

STORY AND PHOTOS: ANDREW DAWSON

Peter gets a fortnightly carer's allowance for looking after a close friend in Melbourne who is battling a "duopoly of psychiatric and medical issues". On a conservative twelve hour day that amounts to "about 59 cents an hour".

He is one of an estimated 2.5 million carers in Australia, including more than 470,000 people who provide primary care to people in need of support.

Australia's ageing population and a shift from institutional care to community care is leading to a dramatic increase in the number of people, particularly women, caring for family members with a disability or long-term health problem. The Australian Institute of Health and Welfare anticipates there will be more than 600,000 primary carers by 2013, with 70 per cent of them likely to be women.

It's estimated this community based care is saving governments billions of dollars in health care, transport and housing costs. That's one of the issues highlighted in more than 1,200 submissions received by the House of Representatives Family and Community Committee for its public inquiry into better support for carers.

Committee chair Annette Ellis (Member for Canberra, ACT) said carers are often the hidden and unsung heroes who tirelessly look after family members and friends who cannot look after themselves.

"The demands placed on these carers often mean that they are exhausted, socially isolated and under extreme financial pressure, particularly as they are unable to access mainstream employment opportunities," Ms Ellis said. "Not surprisingly, carers have been found to have significantly worse physical health and psychological wellbeing than the general population."

Personal stories about the emotional, physical and financial costs of being a carer fill the pages of the hundreds of submissions already received by the committee.

In his submission, Peter from Melbourne said his carer's allowance does not stretch far.

"My 59 cents an hour is mostly absorbed in fuel for the motor car and medication." He added that the "so called safety net for pharmaceutical supplies is often times ineffective in that not all the medication prescribed is covered by the Pharmaceutical Benefits Scheme and this can become problematic when one lives on a fixed income".

Peter also highlighted the need for carers to have some respite from their daily responsibilities of looking after very needy people.

"There are many carers who are at a point in their life where accumulating fatigue makes an already difficult undertaking even more challenging," he said.

"This is because carers have needs just as much as the one they care for ... carers need respite as much as those we care for need carers."

The story 20-year-old Carreen Dew from NSW told a public hearing in Sydney highlights the plight of the more than 300,000 young carers across Australia.

For the past nine years, Careen, her mother and 18-year-old brother have been caring for her younger brother Alec. He

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Desperate care
and friends, an

"The emphasis on in-home support has effectively entrapped carers within their own homes."



CARERS HAVE NEEDS TOO: Lisa Humphries (right) spoke about the emotional, physical and financial costs of being a carer at the carers inquiry hearing in Sydney (inset).

tered lives

ers speak up about the pressures of looking after family
and the support they need to keep going.





has multiple disabilities including a facial paralysis syndrome that requires him to breathe through a tube into his neck.

“It’s been very hard, my dad doesn’t live with us and I was 12 when my brother was born, so straight away I became the second parent of the house,” she said.

“My brother has had over 150 hospital admissions, so when he’s in hospital I’m in charge of the house doing all the cooking, cleaning and getting Alec’s twin to and from school.

“School was very hard and you don’t think many people understood what went on at home.

“My brother can’t breathe through his mouth and he has to breathe through a tractotomy so when I was 12 I had to learn to change it weekly. He also can’t eat because of this and he has to be fed through a gastrostomy button in his stomach and that also has to be changed regularly. So from an early age I was learning how to do some pretty scary things and it didn’t always go to plan.”

Carreen’s teenage years were anything but normal. She lamented: “We didn’t have many family holidays—it’s a bit hard going out to dinner even. A lot of medical equipment has to follow my brother around such as oxygen bottles. We’d attach them all to his wheelchair but it’s a physical struggle just to get out the door so we haven’t done a lot.”

She wanted to tell the MPs on the Family and Community Committee about the importance of respite care for families like hers.

“A lot of respite agencies don’t consider my brother to be disabled even though he has a lot of disabilities and has all these life threatening illnesses. He doesn’t fit all these criteria that respite agencies send out so we have not been eligible for a lot of respite.

“Because of his tractotomy we have to keep an eye on it every three minutes because if it blocks or comes out it only takes three minutes for brain damage. Even at night you constantly sleep with one eye open and in the past nine

“Carers need respite as much as those we care for need carers.”

years my family has only had two nights where we have been relieved of this responsibility, so the need for respite care was definitely one of my main points to tell the committee.”

Twenty-year-old Maggie Malak from Sydney has been one of the main carers of her mother from an early age. She spoke at the committee’s roundtable in Sydney about the challenges of looking after a mother with a spinal cord injury as well as a disabled brother.

“We save every penny we can get,” Maggie said. “It’s very financially hard for us with the cost of medication, household bills and paying off the home loan. Basically my mum’s disability pension goes towards the home loan and my carer’s payment goes on food, electricity, bills and medication.

“My sister has also just been diagnosed with rheumatoid arthritis so her medical bills are just going through the roof—it’s \$400 just to get a scan to see what’s wrong and we don’t have that money. We have to save it up. My carer’s pension is basically about \$500 a fortnight and my mum gets about the same.”

Maggie told MPs about her challenge of balancing the requirements of high school with those of being a carer and still qualifying for the carer payments.

“There is a limit to how long you can be away from the person you care for—you can’t be away from them for more than 30 hours a week. When you are at school, you are away more than 30 hours so therefore I had to take time off school just so I could receive that payment.”



UNSUNG HEROES:
Lisa Humphries (opposite page) and Carreen Dew (left and below with Maggie Malak) spoke about the pressures of being young carers.



Maggie believes the bureaucracy is too rigid in how it manages support services.

“When I was five and my sister nine, we basically learnt how to do everything at home. We only received home care many years later when we found out about it from my brother’s school. But because my mother has now had an operation and can walk for five minutes at a time, she isn’t disabled enough to receive home care.”

Thirty-five year old Lisa Humphries from Sydney was only 16 when she and her younger brother became the

carers of her mother after she suffered a severe brain injury from a car accident. Eleven years later her mother died from breast cancer. She now balances work with caring for her grandparents who are battling cancer and dementia.

“Being a young carer was so difficult—it was really isolating. The time when I was at school as a 16, 17 and 18 year old, it was just horrendous to try and study as well as look after someone with a brain injury. I felt like an outcast at school. The teacher would come in and say I’d need to go to the hospital in front of everybody.”

It was a stressful environment for Lisa and her younger brother to grow up in as they learnt to cope with their own anxiety and post traumatic stress-related depression.

“Spending so much time in hospital in your teenage years is quite traumatic. A brain injury is something that takes away the person you know. My mum lost her personality. She lost her ability to walk, talk and eat and we needed to teach her to do all those things in conjunction with the medical teams.

“We’d just hope everyday that she’d come out of a coma that went on for months—it’s very difficult to understand the level of care that someone with a brain injury needs. She also had epilepsy as a result of her brain injury and at any given moment she could have a massive seizure and need to be incubated.”

Lisa told MPs about the financial struggle for carers. “When she was diagnosed with breast cancer in my 20s, I then quit work and cared for her full-time. I recall I went on the carer’s pension which was about \$200 per week, it basically only paid for me to clothe and feed myself, that was it. As someone in my 30s, I am now 10 years behind my friends and peers in financial terms because I couldn’t earn anything or grow my career.”

Lisa says governments need to help young carers through their school years.

“The support through schools is really important and there needs to be more education of teachers and principals

about what carers are going through, while they are at school. Trying to keep them at school is really important—my brother didn't stay to finish his HSC.”

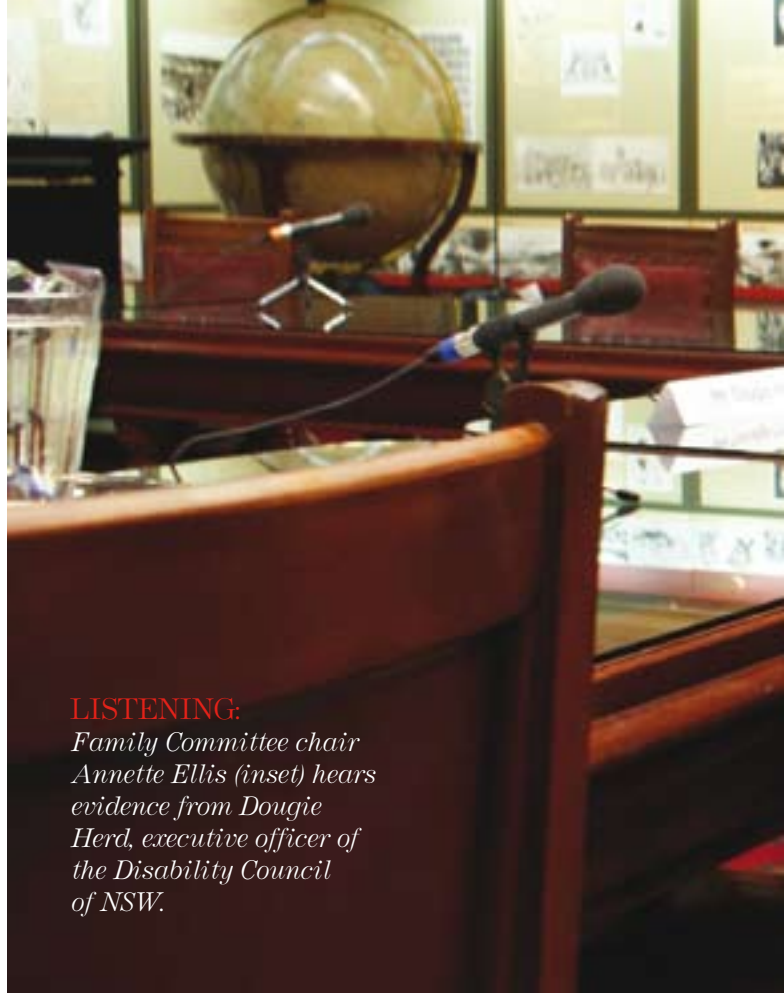
Cathy, who is on a waiting list for government housing in Canberra, tells in her submission about her 22 years of caring for a sister who suffered a brain injury from a car accident in the 1980s.

Cathy moved her sister into the family home in order to provide the care she needed. The brain injury makes Cathy's sister repeat herself all day and has also led to alcoholism. On top of this, Cathy has had to deal with the difficulties of a son battling mental health problems and a marriage that fell apart last year.

“I feel exhausted and try to put my energies into looking after my family and deal with the housing issue and the rest,” she said. “Not to mention I am also dealing with the grief of a failed marriage after 26 years ... because I am stressed out to the maximum I find it difficult to handle.

“I am finding it difficult to keep up both my caring roles but keep on pushing myself. I do not know how long I can keep this up without support, particularly housing.”

She believes many of the issues she faces are common for most carers: “stress from the demands of caring every day coupled with day to day issues of existence, financial constraint from being a carer, loneliness, lack of opportunities such as education, work, recreation and being devalued by society”.



LISTENING:

Family Committee chair Annette Ellis (inset) hears evidence from Dougie Herd, executive officer of the Disability Council of NSW.

“Seven out of 10 carers want to be employed but have difficulty finding flexible working hours and alternative care for their family member.”

Many submissions lament the challenges carers face in finding suitable employment that fits in with their responsibilities as carers. New research by the Australian Institute of Family Studies examines the impact of caring responsibilities on labour market participation by carers.

Deputy director of research at the institute, Dr Matthew Gray, said the recent study revealed the significant financial cost of becoming a carer.

“Even one year of informal care had a significant financial impact on the gross personal income of carers,” Dr Gray said.

The study found seven out of 10 carers want to be employed but have difficulty finding flexible working hours and alternative care for their family member.

Last year, 116,614 people received a carer payment, an increase of 145 per cent since June 2000, and 393,263 received a carer allowance, an increase of 102 per cent in the same period.

Dr Gray, who co-authored the study of 1,002 carers, said little was previously known about the impact of caring on the labour market participation of carers.

The study also found that 70 per cent of those receiving a carer allowance and 54 per cent of those receiving the carer payment, who were not employed, said they wanted to work. It found 83 per cent of those receiving a carer allowance and

78 per cent of those receiving a carer payment said providing care was the main reason for leaving their job.

“Carers make a significant contribution to the Australian economy and society, but they also bear significant personal costs,” Dr Gray said. “Carers experience lower than average employment rates and, for many, taking on carer responsibilities leads to a decline in employment. Whether this decline in employment is temporary or permanent, it impacts on the carer and their family.”

Dr Gray believes supporting carers who are not in paid employment but wish to be could lead to a number of benefits including higher levels of social inclusion and improved labour market participation rates.

While the statistics in the recent study paint a broad picture, it is the personal stories contained in submissions to the parliamentary inquiry that underpin the realities of being a carer.

Terence, a grandfather on the Gold Coast, helps his wife look after their grandchild who they have custody of and requires around the clock care. He lamented the restrictions that come with the carer allowance.

“The greatest singular burden on us carers is the ability to raise more income on top of our carer's pension without being penalised by Centrelink through asset testing on our extra income that many of us are trying to earn to subsidise



the immense financial burden that we have,” he said. “We want to be able to contribute, but please remove this terrible obstacle of asset testing incomes.”

Denise Redmond, the project manager for Nardy House, a respite care facility unit in Bega (NSW) for people with profound disabilities, warned that the huge burden on carers’ finances and their social lives is taking its toll.

“The emphasis on in-home support, because it is believed to be economically effective, has turned carers’ homes into service provision points and has effectively entrapped carers within their own homes,” she said.

“Many highly skilled people have been de-skilled by the necessity of the caring role. The reward for care is de-skilling, entrapment and poverty. While great joy is derived from the caring role by many carers, they feel that they are treated with enormous disdain by those in power (both economically and monetarily).”

Denise believes a range of financial recommendations will help ease some of the pressure upon carers of people with disabilities, especially in overcoming their lack of income. She has proposed a payment of a wage for the caring role, assistance to set up small business enterprises within the home if desired, and the introduction of a nationwide compulsory insurance against disability and accident scheme that funds all levels of disabilities.

“This scheme should include disability of all kinds, genetic and acquired, and should take the form of whole of

life support and needs a levy that is generous enough to cover carer wages,” Denise said.

She also highlighted the growing concern ageing carers have about what will happen to the people they care for in the future.

“Most carers have one constant fear. What will happen to the person in my care if something happens to me? They cannot effectively plan for the future because there are not the choices available to them to do so.”

She said carers of people with profound disabilities currently have only one choice—an aged care facility. Her recommendation is that governments need to offer a choice of group home models appropriately staffed to cater for the long-term supported accommodation needs of people with very high support needs.

Middle-aged parents Jill and Will of Perth echoed this fear. They are concerned about what will happen to their disabled daughter when they are no longer able to help her.

“We are both in our late 50s and the future of our 26-year-old daughter is a constant worry,” they said. “Once we are unable to care for her for a variety of reasons, what happens?”

“At the moment alternative accommodation is only available in a crisis situation like death of the carer, health issues with the carer or total exhaustion or mental breakdown. What would be much better for all concerned is a wider gradual change from living with the carer parent or parents to living part-time away from the carer.” •

For more information on the House of Representatives Family and Community Committee’s inquiry into better support for carers, including submissions, the program of public hearings and transcripts from hearings, visit www.aph.gov.au/fchy or email fchy.reps@aph.gov.au or phone (02) 6277 4566.