

From : Nevil J Wells



To: Committee Secretary
Senate Standing Committee on Community Affairs
P.O. Box 6100 Parliament House
CANBERRA ACT 2600

Dear Committee Secretary,

SENATE INQUIRY INTO PALLIATIVE CARE

As a primary palliative carer of my totally paralysed wife for the past five years I would like to make the following observations as input to the Senate Inquiry.

Palliative Care defined as “relieving symptoms of the disease without treating the cause” has been an integral part of my life for the past five years. My wife of 54 years was stricken with what was ultimately defined by her doctors as “an undiagnosed seriously degenerative brain disease” in early 2007. All of her symptoms were stroke like but deemed not to be a stroke. She has been totally paralysed ever since and cared for at home by myself and family with the assistance of wonderful community nurses who call every day.

My main concern, after five years of experiencing many frustrations accessing funding, rests with the apparent definition of “Palliative Care” at home for funding purposes. I was informed very early in the piece by Hospital Management that Palliative Care Funding was available for only three months. Presumably patients were expected to depart this life within that time frame.

My wife has disproved that theory twenty times over and I would be greatly surprised if there were not similar cases around. The reality is that although she is without question classified as “palliative care”, being totally dependent upon others for her very survival, she does not tick all the “palliative care” boxes. ON this basis I guess my comments relate to items (A); (B); (C) and (D) of your terms of reference.

I deem it a privilege to be able to care at home for my wife and wouldn't want it any other way. But a “Carer's Lot” would be greatly improved if they were provided up front with a list of services available, the criteria for accessing them, the funding arrangements and how to access them and what it is likely to cost to care for a Palliative Patient at home. For example in addition to the Community Care services we have had to acquire a hospital bed, air mattress, hoist and air-condition the room.

Trusting that this submission will be of some assistance to the Senate Committee.

Yours sincerely,

Nev Wells
24 February 2012