

# "WHO CARES REPORT"

by

## The House of Representatives Standing Committee on Family Housing, Community and Youth

<http://www.aph.gov.au/house/committee/fchy/carers/report.htm>

Over 300 pages on the inquiry by the Federal Government into better support for carers.

### Forward

by Ms Annette Ellis MP, Chair:

"Carers usually spouses, parents, grandparents, children, siblings and sometimes friends or neighbours have asked to be heard to have a voice of their own. So when the Committee embarked on this Inquiry into better support for carers, it clearly indicated that its objective was to learn more about the needs of carers from the experts that is from carers themselves. And carers responded. Through written submissions to the Inquiry, and through participation in public hearings, more than 1300 carers shared their very personal and often distressing experiences with the Committee.

Many carers have observed that it is not possible for anyone to understand what caring entails unless they are, or have been, a carer that reality is not disputed. However, thanks to the generosity and candour of so many carers, the Committee has been able to gain a degree of insight. The Inquiry's body of evidence clearly illustrates the profound physical, emotional and financial effects that providing care has on carers and on their families.

Becoming a carer is not a choice. Some people find that they are thrust into the role without warning after the birth of a child with an illness or disability, or following a traumatic event or accident involving a loved one. For others, becoming a carer is a more gradual process, though ultimately equally devastating. When does a husband, or a wife, recognise that they have also become a carer for their partner with dementia for example? While every caring situation is unique, the love, grief, guilt, fear, anger and frustration, coupled with sheer physical and mental exhaustion are all part and parcel of carers' lived experiences.

Despite the uniqueness of each caring situation described in evidence to the Inquiry, several consistent themes have emerged. The Committee has heard loud and clear from carers that they want choices ~ choices for themselves, for the people they care for and for their families. The Committee has also been

reminded repeatedly that the needs of carers and those they care for are inextricably bound. While the carers are the focus of this Inquiry, the Committee has sought to achieve a balance in the report that reflects the interrelationship of the needs of carers and care receivers without transgressing the Inquiry's terms of reference.

Over the years, the shift from institutional care to care in the community has greatly increased reliance on informal care provided by family and friends. In the absence of adequate support, carers are already in crisis. Emerging demographic and social trends are predicted to result in larger numbers of people requiring care and smaller numbers of people able and willing to provide it. Existing pressures on systems of support for carers which have been building over decades are therefore projected to increase. This means that action needs to be taken urgently.

With this in mind, the Committee has given consideration to diverse options for reform to address deficiencies in the current systems of support for carers. In some areas, such as respite care and in home assistance, the Committee has recommended an increase in expenditure so that supply of services more closely matches demand.

Consideration has also been given to options for the more efficient use of existing resources. To this end, some recommendations have called for a reduction in the red tape associated with accessing some forms of carer support, and for greater cooperation across jurisdictional and portfolio divides to encourage the development of more coherent and coordinated systems.

The Committee has also considered the case for significant fundamental reform. Of particular note, is the recommendation for an examination of income support for carers to determine whether the system of carer payments can be restructured to better reflect the level of care provided. In addition, the Committee has also recommended consideration of increasing access to individualised or self-managed funding packages to provide carers with greater choice and flexibility to purchase the services they need.

Importantly, the Committee understands that with adequate levels of appropriate support in place, most carers wish to continue to provide care for as long as they feel able to do so. It is therefore in the best interests of all concerned carers, care receivers, governments and society to share the responsibility of providing care

more evenly. If realised, this will allow carers and their families to participate more fully in society through engagement with education, employment and social activities.

In concluding, I would like to extend my sincere thanks to all those carers who have contributed to this Inquiry. It is your experiences, described in your own words that have provided the foundation for this report and its recommendations. I also thank the Deputy Chair, the Hon Judi Moylan MP, and the other Members of the Committee for their participation and commitment to the Inquiry.

As Chair of the Committee it is my view that many of the report's recommendations are a starting point only, providing a baseline for more fundamental and significant reforms to systems of support for carers. In considering the report, I urge the Australian Government and others to look beyond the specifics of the recommendations and to also consider their context and intent that is to significantly improve the lives of carers and those they care for. Importantly, implementation of reform will be key to effecting meaningful change. It is my sincere hope that this report and its recommendations will act as a stimulus for action."

**LISA Comment:** This is a wonderful achievement for carers who do it really tough with little or no light at the end of the tunnel - No hope for the future!

"Where is the hope for the future?" No matter how hard carers might try, and they do, we are all eventually unable to continue to provide that love and care - and finally depart this world leaving our loved-one to who knows what future....

We see the future as three components: "Carer Support", "Accommodation and Support" and the "Disability Insurance Scheme".

Families need the support to be carers for as long as they wish to be, in the knowledge they have the right to a quality of life care accommodation and support package for their family member with a disability whenever they choose.

**Tony & Heather Tregale**

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