur. Having the medical practitioner identify that they may not live past 3 months destroys hope and changes the dynamic of hope. The carer is left to handle this issue and knows that the stress of this issue adds to the burden of caring and has the potential of shortening the persons life.
- When someone is told they require palliative care there is an enormous transition through grief and loss and many changes they need to adjust to including their change in role. This is particularly a problem if they are the primary carers for someone else. The emotion of dealing with how the surviving person will be cared for in the future is often beyond people. Having to navigate the care system and find options is extremely difficult for the person.
- The need for flexible respite both crisis and booked longer term is also an issue for carers of recipients of palliative care. The burden of caring can be very draining and sometimes just occasional respite is

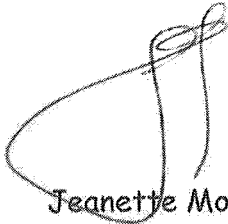
required. However for others the need for longer term nursing respite is required. Presently the access to Nursing respite is very limited but needs to be available for a least 1 week regularly. E.g. every night for a week

- Many carers are in employment but unable to maintain this employment the role of carer may be just for a few months and this may jeopardize their longer term employment.
- Social isolation of carers and assistance with family commitment such as school activities.
- The complication of mental illness and caring - isolation, lack of understanding and social stigma add to the caring burden.
- Financial issues of carers including financial burden on self funded retirees.
- The changing role from partner/son/daughter/friend to carer. How this impacts on people and how they cope when caring is no longer required.
- Enormous change when caring is no longer required. One day full time carer and the next day bereaved person.
- Centrelink caused stress due to feeling unable to cope with claim systems.
- Respite for carers with young children.
- Needs of families with disabled children.
- Some of the palliative care drugs are not PBS listed and are expensive. In many cases the carer has to pay for these e.g. Midazolam, Clonazepam, Lorazepam.
- Due to OH&S requirements for community care provision, the client is required to have a hospital bed in their home. The carer often has to pay for this including the delivery and pick up.
- After the client has passed away, limited resources are available to support the carer. Resources for example for the provision of a carer massage are very hard to obtain.

Carers are an integral part of the Australian community. Respecting and valuing their role should be a key Government Policy. Without carers Australia would grind to a halt.

Thank you for this opportunity.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Jeanette Moody'. The signature is stylized with a large loop on the left side and a vertical stroke on the right.

Jeanette Moody  
Chief Executive Officer