

Caring for the carers

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Is Australia a caring country? Going by the numbers of people who are **carers**, the answer ought to be **yes!**

For the purposes of a current Federal inquiry into *Better Support for Carers*, the definition of a carer is an individual 'providing unpaid support for others with ongoing needs due to a long-term medical condition, a mental illness, a disability or frailty'.

It is worth pausing to imagine just who we mean here. Think of the parents who care for a child or an adult with Down's syndrome, or with some complicated set of profound physical and intellectual disabilities. Think of the man or woman whose partner is incapacitated with emphysema, kidney disease or cancer. Think of the single or married son or daughter of a very old and frail person. Every waking moment, people like these consider and serve the needs of the other. In many cases, they have been doing so for decades.

Recent figures from an Australian Bureau of Statistics survey found there were over 2.5 million carers in Australia, including more than 470,000 primary carers. The Australian Institute of Health and Welfare anticipates there will be more than 600,000 primary carers by 2013, with 70% likely to be women. Access Economics (2005) estimated the annual value of informal care in Australia ranged from \$4.9 billion or \$30.5 billion (in 2005 dollars), depending on the methodology used. Carers NSW tell us that the median gross personal income for a primary carer is \$237 per week versus \$397 for the general population. 11.5% of the Indigenous population are carers. Young people are carers too - 3.6% of all people under 18, and 5.2% of all people under 25 are carers.

We can be very glad that this society does not support abandoning people with disabilities to street begging, or killing off the elderly and frail, or allowing the very ill to expire alone in some corner. But the problem with this fine sentiment is what we fail to see. In some ways our society does allow these practices to occur, and when they don't occur it is precisely because *there are carers who care*.

The Federal inquiry (by the Standing Committee on Family, Community, Housing and Youth) has had an overwhelming response with nearly 1200 submissions. If you needed convincing that carers need better support, you can read the submissions yourself. You won't need to read very far to be convinced, for carers are often in very dire straits, and are not well cared for themselves. In a study into carers' perspectives on caring, some of their common concerns were:

- The Carer's Allowance is inadequate.
- More quality respite services are desperately needed. ('Respite services' mean that the carer gets a break while some paid person takes over the task of care, e.g. for a day a week.) Carers will choose no respite over substandard respite—which goes to show how much they love the person they are caring for.
- There is a lack of suitable and supported accommodation available for loved ones when the carer is no longer able to meet their needs.
- The important work carers do is not noticed by society, and carers feel undervalued.
- The sacrifices involved in being a carer, along with the additional expenses it entails, often result in serious financial insecurity (e.g. minimal superannuation savings for the carer's own retirement).
- The carer is time-poor due to their 24/7 caring responsibilities. They usually do not get to participate in a wider social life very much at all.
- They are often anxious about their future, and for the person in their care.
- The carer's own health, wellbeing and relationships often suffer. Health outcomes for carers are among the poorest in Australia.

Many suggestions are emerging from the inquiry, although who will bear the brunt of funding these initiatives is another question. For example carers would benefit from carer's leave' and

‘palliative care leave’ (as opposed to them having to use annual leave); but such leave would clearly affect an employer’s budget. Or in order to improve the quality of respite care, better recruiting, training and working conditions of paid carers is needed; but how this would be funded, and whether by government or by non-government organisations, is unclear. The Government has already made some progress in this area. But it will be complex and challenging for our leaders to keep coming up with the best ways to ensure that everyone has access to the highest quality services, and that the notion of ‘choice’ that we all value so much will not elude people with disabilities or their carers.

And it is inherent to care that it *cannot* be made economically profitable, and nor should we attempt to make it so, for a good society recognises that the whole point of an economy is to sustain care in all its forms. The purpose of money is for relationships, and these relationships of care will cost money and cannot be made to make money. There is nothing wrong with that: we honour the person being cared for by saying ‘you are worth it, and as a society, we will spend our money on you.’

Political solutions: It is right at this point that the Christian political voice becomes very relevant. The inquiry has yet to table its report to Parliament. Every politician will be sympathetic to the needs of carers—but when the hard decisions about funding programs need to be made, *they will need the support of the public*. This is not a popular, trendy issue that attracts the support of celebrities and the average person in the street. It is all too easily eclipsed by discussions about interest rates, fuel prices or salary caps in football.

So, Christians can begin a groundswell of support for our MPs to generously allocate public money to the needs of carers. MPs will need a mandate to boldly argue for increased spending. If we are to have ‘a caring society’, there aren’t too many more important matters of public policy than this one.

The matter might be worth a letter or visit to your MP. It might also be that you are willing to help him or her argue that the comfortable middle class accept a smaller piece of the pie next budget in the interests of sharing resources with those who need it most. For example: could family allowances be reduced for some? Or, could a voluntary tax levy be introduced to create a ‘caring fund’?

‘Ecclesial’ solutions: Carers need more than a government to support them. Many non-government, community and Church organisations already deliver services to people with disabilities and their carers. For example Anglicare plays an important role as a service provider, and speaks with great authority on our behalf about the pressing needs of this sector.

But an ‘ecclesial’ solution to the problem also springs from the life of local church communities. Carers need more than an Anglicare to care for them. After reading this briefing, could *you* begin a constructive conversation within your church about the needs of carers? Could a ‘caring for carers’ group be formed, where a few people gather to support carers? You could start out by finding answers to the following questions:

1. Has anyone taken a ‘local census’ of carers lately?
Who are the carers that come to your church?
Who are the carers for whom it is getting harder to be at church, due to the demands of care?
Do we know of other carers in our neighbourhood?
2. In each case, what would they list as their main needs, difficulties and concerns?
(This would require someone to visit and ask them, and then quietly listen to their responses.)
3. Are any of these problems true for them?
They have had to leave the workforce because of inflexible work arrangements.
They are neglecting their own health.
They are starved of social interaction.
They are in financial difficulty, or have some pressing one-off expense.

4. Within the household of someone with a disability, are siblings carrying extra responsibilities and strain that has gone unnoticed? What are their needs?
5. Would a carer accept any of the following, if done properly, from church folk?
 - A low-stress social event at the carer's house (where others cater and clean up).
 - Some regular spiritual support (e.g. prayer and bible study) at the carer's house.
 - Someone with the proper gifts and skills being trained for short periods of respite care.
 - A collection for some pressing one-off financial need.
 - A knowledgeable helper who can assist the carer to access government services.

Now in writing these suggestions we realise that many people in churches are usually pushing themselves hard already. It is not our intention to trigger guilt about another 'to do' agenda. The idea might not be for everyone. But there are probably people in every church who *could* help carers, whose gifts and skills are untapped, who have difficulty forming connections with carers, but who would really like to try helping if they could.

Also, it seems important to care for carers when we consider the way conservative Christian communities are usually opposed to abortion and euthanasia. These are matters of moral importance for the whole of our society—but it is the *carers* who bear the brunt of the decision to honour life. The ill can only be tended with love, or broken people welcomed into life, because *someone is willing to care for them*.

So when Christian communities declare the good of life, the declaration only carries real meaning when it is embodied in some practice; and ongoing practical care for carers is something well within the capacities of a local church community.

It will be important for Christians to go to the carers and find out their needs, rather than waiting for them to come to us at church. It will also be important for Christians to only offer help in response to what a carer *says* they need (rather than what we *imagine* they need). It will be very important only to offer what can be offered *competently* and without compromising the dignity of the person in need of care.

The report from the inquiry, and our society's responses to its recommendations, will be an important moment for the Australian community. But people in churches do not have to wait until then. *Now* we can be vocal; and we can go to our carers, and try to care.

'Share with the saints in their needs; pursue hospitality.' [Romans 12:13]

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Sources/Further Reading:

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http://www.sane.org/images/stories/information/research/0707_info_rb5.pdf

Carers NSW - <http://www.carersnsw.asn.au>

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