



University of Wollongong



Working with and supporting informal carers

Supporting family or 'informal' carers is an increasingly important part of providing community care. More programs are being designed directly for carers, and finding the best ways to support them in a joint approach to care and support is a growing challenge for all service providers.

This Briefing reviews some key facts about carers and the research on what works for them in terms of effective service responses. Its focus is carers of older people, and carers who are themselves ageing.

This briefing has been prepared by the Centre for Health Service Development, University of Wollongong, in partnership with The Benevolent Society.

Research to Practice Briefings bring together lessons learned from the literature on a topical issue in community aged care as a resource for those working in this sector. As in most areas of social policy and practice, the research evidence on community care is continually evolving. The Briefings aim to distil key themes and messages from the research and to point to promising and innovative practices.

An advisory group of academics and expert practitioners working in the area of aged care provide advice and peer review.

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Who are carers?

In the context of community care, a carer is a person who, through family relationship or friendship, looks after a frail older person or someone with a disability, chronic illness or mental illness on an unpaid basis.

Comprehensive information about Australian carers is collected through the Survey of Disability, Ageing and Carers, a national survey conducted by the Australian Bureau of Statistics (ABS 2005). It is estimated that in 2003 there were 2.56 million Australians providing unpaid assistance of one type or another, or 12.9% of the Australian population.

Primary and non-primary carers

The ABS defines primary carers as the people who provide the majority of the informal help needed by a person because of disability or age. Non-primary carers are those who provided some assistance, but not the majority, to those who need help.

Most carers are middle-aged (35 to 54) and over three quarters are of working age (18 to 64 years of age). There were also 169,900 young people (under 18) who were carers, with 2,900 being primary carers. The majority of carers are female (54.1%). However, among carers aged over 65, the picture is reversed and a higher proportion are men (53.9%). Among primary carers, women predominate at all ages although among those aged over 65, 42% are men.

An estimated 450,000 carers are aged over 65 and may themselves be frail or have a disability or chronic illness.

How we think about carers

The concepts and language commonly used in the carer support sector have been changing over the past decades. As well as distinguishing 'formal' (i.e. paid providers of care services) from informal care (i.e. care by a family member or friend), there has been increased recognition of carers also having needs to be met in their own right (Ramsay et al. 2007).

Carers are also being acknowledged as the experts in their own lives, and for the detailed and day-to-day knowledge they have of the person they are helping. Services are being encouraged to see carers as in charge of the situation most of the time, often 24 hours a day, and to see professionals and care workers, who may be present for a few hours per week, as a secondary 'add-on' support (Fine 2007).

The promotion of more personalised and consumer-directed service responses challenges providers to give carers opportunities to actively manage their own support services. This flexibility may change the roles of family carers and service providers so that formal and informal care and Centrelink carer support payments (Carer Payment and Carer Allowance) may all start to look more like parts of one coherent 'package'.

There has been an evolution in how carers' roles are understood by the service system, from the more negative focus on the 'burden of care' towards strength-based approaches (Eagar et al. 2007). This has led to specific programs aimed at giving carers more support and more control over how services are provided.

Our understanding of the complexity of carers' roles has greatly increased thanks to evidence from

Table 1: Carers by Age and Gender, Australia (000s) (ABS 2005)

Age Group	< 18	18-24	25-34	35-44	45-54	55-64	65-74	75+	Total
Primary Carer Male	1.4	3.1	9.0	17.7	32.2	25.0	22.9	24.9	136.2
Primary Carer Female	1.5	12.6	5.1	65.6	83.4	74.8	38.6	26.8	338.4
All Primary Carers	2.9	15.8	44.1	83.4	115.6	99.7	61.5	51.6	474.6
All Carers Male	87.5	90.9	140.3	196.5	219.3	195.6	139.6	105.0	1,174.6
All Carers Female	82.4	86.9	177.0	288.3	301.7	237.0	129.4	79.6	1,382.3
Total Carers	169.9	177.8	317.2	484.8	521.0	432.7	269.0	184.6	2,557.0

Changes in the focus on caring

Over the years, the way that services have thought about carers has been changing. The table below shows the main focus of each period.

1960s	Carer burden, the impact of caring on carers' mental health, physical health, other family relationships, employment and financial problems.
1980s	Stress models, mastery, role overload, role captivity.
1990s	Multiple impacts of caring. Positive aspects of caring, with strengths and resilience models emerging.
Late 1990s	Carers as 'clients', with needs to be met in their own right.
2000s	Carers as joint partners - with the care recipient, with formal services and as a recipient of support services - and where the aim is to 'personalise' care.

policy studies (Fine 2007a), the 2003 National Survey of Disability Ageing and Carers (ABS 2004) and specific studies of the views of people who identify themselves as carers (Cummins et al. 2007).

There is a diversity of caring arrangements that can differ between cultures. Attitudes to the roles of adult children in caring for their aged parents vary across cultures. For example, in Aboriginal, and Torres Strait Islander communities a number of people may share the role of carer and so asking about a 'primary carer' may not always be useful. In some cultures, caring is seen as a family obligation resulting in criticism for those who relinquish it. Culture can also influence how much the carer, care recipient or family will allow a service provider to do.

Carers often have to manage multiple roles - as a carer and paid worker, as a carer and parent, or as both carer and being 'cared for' at the same time. Population surveys also show that some people prefer to see themselves as a husband, wife, son or daughter, rather than as a carer. Caring is not always seen in negative terms, but can provide a deep sense of meaning and purpose for the carer.

Assessment of what carers need

While the specific needs of carers will differ in each situation, evidence suggests there are many similarities to be considered during assessment of

carers' needs. Carers are likely to be concerned about financial and emotional costs, the future prospects of the care recipient (especially if the carer is not around), the need for practical assistance and more confidence, and 'time out' for themselves.

An initial assessment of carers' needs will involve identifying:

- whether a person sees themselves as a primary carer
- how much support they expect in their carer role
- for what activities of daily living their care recipient needs a carer.

Other factors to take into consideration include:

- gender and age of the carer and care recipient
- the carer's own functional abilities
- whether they are a live-in carer or not
- the intensity and duration of caring
- whether they have single or multiple caring responsibilities
- other roles they perform and responsibilities they have (Eagar et al. 2007).

A broad but shallow screening process allows for early detection of problems, followed by timely and relevant interventions.

Differences in carer needs

Although there are more similarities than major differences between the carers of different types of care recipients (Eagar 2007), some differences in the need for support and practical assistance do arise from the particular characteristics of the care recipients. For example, carers might be:

- facing the emotional pressures of dealing with challenging behaviour in people with dementia
- experiencing grief due to the expected death of the care recipient
- dealing with complex technical tasks in caring for the chronically ill
- dealing with the unpredictable nature of mental illness.

Providing effective support means being able to assess the carer's needs and strengths in whatever domains are relevant to their circumstances.

Domains of carer assessment

Most community care assessment systems cover similar areas (Ramsay et al. 2007). These include:

- Caring context – where the caring takes place, how often, what other services are used, and the carer's relationship to the care recipient.
- Functional level of care – the activities of daily living that the carer helps with and how this relates to the level of the care recipient's independence.
- Health – the carer's own health and wellbeing, as well as the health and wellbeing of the care recipient.
- Financial, legal and employment – the carer's financial and employment situation, access to benefit entitlements, the legal relationships and obligations to the care recipient, like power of attorney, financial management and guardianship.
- Confidence and competence – the carer's skill level and confidence in performing the required caring tasks, including any medical tasks like giving medication or using equipment, or physical tasks like lifting.
- Positive aspects of caring – how the carer feels about the situation and what the carer gets out of it.
- Knowledge – the carer's knowledge of available support options for themselves and the care recipient, like respite care.
- Social support – the carer and care recipient's support networks including friends, family, community groups and services like transport and shopping.
- Coping strategies – how the carer copes with the situation and what, if anything, might place the situation at risk of breakdown.
- Values and preferences – including cultural and religious values and beliefs that reflect on the situation.
- Strengths and risks – areas where the carer is doing well, and areas where they need support – the kind of support that would make the biggest difference for the future.

Changing needs over time

The needs of carers may change over time as the care recipient becomes better able to function, or conversely develops different, more complex or intense needs.

If we are helping carers to plan for the longer term we may also be interested in their transitions into and out of the workforce. Understanding the impact on the carer of beginning, changing, continuing or ending their informal care role will be relevant to providing a personalised service.

Access to flexible working hours, a range of affordable formal support services and being able to share the load with other family members can help women in particular in continuing in their caring roles (Berecki et al. 2008).

Options for supporting carers

The options for supporting carers have expanded greatly in the past two decades, especially due to the advent of dedicated programs for respite and for access to information. The growth of carer

advocacy bodies has meant that the pressure for continued improvements and expansions to services has also grown.

Carer support programs can be grouped into several types, each with differing challenges and evidence of effectiveness:

Information resources

There is now a great deal of information available about support services and counselling, self-help and condition-specific groups in local communities, operating through neighbourhood centres, local councils, community health and aged care agencies (Commonwealth Respite and Carelink Centres 2010). However, evidence suggests that giving information alone (whether verbal, printed or online) is not effective. Teaching specific skills like medication management or dealing with problem behaviour is better practice.

Carer support groups

Support groups give carers an opportunity for mutual support from other people in similar situations. There

is emerging evidence that support groups may be helpful for carers of CALD backgrounds, carers of children with disabilities and carers of people with mental illness. Carer support groups can be a good source of emotional support and information and can help reduce the sense of isolation.

Family support

Family support interventions are delivered in the home and focus on role modeling, problem solving, coaching and emotional and practical support. Reviews of family support services for people with a mental illness conclude that family support interventions are effective.

Education

Educational interventions focus on increasing carers' knowledge about their care recipient or situation. For example, dementia education can help carers understand behavioural issues, learn stress management techniques and manage medication. The overall evidence on educational interventions is good, especially for carers of people with dementia, mental illness and disability.

Counselling

The overall evidence on counselling interventions is positive. However, there is little evidence on the effectiveness of different types of counselling or on 'how much' is needed to be effective. Some studies and reviews report no measurable effects. Likewise, the evidence on the effectiveness of counselling and other psychosocial interventions for different types of carers (spouses, parents, children, resident, non-resident, employed, young, old etc) is not strong.

Case management and care coordination

Case management and care coordination interventions increase and streamline carers' and care recipients' access to support and services. The small number of studies investigating case management and care coordination and their impact on the carer, show promising evidence of being effective. Benefits included reduced carer stress, reduction in hospitalisation and an increase in carer satisfaction.

Respite care

Various types of respite care are available: in-home, residential, centre-based, and host families. To date, the overall research evidence is that respite care can provide small benefits. One study found that while it does not relieve carer burden or improve mental health, carer satisfaction with the service was high.

Barriers to the use of respite

Even where respite care is available, carers may not use it. For example, carers of people with dementia have identified respite care as one of their critical care needs, but their low use of residential respite care does not reflect this. Only about a quarter (27%) of people approved for residential respite care actually used it within 12 months of receiving approval. Carers described barriers such as local shortages of respite places, affordability, insufficient flexibility in respite care options and difficulties in understanding and accessing available services (AIHW 2010).

Carers' attitudes towards respite care also influence whether they will use it. Among carers of people with dementia, attitudes regarding the perceived utility and quality of respite services accounted for more of the differences in how carers use services than either carer or care recipient need (Kosloski and Montgomery, 1993). Likewise more recent research with Australian dementia carers (Phillipson, Jones and Magee, 2010) suggests that carers' beliefs about service outcomes (e.g. that they will be negative for the care recipient) are stronger predictors of which carers will use respite than their assessed need (e.g. burden or depression scores). Carers who believe that outcomes associated with respite use will be negative may actually start with the intention of not using it (Phillipson and Jones, 2010).

This highlights the importance of initial assessment and ongoing monitoring in identifying and understanding the factors that may prevent a carer from using services.

Other studies found that respite resulted in reduced stress and emotional distress. Some studies and reviews report no measurable effects, although this could be due to methodological problems in the research or real world factors like the respite being hard to use or not tailored to the carers' cultural expectations (Eagar et al. 2007).

Multi-component interventions

Multi-component interventions incorporate a variety of components such as skills training, information and referral, respite, and counselling. There is good evidence for the effectiveness of multi-component interventions. Benefits included positive effects on carer burden, wellbeing and knowledge.

A good fit between the carers' stated or assessed needs, and the goal of the service to be provided, is not always easy to achieve. Care agencies need to find the right mix of carer support interventions and the best time to provide them. Is the service mainly geared to benefit the carer, or the care recipient, or both? Is it expected to achieve something in the short term to fix an immediate problem, like training on better management of a person's problem behaviour, equipment for lifting or bathing, or assistance with medication management? Or are longer-term impacts more likely?

Challenges in carer support research

Because of the community sector's complexity, the results from evaluation research and systematic reviews of the literature on existing programs (such as educational interventions, respite services, support groups) have not been very conclusive (Eagar et al 2007, Williams and Owen 2009).

It is also difficult to conduct rigorous evaluation studies of community support interventions when these vary so much in their design and implementation, and because denying a potentially beneficial service to a control group presents ethical issues.

So it is not surprising that much of the evidence about what works best for carers is not of gold standard quality or that the results are sometimes unclear. However, it should be emphasised that a lack of good evidence for whether an intervention is successful is not the same as evidence of its ineffectiveness.

We do know that individual approaches are more likely to have significant effects in terms of improving carer wellbeing than those based on group approaches. This is because individual sessions can be better targeted, more personalised and more intense.

We also know that some services offered to carers do not seem to have an impact on carer burden; that is, the interventions are not therapeutic in the sense of reducing a carer's score on a particular burden scale in the short term. Nevertheless, such services may be preventive or protective, for example they may increase the carer's capacity and resilience, build self-worth or enhance social support. So a carer might feel better, although no less burdened, or may be more capable of staying in the caring situation for longer (Sörensen et al. 2002).

Measuring change

When we talk about effective interventions, this implies that the expected outcomes have been defined and can be measured. In order to measure change (or lack of change) over time, practical measurement tools are required. Some assessment items and scales in current use include:

Care recipient health, wellbeing and function:

Twelve items cover self-reported health status, bodily pain, mental health and well being functional ability scores (i.e. the SF36, K10, HACC Screen).

Carer health, wellbeing and function: This is the same as for the care recipient plus ten or more items on carer quality of life, carer strain and burden; the supports being used; the quality and sustainability of the care-giving relationship.

Continuity of relationships between formal and informal carers:

The best indicators are three items: evidence of a carer having a role in care planning and service delivery; the carer's relationships with service providers; cooperation with treatment.

For more information and sources of measurement scales and assessment tools see the References list.

Emerging issues in the carer support sector

In the most recent UK social policy thinking, carers are now seen as joint partners in caring – with the care recipient, with formal care and as a recipient of support services in their own right – and where the overall aim is to achieve the right mix and to personalise care (Limbery 2010).

In Australia, a variety of service delivery models reflect this same shift, towards 'consumer-directed care'. Under these models, a case manager may arrange services on behalf of a client, or the client and/or the family or carer receives funds to purchase services themselves (Australian Department of Health and Ageing 2010).

The growth of 'enabling' and 'strength-based' models also reflect a concern for supporting more personalised, capacity building and consumer-controlled service models. Good examples of these models exist at different stages of evolution in most states and territories, such as in the Victorian community care sector's HACC-based Active Service Model (Victorian Department of Health 2010, Western Australia Silver Chain 2010, NSW IMPACT Services 2010).

The intention to give more control to care recipients and carers over the type of services they receive and the goals they wish to achieve has been a recognised feature of service provision for many decades (Ozanne 1990) but there is validity in the idea that all services should continually strive to move their daily practice in the direction of more consumer-friendly carer support interventions.



Discussion guide

1. People in a caring role won't always identify as a 'carer'. How might the use of language impede or encourage the engagement of carers?
2. Describe a best practice approach to assessment and referral that ensures the needs of both carers and care recipients are identified and addressed.
3. People from diverse cultural backgrounds have many different approaches, roles and expectations when it comes to informal care. Discuss what this means for us in the provision of formal support to carers.
4. How might service providers put more focus on resilience building and holistic support so that carers can feel more equipped to manage adversity? What does strengths based service delivery 'look like' when we work with carers?
5. Using real practice examples, explore the role that broader informal support networks play in supporting care recipients and carers. As service providers, how do we empower and facilitate the development of informal support networks?
6. In Aboriginal and/or Torres Strait Islander communities, extended families and other community members often play a greater role within informal care arrangements. How would you go about finding out about existing care arrangements and providing culturally respectful support?
7. What could be some of the reasons a carer is resistant to support? Based on the reasons identified, how might you go about building trust and/or providing person-centred care in this context?
8. What would be your approach to supporting an older couple, both in poor health, caring for each other?
9. At times, the needs and interests of a carer and a care recipient may be in contradiction. Can you think of examples of this? How do we effectively identify and manage these tensions? How do we ensure that the rights and choices of the care recipient are upheld in the provision of formal service support (such as respite) to carers?

Thanks to Community Care (Northern Beaches) for their assistance with these discussion questions.

Some useful resources

Carers Australia (including links to state based carers associations): www.carersaustralia.com.au

Alzheimer's Association: www.alzheimers.org.au

Commonwealth Respite and Carelink Centre: www.commcarelink.health.gov.au or phone: 1800 052 222

We welcome feedback on this Briefing.

A full list of references can be accessed on The Benevolent Society's website.

Practice implications

Know the carer and the care recipient and plan in partnership with them. All carers and care recipients are individuals and what they need in order to lead fulfilling and active lives will differ.

Think of assessment as a continuous process. Carer and care recipients' needs will change over time. Each meeting with a carer is an opportunity to understand more about the complexity of the caring arrangements. It is a chance to ask whether other supports are needed, and to consider what would work best in the particular circumstances of this carer and of this care recipient.

Talk about the barriers to service access. If carers expect the outcomes of services, such as respite, to be positive they are likely to accept them. Some carers' fear of what will happen if someone other than themselves provides care to the care recipient may be a huge obstacle. In such circumstances, carers are likely to require support and evidence to persuade them that the use of respite services will in the long run (if not immediate term) be positive, not only for themselves, but also for the care recipient.

Give carers the chance to do things for themselves. Care workers may be tempted to step in and help out with complex problems but should also consider approaches that will help carers become less reliant in the longer term. Getting the right mix of useful interventions, while actively encouraging clients and their carers to do as much for themselves as possible, is the aim. However this should be balanced with recognition that many will need continuing practical support to prevent further decline in their abilities.

Talk to carers about the full range of their support options – not just the ones you have to offer in your service. Describe the different types of respite, support groups, training, counselling and Centrelink payments etc. Find out about possible sources of additional help within their own family and local networks.

Support carers' own health. Talk about and offer information and support around the carer's health. Carers often think that their health needs are secondary to those of the person they assist.

Acknowledge carers' expertise. Carers are the direct link to the experiences of the person to whom they are giving care. Explicitly acknowledging their expertise and knowledge of the person they looking after is part of building a carer's confidence and resilience.

Work with carers to set and review achievable goals. Work alongside the clients, their carers and families to plan what support is required to enable them to maintain their independence and work towards their personal goals. Review the situation regularly to check whether the goals in the care plan have been met. But checking on progress should not be too cumbersome. Depending on the circumstances, this may involve a follow-up phone call or a fuller re-assessment.

Listen to carers' feedback on the ways that services could be improved to better meet their needs and those of care recipients. For many services 'drop out' rates are quite high. In addition to identifying whether a carer's goals have been achieved, there may be a need to identify any obstacles encountered in attempts to use recommended services.

The Benevolent Society is Australia's first charity. Established in 1813, we have been caring for Australians and their communities for nearly 200 years, working to bring about positive social change in response to community needs.

The Centre for Health Service Development is a research centre of the Sydney Business School, University of Wollongong. It was established in 1993 with the aim to improve the funding and delivery of health services in Australia, including better continuity within and across the health and community care sectors, and basing management decisions on evidence.

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