

# Understanding the role of Family Carers in Health Care

*Implications for the Health and Community Service System*

Monograph



# Summary of Key Points

## 1. Declining ratios of Carers

The number and percentage of family Carers has increased and will continue to do so. However, the ratio of Carers to people requiring care is dramatically decreasing (Percival & Kelly 2004), partly due to conditions associated with an ageing population. In the future, the number of older people requiring care will far outstrip the proportion of family members who can or are willing to provide care.

## Context of caring

### 2. Carers and State and Federal Policy

Informal caregiving is influenced by socio-demographic changes as well as health system and community care policy and practices. Fundamental to policies is the assumption that Carers are a static group who are healthy, able and willing to take on the caring role.

## Carers are not only 'Consumers'

### 3. Separate Carer policies required

Policies on 'community or consumer participation' can easily overlook Carers' needs and interests and Carers should be separately identified within policy, programs and practices.

## Carers as Partners in Care

### 4. Carer information needs

Informal caregiving responsibilities are beyond the normal expectations of relationships (Schofield et al 1998), and may include tasks and activities that were previously the domain of professionals, e.g. peg feeding and tracheostomy care. Duty of care is increasingly an issue for Carers as they are taking more responsibility for professional tasks and activities. Privacy legislation requirements must be balanced with Carers' information needs in providing care. It is desirable that Carers be routinely involved in care planning and case conferencing, in the hospital, general practice and community care service setting.

## Carers as an 'at Risk' Population Group

### 5. Carers rarely exist as a population group in population epidemiology

Carers are a population health group in their own right as their health and wellbeing is affected by their caring role. Anxiety and depression, poor sleep and musculoskeletal (particularly back) problems are just some of the concerns of Carers (Carers Association of Australia 2000).

Sequential and multiple caring roles can lead to long term stress states. There is scope for more research on the way in which psychosocial factors associated with caregiving impact upon Carers' health.

## Carers as Patients

### 6. Professionals' recognition of Carers, predictors of Carer stress and support needs

Carer stress is predicted by a Carer's gender, the kin relationship involved, amount of hours spent caring, and the circumstances of living arrangements (Hirst 2004). Carers' health issues need to be carefully monitored, especially in the event of an acute illness episode of the care-recipient. Also, current chronic disease self-management approaches can easily fail to assess the needs of Carers. In the clinical environment, Carers can be identified and encouraged to monitor their own health (e.g. by attending screenings).

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Cover photo: Courtesy of *The Australian*. Denise McEvoy and her father Clarrie (deceased).

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# Introduction

*There is a need to recognize that rates of informal care are increasing, in a new social and service delivery context.*

Informal Carers, whether partners, family or friends, make a significant economic and service delivery contribution to the health sector, and yet the role of 'Carer' has only relatively recently been recognized. Trends such as the increased number of conditions associated with an older population (neurodegenerative diseases, disability and handicap), and the rise in chronic or long term illness will have a significant impact on informal caregiving work. Trends in health such as the increasing privatization of care, early discharge policies, increase in day surgery and emphasis on providing care within the community rather than hospital or institutional care,

point towards implicit expectations for informal care, especially for the care of older people. Carers are in a range of possible relationships and can also be young Carers providing support to a parent or sibling, or younger parents caring for children with a chronic illness or disability.

Results from South Australian Health Omnibus surveys (1994 to 2004) show that the percentage of those identifying as primary Carers in the general population has steadily risen over the last 10 years, from 3.4% in 1994, to 4.2% in 1998, to 5.9% in 2004 (Health Harrison Research 2004)<sup>1</sup>. Carers were more common amongst the older (9.7%) and middle age group (8.5%) and women and people of

low income (Health Harrison Research 2004).

A national population based cohort study on women has shown a high proportion of Carers (12.7%) amongst middle age women (Lee & Porteous 2002) and there is a high degree of transition into and out of the caring role (Lee 2004). By 2031 the percentage of Carers is projected to increase by 57% (Percival & Kelly 2004), with 71% more co-resident Carers; it is more likely that Carers will be older, with an anticipated 56% of Carers over the age of 65 in 2031, up from 42% in 2001 (Percival & Kelly 2004). Although the number and percentage of Carers has increased, recent projections show that the ratio of unpaid primary Carers to

## Anthony

Anthony was 8 when he first started helping his mother. At this young age he realised how sick his mother was and started to "help out around the house" by doing the dishes, cooking tea, looking after his younger sister and behaving himself. Anthony missed a lot of school due to his caring role and left school at 16. Anthony now 23 has been caring for his mother for 15 years and has been her "official" Carer since the age of 16 when he started receiving the Carers Payment. His mother faints a lot and Anthony administers first aid to ensure that she is still breathing. Anthony sums up his role as a Carer by saying "Mum is my life, with any opportunities for me on the side". After going years without any support Anthony is now a member of the South Coast Carer Support and encourages other young Carers to join support groups and have a voice.



Photo: Courtesy of *The Advertiser*.

the number of people requiring care will decrease dramatically over the next 30 years. The current ratio of Carers to people requiring care aged over 65 years is 57 to 100, but this figure will be reduced to around 35 Carers for every 100 people aged over 65 years (Percival & Kelly 2004).

Carers now have less access to additional informal support than in past generations, due to the changed family structure. They may also be juggling multiple roles in paid and unpaid work, especially women who are Carers of middle age. Younger, female Carers are more likely to want to increase their current workforce participation (Schofield et al 1998).

There is a need to recognize that rates of informal care are increasing in a new social and service delivery context. In this context providing support for Carers as partners in care, whilst also addressing health issues for Carers, is crucial. Whilst an adequate, affordable and coordinated Australian public health system is desirable, the reality is that informal Carers will continue to have an essential role to play in health service delivery. Early identification of the Carer role and monitoring predictors of distress and illness amongst Carers, is necessary.

Whilst the caregiving role should not be 'typified by burden' (Schofield et al 1998), Carers' lives

and long term life opportunities can be deeply affected by the assistance provided to family members and as a group their health is affected by the caregiving role (Schofield et al 1998). Carers have their own unique health concerns and support needs and need to be identified as a population health group within a public health framework. Generic policies on 'community participation' often lead to Carers' interests and needs being overlooked. 'Carers' must be separated from health service users or consumers within language, policy and programs and identified in their own right.

1. Health Omnibus Survey results were compiled by Harrison Health Research (2004). In 2004 a Carer was deemed a person who 'provide[d] long term care [minimum 6 months] at home for a parent, partner, child, other relative or friend who has a disability, is frail, aged or who has a chronic mental or physical illness'.

## Implications for the Health and Community Service System

*Carers are increasingly important players in the theories and debates about preferred approaches to health and community care.*

The final report of the South Australian Generational Health Review (2003) has rightly acknowledged family Carers as part of the primary health care workforce, or 'community care'. They are identified as one group of providers not recognized as part of the public health system, but who are in fact critical to it. The review also reinforced many Carers' view that there is no 'health system' but rather a myriad of fragmented services. Carers with young children with disabilities are particularly affected by such fragmentation of services with access to assessment, therapy, early intervention, and respite services significantly affected by the timely diagnosis of disabilities and the geographical

proximity to services. In this environment Carers actively contribute to primary health care by providing continuity and coordination of care and services within and across sectors.

They also have an important role in translating health information to health service users. They also provide observations and feedback to health professionals to maximise the wellbeing of the care recipient.

### Context of Caring: State and Federal Policy and Practices

Carers are increasingly important players in the theories and debates about preferred approaches to

health and community care and actual federal and state policies, programs and practices. However, they are frequently ignored. For example:

#### Ageing in Place

Federal and state policies on ageing, such as the National Strategy for an Ageing Australia (1999) promote 'ageing in place', or maintaining people in their own homes for as long as possible and may ultimately rely upon the available supply of family Carers. However, even in an institutional environment, Carers can have a significant role to play in the support of people in residential care.

## Primary Care

'Primary care' is highlighted as an area to be strengthened within the health sector by the SA Generational Health Review (2003) and the federal government's 'Enhanced Primary Care' package and 'Sharing Health Care Initiative'. 'Chronic Disease Self-Management' promoted in the primary care setting relies upon the support of informal care and the family unit. South Australia's Primary Health Care Policy (2003) aims to strengthen the primary care sector, requiring the involvement of family Carers.

## Deinstitutionalisation in the Disability Sector

The 'deinstitutionalisation' of people with disabilities has placed a burden on families as it has not been matched by accommodation facilities for people with intellectual disability, acquired brain injury and physical disabilities.

## Deinstitutionalisation of People with a Mental Illness

Mental illness has not been recognized as a disability in South Australia and has missed out on disability funding; community support for people with a mental illness, such as residential support, is the lowest in Australia (SCRGSP 2004).

## Chronic Disease Self-Management

One of the latest trends in primary health care, 'chronic disease self management' (CDSM), promoting responsibility for one's health and treatment, unfortunately appears to largely overlook the role and experience of Carers in service delivery and care coordination and their particular knowledge of the care recipient, whilst actually potentially requiring more support from informal Carers. The objectives of the federal government's 'Shared Care' initiative from which CDSM

programs have been funded includes the positive objective 'for individuals, families and health care professionals to work together in the management of chronic conditions'<sup>2</sup>. However, the role of Carers and families in this approach is not explicit as is evident in the title of this approach, particularly Carers' contribution to needs identification and ongoing treatment and support. Turnover of health professionals or changes in programs or funding may mean that Carers are often the ones left to 'pick up the pieces' in terms of ongoing care.

The problem of how to support Carers who are vulnerable to their own illnesses is not explicit in the CDSM approach, i.e. the 'self-care' of Carers. Whilst there is an assessment of 'clients' there is no Carer Assessment Tool adopted. Any professional assumption that Carers will assist in chronic disease 'self-management' without

## Pat

Pat cares for her two sons who have schizophrenia. They were diagnosed when they were 23 and 17 and are now 34 and 30. Pat's sons live in a house purchased by her and her husband within walking distance from their family home.

Pat's role as a Carer for her 2 sons involves assisting them to live independently and also assisting them to cope with symptoms of their illness. She provides essential support with all home duties, including cooking, cleaning, shopping, etc, as well as managing finances and other duties as required.

Pat often experiences feelings of guilt: guilt that she can afford to live in a nice home, eats healthy and interesting food, is able to have close friendships and relationships and is often not able to spend as much time as she would like with her other children. She struggles to find a proper balance between spending enough time with her sons or spending too much time with them, thereby stifling their independence.

The stigma attached to this illness has inspired Pat to

advocate on behalf of her sons and other Carers of people with schizophrenia. Pat lobbies for more community services to allow people with mental illness to live independent lives with effective community reintegration and for greater community awareness and acceptance of schizophrenia.



Photo: Courtesy of *The Advertiser*.

negotiation with Carers is unacceptable. A failure to assess or monitor Carers' health or the health service trends upon their Carer role is potentially detrimental, particularly with the prediction that Carers will be a significantly older group in the future.

### **Hospital practices**

Hospital practices such as early discharge policies, 'hospital at home', the decline in the use of acute hospital beds, medical advances and associated increase in day surgery and cuts in services can put severe pressure on (predominantly female) Carers within the community (Guillemin 1997). The National Demonstration Hospital Program 4 focuses on ageing issues and improving patient outcomes whilst at the same time producing 'cost efficiencies'. It is recognized that the hospital 'casemix' system with recommended average bed stays according to conditions, is economically driven and problematic for people with multiple and complex conditions. Once again, an expectation for family care without negotiation is unacceptable. There is a training issue for family Carers arising from these new treatment practices that often goes unacknowledged.

## **Equity Issues for Carers in Policies**

There are often issues of equity in many of the above policies and programs, for example the current subsidies on and subsequent cost of residential aged care may mean that many older people and their families can not afford residential care and are forced into a caregiving role with limited publicly funded home based support. Families of people with disabilities (e.g. intellectual, psychiatric) may have had a financial role to play in assisting their family member with housing in the absence of adequate community care and with the reduction of public housing stock in South Australia, but meeting capital costs that were previously met by disability programs may only be an option for very few.

Many Carers experience a loss of income and financial stress associated with this. These issues doubly impact upon Carers of low socio-economic status and women Carers. For example, Carers in low status employment may feel pressure to relinquish their paid work roles either through direct pressure or stressors encountered. Transporting a relative to hospital, waiting in a public hospital casualty department for 10 hours with a sick relative and being there for 'early discharge' (without consequences on paid work) may only be possible for Carers either already outside the

paid workforce or the self-employed. Flexibility of work conditions is important for caregiving and not widespread. Carers who are parents are likely to have had their employment affected by their caring role, having reduced hours of employment or taken on unpaid or less 'responsible' work (Schofield et al 1998). Women are also more likely to have had their employment affected by caring than men, e.g. reducing hours, level of responsibility of working, unpaid leave or changing jobs (Schofield et al 1998).

Often the differential impact of such social and health trends and policies upon families are not assessed or sometimes even acknowledged. Whilst there is data on the reduction of average bed stays in hospitals, for example, and evidence that deinstitutionalisation has not been followed up by community care in the mental health sector in South Australia (SCRGSP 2004), there is no longitudinal data to assess how families are coping with such trends. Carers must be able to negotiate with services what is possible in terms of ability to care in the context of resources available (whether economic or social), just as the health system and community services staff have a responsibility to set limits on the caregiving role.

# Carers are not only 'Consumers'

In the health sector, including health advocacy, Carers' needs and interests are often confused with those of health service users. The term 'consumer participation' is often used to cover both health service users and Carers. But whilst health service users' (Consumers) and their family or friends' (Carers) interests may often coincide, they are sometimes different or even in conflict. It is important that Carers are not defined as having the same interests as health service users because of their unique role and interests:

## Carers as Proxy Service Providers

### Service delivery and Support role

Whilst caregiving may occur within familial relationships it goes beyond 'normal' expectations for relationships in terms of responsibility taken and work done for others (Schofield et al 1998). Informal care work is actual service delivery and Carers must be viewed as partners in care with professionals, e.g. in activities such as care planning. The caring tasks are diverse and can include tasks

that are currently or were previously defined as nursing tasks or those of other health care professionals. Carers who are spouses or parents of the care-receiver are more likely to be providing more assistance with tasks of daily living and common caring tasks include assistance with going out, organizing appointments and social services and managing money (Schofield et al 1998). Over half of care-recipients require assistance with medications or dressings (Schofield et al 1998). The range of possible tasks of caregiving work can be divided into four main roles:

## John and Margie

John and his wife Margie care for their 23 year old daughter who has a severe intellectual disability and behavioural issues which include throwing things around the room (including ghetto blasters and plates), tearing pieces of paper into confetti, clawing and pulling people's hair, smearing faeces on walls and chewing through electrical cords. Margie has been in hospital twice as a result of injuries from their daughter's behaviour. John (a GP) describes these as "Carer injuries". John has his own practice and is fortunate to be able to take time off from his work to provide extra care and support his family.

John understands the social isolation with being a Carer having experienced it at home and seen it at work. When a patient who is a Carer comes to him, for them or the person that they are caring for, John looks for physical damage to the Carer which is a direct result of sleep deprivation and repetitive lifting. John also recognises the unmet needs of people with a disability and their Carers and the dependence on formal and informal respite care. John strongly advocates for disability to be included in subjects at Medical School and looks forward to the day when people can visit their GP or specialist and expect them to know the issues involved in disability and caring.

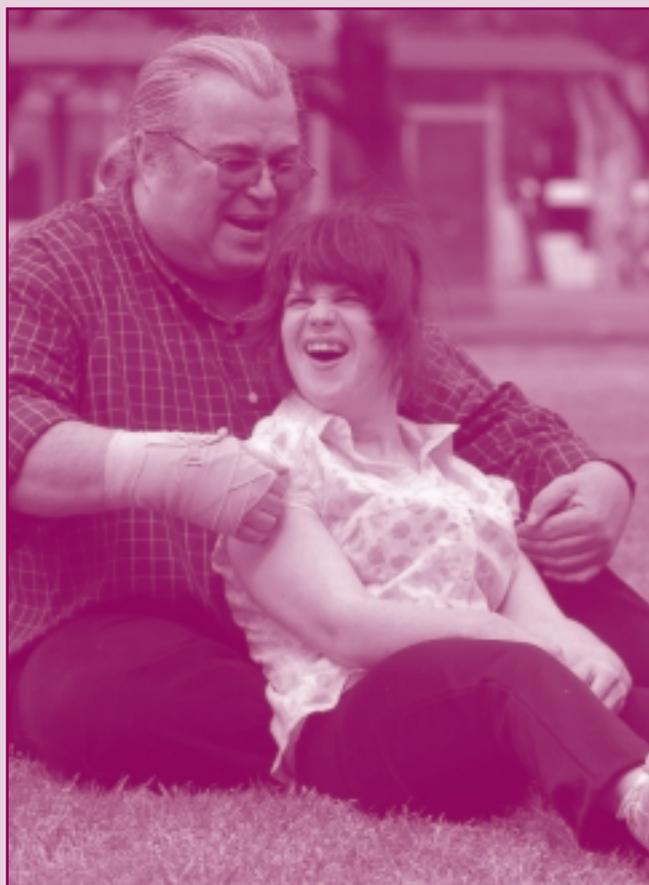


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### **a) Professional tasks and activities**

- Peg feeding, wound management, tracheostomy care
- Administering medication e.g. intra-nasal medasalam
- Monitoring treatment plans and communicating health information
- Coordination of care and support within and across sectors. Carers are often the main 'care coordinators' for patients, especially for services beyond the health sector
- Diet and nutrition (including ensuring that diet improves if care-recipients experience undernourishment in the hospital setting)

### **b) Duty of care and responsibility**

Carers often take responsibility for tasks formerly the duty of formal services, however it is sometimes unclear who has the 'duty of care' or ultimate responsibility should treatment go wrong.

- Taking responsibility for care-recipients whilst on hospital premises (e.g. waiting 10 hours in casualty with a mentally unsettled person)
- Taking responsibility for treatment in the context of 'Hospital in the home' programs, after health professionals first prescribe this

### **c) Informal and Formal Advocacy roles**

- Where formal arrangements exist (e.g. guardianship), health decision-making and consulting with health professionals over treatment options
- Advocacy on behalf of patients whilst in treatment settings
- Advocating for accessing services such as housing and respite
- Advocacy in groups for obtaining services that do not exist (e.g. accommodation for younger people with disabilities)

### **d) Routine roles**

- Organising or providing accommodation and housing support such as cleaning, gardening, food shopping and meal preparation
- Personal assistance with bathing, showering, dressing and cosmetics
- In the case of parents of children with disabilities, organizing specialist appointments, engaging in remedial play and learning and balancing work/study with the constraints of school based or other support
- Organising finances or assistance with financial planning
- Providing transport to shopping, recreational, medical and allied health appointments
- Selecting and purchasing aids and equipment and/or making home modifications
- Providing important emotional support to care-recipients and other family members

## **Carers as Partners in Care**

Due to their role in the provision and coordination of care, Carers' participation in care planning with health and community care professionals can be crucial to the health of the patient or family member. Studies have shown that Carers can be better judges of the life skills/impairment in social functioning of people with a mental health problem than formal care coordinators (Wooff et al 2003).

One obvious area for partnerships is with General Practitioners and others located within formal 'primary care' services. The Enhanced Primary Care package has enabled GPs to be remunerated for care planning and case conferencing with patients and family Carers and engaging with Carers in this way is seen as 'best practice' in treatment. However, the extent to which Carers are being routinely involved in care plans and case conferences is questionable. One UK study showed that even in mental health services that were considered 'above-average', Carers were not receiving adequate information about care plans, medication and complaints procedures for services (Wooff et al 2003). Only half of Carers were aware that there was a care plan, although most were willing to be involved in care planning (Wooff et al 2003).

Health professionals need education on Carer needs and concerns and to involve Carers in the treatment process (Hight, Thompson & McNair 2004). Providing information to Carers on the diagnosis, treatment and health condition of the care-recipient is important, not only for the care-recipient. Participation in care planning can also positively affect

Carers' attitude toward their caring role and assist with coping (Wooff et al 2003). Unfortunately, Carers of people with a mental illness have historically encountered negative attitudes towards them from health professionals which continue to this day (Highet, Thompson & McNair 2004), related

to false perceptions about the causes of illnesses and onset of episodes. Such attitudes and beliefs must be addressed to develop a true partnership relationship.

Privacy legislation needs to be balanced with Carers' information needs. Widespread rituals of patient

confidentiality may sometimes hinder rather than help the support and wellbeing of care-recipients, especially when there is a mental health component to the condition of the care-recipient when Carers particularly require support.

## Carers as an at-risk Population Group

*Carers rarely exist as a population group in population epidemiology.*

### Epidemiology

In the field of public health, the strength of epidemiology has been the demonstration of causal associations, particularly between clinical risk factors and diseases, and patterns of disease (Baum 1998), but has seen social factors such as class and economic status

as 'confounding' rather than causal (Shy 1997 cited in Baum 1998).

This is a particular issue for Carers, as socio-demographic issues such as downward mobility and poverty are associated with caregiving and the uptake of the Carer role and its effects are undoubtedly influenced by gender/class and labour market position.

Carers rarely exist as a population group studied in population epidemiology and the demographic data upon which epidemiology may rely has only recently been available as Carers were considered within Australian census data only relatively recently. Whilst it may be possible to undertake descriptive

## Denise

Denise cared for her father Clarrie, a high dependency patient requiring 24 hour nursing care. The tasks she performed daily for Clarrie (and often on numerous occasions throughout the day) as his Carer included; suctioning, PEG feeding, administering medication, transferring him in and out of bed, turning him, dressing pressure sores and ulcers, showering, toileting and dressing him. Denise also managed the house by cooking, cleaning, shopping, and paying bills etc. During the night Denise's sleep was broken as she was up with Clarrie turning and changing him as well as administering medication, checking his temperature and suctioning him (which alone could sometimes take up to 2 hours).

Denise suffers from chronic fatigue syndrome, sleep deprivation, asthma, toxic poisoning, lung damage, extreme back, neck and shoulder pain and she has a fractured lumbar vertebra. Whilst she was her father's primary Carer Denise was unable to have much needed surgery because she could not take six weeks off from caring for Clarrie to recuperate following surgery. Denise

put everything on hold in her life including her own health to care for her father. The little time that Denise had to herself to catch up with friends and socialise outside of the house was used to catch up on lost sleep. Denise says that when she was caring for her father she could not concentrate on anything else apart from caring because she was simply exhausted.



Photo: Courtesy of *The Australian*.

ecological studies to consider the Carer role and associated health effects of caring, analytical and experimental studies may be more difficult. There is currently a large longitudinal cohort study being undertaken (Australian Longitudinal Study on Women's Health ALSWH) considering women Carers and the health issues associated with this role through a sub-study (see Lee 2001, 2004, Lee & Porteous 2002). This has found that moving into the caregiving role is associated with increased GP visits, increased use of medications (e.g. for nerves, depression and sleeplessness), experiences of stress and increased Body Mass Index (Lee 2004).

Some clinical epidemiological research has been more mindful of Carers and there are a number of clinical epidemiology studies to assess health interventions targeted towards family Carers. The focus of these studies is not Carers as a general population health group, but as a group defined in relation to the disability or illness of the person they are caring for and successful treatment strategies for Carers. Such research often uses a bio-medical approach (undertaken by or through clinical services) and has sought to demonstrate effective treatment interventions mainly for Carers of stroke sufferers (see Low et al 1999), people with dementia (see Pusey et al 2001), Alzheimer's disease (see Marriott et al 2001), people with a psychosis (Szmukler et al 2003) or schizophrenia (Sellwood et al 2001).

Caring itself is associated with sharing the burden of disease and disability. If we consider the burden of disease measures such as Disability Adjusted Life Years (DALYs) and the healthy years of life lost due to disability and illness, primary Carers can be seen as partners in carrying the burden of

disease and disability, as their own 'healthy years' are affected (Stacey 2002).

Some epidemiological studies have suggested that the aetiology of disease or death is associated with caring. Studies indicate links between high demand caregiving and mortality amongst older caregivers. A US prospective cohort study claims that caregiving is an independent risk factor for mortality amongst older Carers (over 65 years) of live-in spouses (Schulz & Beach 1999). Researchers found that after 4 years of follow up (and controlling for sociodemographic factors, existing disease and sub-clinical cardiovascular disease), people who were providing care and reporting caregiver strain had mortality risks that were 63% higher than non Carers (Schulz & Beach 1999). Strained caregivers, when matched with control groups, were more likely to have depressive symptoms, higher levels of anxiety and lower self-ratings on health scales (Schulz & Beach 1999). 'Mediating factors' could include the fact that these strained caregivers were less likely to rest (even when sick) or have time for exercise (Schulz & Beach 1999). Commentators on this research suggest that caregiving accelerates mortality via prolonged distress that has the potential to impact on the cardiovascular system, immune system and endocrine functioning (Kiecolt-Glaser & Glaser 1999). Research has already indicated the relationship between stressors associated with psychosocial factors and neuroendocrine reactions and their consequences, although there is more scope for multidisciplinary work to explain biopsychosocial pathways and health (O Dea & Daniel 2001).

## Carers as Patients

The Carers Association of SA adopts the WHO definition (1946) of health as being the 'complete state of physical, mental and social well-being and not merely the absence of disease or infirmity'. (Carers Association of SA Policy Sub-committee)

A population based South Australian study showed that Carers' emotional and mental health was worse than non-Carers, although not reaching 'clinical' levels (Stacey 2002). This is supported by the ALSWH sub-study showing that that whilst women Carers, especially the middle age cohort, used more prescription medications (for nerves, depression and sleeping difficulties), clinical depression was not indicated (Lee 2004).

Similarly, self-identified Carers from a national survey reported problems with their health such as anxiety and depression, sleeping difficulties and back problems (Carers Association of Australia 2000). Carers of people with a mental illness score lower than members of the general population on items relating to physical functioning, role functioning, bodily pain, general health, vitality, social functioning and emotional and mental health (Wilson & Menon 2004). The national Carers Australia survey found that changes to the mental and emotional wellbeing felt by most Carer respondents is influenced by factors such as: the stress of caring and social isolation, changes in family and other relationships and a sense of grief and loss (Carers Association of Australia 2000).

Grief and loss experiences can result from felt loss over Carers' former lifestyle, plans for the future such as retirement or challenged

hopes for children with disabilities. Grief and trauma can be experienced in witnessing the treatment within the health system of a child with a disability or about one's perceived contribution to diseases, illnesses or conditions (e.g. depression: Highet, Thompson & McNair 2004). Loss can also be experienced due to changes in family relationships. For example, Carers of people with depression report that the illness can reduce intimacy with loved ones, lead to social and emotional distancing and restricted social relationships (Highet, Thompson & McNair 2004). One study has shown that the year after the Carer role ceases is associated with a high rate of Carer distress, related to grief and depression either over the loss of the care-recipient and/or loss of role (Hirst 2004).

For all of these reasons, it is important to identify Carers in the clinical setting. An important reason for actively identifying Carers as patients is that they often ignore their own symptoms of ill health and can rate them as relatively unimportant when compared to the health of their care recipient (Stacey 2002). Carers especially fail to undertake routine assessments such as screenings (Stone et al 1987, cited in Schofield 1998). Also, at the worst times of ill health for the care-recipient, Carers can easily fail to maintain their own treatment plans for conditions such as diabetes. Although in one study older women Carers were no different from non-Carers on physical health measures, their emotional state was poorly affected and they were less likely to be

receiving medical care perhaps due to the demands on their time resulting from caregiving (Lee 2001).

A proportion of Carers fail to achieve their optimum health due to the restricted lifestyles associated with their caring role (Stacey 2002). It may be difficult for Carers to participate in recommended behavioural lifestyle practices (diet and exercise) for optimum health due to the nature of the caregiving. For example, Carers need respite to engage in some of the lifestyle interventions recommended by health professionals, but even then, due to the fatigue (expressed as 'exhaustion') associated with the caring role or loss of the ability to consider their own health needs, many struggle to take care of

## Margaret

Margaret's son was diagnosed with schizophrenia when he was 19 and is now aged 33. Although slow, there has been a steady progression and for some years he has been able to live independently and take good care of himself and his home. Until 12 months ago he had avoided a hospital stay for 12 years. Margaret's role as a Carer involves being the person on the end of the phone when her son needs reassurance, being a member of his support team (which also includes his mental health team) and providing him with other assistance and support as he needs it. Margaret sometimes feels guilty that she inadvertently contributes to Robert's setbacks. For example at the time of his recent set back Margaret had just started a new job and was very busy with that. She had also changed her routine with him where they would walk together every morning prior to her new job. He had started to hide things from Margaret as he understood that she had her own things to deal with. He will often come to Margaret's house and spend the night as he hates to be alone.

Margaret advocates for services to be better tailored for people who have schizophrenia. She believes that there needs to be a middle level of service that fits somewhere

between acute clinical services and non acute support services, with psychological services being an alternative clinical option.



Photo: Courtesy of *The Advertiser*.

themselves (Stacey 2002). The ALSWH sub-study has indicated not only increased Body Mass Index (BMI) associated with taking on the Carer role, but also a decrease in BMI and increase in physical activity once the role had ceased (Lee 2004).

Predictors of Carer stress can include gender (with women more likely to experience stress than men), the care relationship (with caring for a partner or child being most stressful), amount of hours spent caring and live-in care relationships (Hirst 2004). In one study, women Carers who spent over 36 hours per week caregiving for a spouse were more likely to experience depression or anxiety than non-Carers (Cannuscio et al 1996). Another study found women more overloaded and less able to cope and reported caring

for people with more aggressive and cognitive behaviour problems (Schofield et al 1998). Various studies have linked Carers' emotional state to the existence of a mental health component to the disability of older care recipients (Livingston et al 1996), more dependent stroke sufferers (Dennis et al 1998), problem behaviours of older people with dementia (Ballard et al 1996) and the severity of mental health problems of people with a mental illness (Wooff et al 2003). Delay in adequately diagnosing people with depression or anxiety is a common stressor for families as it means they are left to cope alone (Hight, Thompson & McNair 2004 and Hight & Thompson 2004).

Unfortunately, the caring role is also often not identified and so Carers themselves are not seen as being at

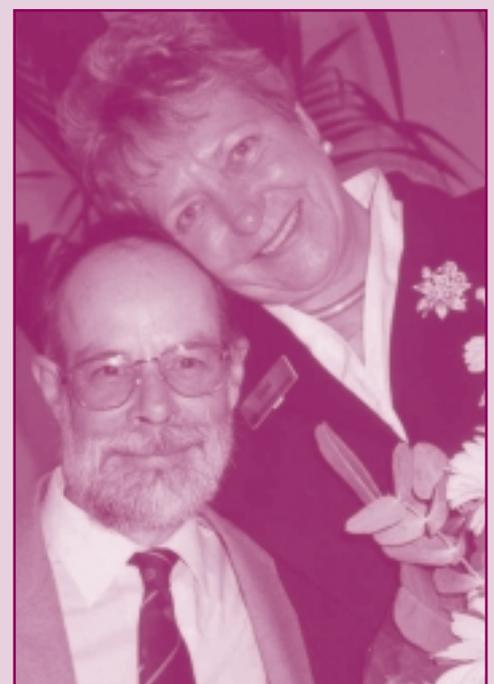
risk of ill health. Carers need to be identified and their health monitored within the clinical setting at the same time as care-recipients. One possible resource for this is the Carer Assessment Tool<sup>3</sup>. Other tools such as the 'Health Assessment for the over 75s' undertaken by General Practitioners could routinely include questions about caring responsibilities. These questions should allow for the possibility that Carers can be in multiple caring roles simultaneously or be involved in consecutive caring roles. The adage 'prevention is better than cure' is particularly important to the caregiving situation, where a deterioration of Carer health has the potential to impact upon two lives as well as formal services.

3. Developed in conjunction with the Carers Association of SA, the Carer Assessment Tool has been trialed but is currently not commonly used.

## Carol

Carol and her partner Tony were competitive horse riders. At an event Tony had a fall which resulted in him having a spinal cord injury and brain damage. When Carol found out the nature of the injury she instinctively went into overdrive and raided the local shop for frozen food, filled the car with petrol, got dog food, cat food and horse feed, logs for the fire, a bottle of gin and a large bottle of whiskey.

Carol, as she puts it, became a Carer "as a result from a bolt from the blue". Carol was working part time as a consultant and an academic research fellow. Due to his injuries Tony was not capable of working. Carol found it increasingly hard to juggle her academic work, consulting work and her responsibilities as a Carer and not to mention that prior to Tony's injury they had started a small vineyard and winery. Carol then began to work from home where she found that she was able to juggle her work, their business and caring responsibilities. Working from home has its obvious benefits however it means that Carol misses out on the support that she would receive if she worked with others. Carol would like to see family friendly work policies developed which look after the interests of both employees and employers.



# Conclusion

Carers are a separate group from health service users who need support, as partners in care and as a group with their own particular health concerns. This dual focus is important if we are to fully grasp the extent of the Carer's role and its implications. It is important for Carers to be separately identified in health and community service policies and practices. There is also scope for more research on Carers as a population health group. More research on the impact of social-demographic trends and health and community care trends upon Carers is desirable. Carers will be in relatively short supply when considering the anticipated demand for care of older people in the future.

Carers have a major role in service delivery in the primary care setting and Carers embrace working with care professionals in coordination and treatment plans, whether for chronic and long term conditions, or acute illness episodes. However, it is the task of health professionals to negotiate with family members on the uptake of the Carer role and/or the extent of caring responsibilities undertaken.

In the clinical setting there needs to be careful monitoring of Carer health, whilst still respecting Carers as partners in care. A failure to identify Carers and encourage prevention measures and health monitoring practices (e.g. screening) for Carers, compromises Carer health in the longer term and impacts upon the caring role. Carer-distress can also be particularly high in the immediate post-care period (Hirst 2004).

Policies and practice need to address factors likely to contribute to Carers' health and wellbeing, including:

- early identification of the Carer role and disability or illness of the care-recipient,
- promoting community awareness of disabilities and illnesses,
- assessing and monitoring predictors of Carer stress,
- monitoring Carer health,
- recommending health interventions sensitive to the context of caregiving,

- advocating for Carer support services,
- involving Carers in identifying the needs of and treatment plans for care recipients,
- appropriate community support for an ageing population,
- supported accommodation for people with disabilities,
- peer support and friendly visiting for Carers,
- flexible employment conditions,
- adequate remuneration for the Carer role,
- access to affordable aids and equipment or home modification,
- developing skills to undertake caring and;
- counselling to cope with grief and loss.

These issues may be within the scope of and appropriately addressed through the proposed new South Australian whole of government Carers' policy.

# Checklist for Health Professionals

## Checklist for Health and Community Care Professionals – Carers as Partners

- > Have Carers been invited to actively participate in the care planning process?
- > Does discharge planning take into account the Carer? Have Carers received adequate information upon the discharge of their family member or friend?
- > Have Carers been provided an explanation of treatment, medications and conditions for their care-recipient?
- > Do Carers know about services? Are Carers aware of resources such as the Carers Association, Commonwealth Carer Resource Centre and local Carer support groups?
- > Are Carers aware of financial assistance such as the Carer Payment and Carer Allowance and transport and health care concessions?
- > Are Carers aware of key services and processes in the health system?
- > Are Carers' needs identified in a review of patient care?
- > Did your training affect your perceptions about families' contribution to conditions and illness, particularly mental illness, and are these beliefs or attitudes helpful in the service delivery context?
- > Is adherence to privacy legislation requirements balanced by Carers' need for information and support in their role?

## Checklist for Health and Community Service Professionals – Carers as Patients

- > Are Carers readily identified in your service or in treatment and intervention strategies?
- > Are families assessed as a unit in treatment? Is the health status of a patient and caregiving demands of a friend or relative assessed simultaneously?
- > How could the circumstances of caring be taken into account to ensure that Carers could realistically address individual risk factors to health or be prevented from worse health?
- > How could Carers be encouraged to consider their own health and social needs in the context of their caring role?
- > What would relaxation time mean in the absence of respite care?
- > How could exercise be combined into the daily routine of caring?
- > Do Carers have access to counselling, especially grief and loss resources, if required?
- > For GPs – are Carers (including simultaneous caring roles) identified in Health Assessments for the over 75s?

## Checklist for Health and Community Services Professionals – Policy, Research & Program Staff

- > What is the impact of health and community care policies on Carers, both as care providers and as care partners?
- > What is the potential for a policy's differential impact upon Carers from different socio-economic groups or cultural backgrounds?
- > Are Carers identified in research and practice, both as subjects and as participants in research and practice?
- > Are Carers identified in program evaluation, both as contributors to an evaluation and as subjects of evaluation?

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