

REC 17/17/08

Submission No. 916  
(Inq into better support for carers)

I am submitting to the Inquiry because for the last eight years I have cared for my husband who has Alzheimers and have recently had to relinquish his care and place him in a Dementia Specific Home. The last four years have been intensive caring and during that time I have met Carers of people with differing disabilities through the Carer's Association. From the meetings, get-togethers and general conversation it appears that whilst there are many services available, especially in the Aged Care Sector, nearly all full-time carers experience similar frustrations and burnout. Home caring seems to be still perceived as being a 9 - 5 job, instead of the 24 hr/7days a week/52 weeks a yr undertaking with brief and often irregular respite.

1. Role and Contribution

Family carers are generally taken for granted and as they are unpaid are not seen as having a productive role. There is an expectation that family will care for an aged or disabled person. A carer who is employed as such is viewed with some respect and amazement that they will do a job not considered to have much worth for so little remuneration. Society relies on the family carer having ties of affection, duty and responsibility which are natural but these days support from extended family members is often not available, due to them being in paid employment or away from home. There is an expectation that caring will be done by spouses or family which results in a great feeling of failure on the part of the carer when they finally succumb and place the person in residential care.

2.

As a carer I feel that my role has placed continuous social barriers and would have placed impossible demands on any sort of economic participation.

**Social** - the nature of caring generally obliges the carer to be "on duty" if not 24 hours a day then at specific periods, making it difficult or impossible to be socially involved without detailed and meticulous advanced planning, leaving no room for the unexpected. Even with this the attitude, state and temperament of the person being cared for can still make involvement impossible. Many of the programmes offered are reliant on receiving short term Grants to run a programme - such as extended Day Respite or over-night respite. Therefore they are temporary programmes, usually over-subscribed and not suitable for people with dementia or behavioural problems who need regularity and familiarity to be able to participate.

**Economic** - Problems of getting suitable, reliable care (with adequate emergency back-up) would make it extremely difficult to find employment in the hours available for a carer to work. The demands on caring, exhaustion both physical, mental and the emotional involvement would increase the stress level of carers. The carer's payment and allowance is totally inadequate given the nature of the activity - the allowance of approximately \$50 a week pays for roughly 3 hours of day care at a respite centre. Young families can receive child allowances plus subsidised childcare and they are two people able to work without the stresses and strains attendant on full time caring for people with disabilities.

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3.

**Day respite centres** open from 8am - 6pm with 'drop-in' services and a collection service for certain hours i.e. 10 - 3. These facilities need to receive permanent funding so that they can employ adequate, trained staff at reasonable rates of pay.

**Short term overnight respite cottages** - where those needing care could go for one or three nights in a homely, non-threatening atmosphere.

**Overnight in home respite** - especially for young carers and for those carers looking after someone with problems that make it difficult for them to access external respite.

**Group residential homes** - are urgently needed, especially for young adults with severe disabilities whose carers find the caring role an intolerable burden as they age and worry about the future of their children.

4.

Consumer Choice for carers. This approach is being discussed by organisations, such as Alzheimers. Whilst appearing to have some merits in allowing the carer to appoint a carer of their choice and pay from an allocated budget it would hopefully only be considered as a choice and not as the norm. It would place an added burden on carers, selecting and appointing a carer, rates of pay etc. and would involve a large amount of red-tape and administration and would involve health and safety and insurance issues.

Transition in and out of caring Most specific organisations run education courses, workshops, seminars and conferences for carers of people with specific needs. Due to the problems created by the caring role often these can not be accessed by carers. General Practitioners should play a more prominent role in putting carers in touch with the appropriate organisations, as they are the first point of contact. Funding should be available, again as a proper budget not as something that has to be applied for frequently in order to keep an education support programme going.

There is little or no support for carers who, when unable to care for a person at home places them in residential care, i.e. dementia wings, high care nursing homes or group homes. The emotional stress, sense of grieving, feelings of failure and isolation need to be addressed by providing funds to appropriate organisations or the residential facilities to form support groups for family members.

Carers of young people with disabilities advancing to adulthood need a reliable system of planning for admission into group housing or hostel accommodation and an increase in the provision of such homes.

Young carers need a support worker to help them plan for their future education/training. In some cases maybe a mentor or buddy system could help them to participate in regular social/sporting activities.