

**From:** Martin  
**Sent:** Thursday, 5 June 2008 4:12 PM  
**To:** Committee, FCHY (REPS)  
**Subject:** terms of reference. Inquiry into better support for carers

Dear Sir/Madam,

I am a 63 year old male, and sofar cared for my partner full time for 6 years who has Alzheimer's disease. She is now 60 years of age. My biggest challenge has been, and still is, to come to grips with who does what. There are 9 agencies who all have a finger in the pie, of which none stand out as truly supportive. When all this started I would have loved to have a 'case manager', who would have been my constant source of reference throughout my caring time, some one who might even ring up occasionally to check on how we are going. Particularly as 'a bloke' I don't seek help easily. My next wish would have been to have a 'reference sheet', say an A4 sheet, with pacific info. for our situation and our catchment, listing in clear terms who does what through different stages of the disease. Instead I have a stack of files to try to understand just that, and how each agency might function.

Within the next months I can see myself having to find permanent residential care for my beloved, and am not looking forward to it. Again, as far as I know, there is no specific person who can help me through this, to help for example make a wise choice or even with getting other carers in while I search. The prospect looks daunting on a practical level, let alone on an emotional level.

As a carer I've become increasingly aware as to how important it is to meet my own needs in order to remain an effective carer. Whilst I am determined to do my utmost, and love her till the bitter end, I find it's important to be realistic about finding intimacy beyond our situation. We might be labelled 'carers', but we are also human beings with needs. For a while now I have requested from welfare agencies that a website be created where carers can interact more socially, rather than discuss the daily grind, sothat closer ties may develop.

Finally, we made a pact when we were young that should one of us become a 'vegetable' that euthanasia be sought. Again what a cloud that is hanging over me, considering the present law of the land.

Should you wish more details, don't hesitate to ask.

Kind regards,

MARTIN