

## What are the most effective and cost-effective services for informal carers of older people?

Since the community care reforms of the early 1990s, practical support for informal carers has become one of the key building blocks of community care policy in England and Wales. In 2004, Linda Pickard wrote a report for the Audit Commission called *The Effectiveness and Cost-effectiveness of Support and Services for Informal Carers of Older People*. This summary highlights the key points.

### Why is the issue important to service users?

There are around 5.2 million adults providing unpaid or informal care in England and Wales, representing around one in ten of the population. Of these, approximately 1.6 million provide care for 20 hours a week or more. This is about 4 percent of the adult population. Three-quarters of all informal carers look after older people aged 65 and over. Around half of all disabled older people in the UK rely exclusively on informal help (Comas-Hererra et al, 2004).

The provision of intensive informal care to frail older people can have profound consequences for the carer, particularly where the older person has a cognitive impairment. The responsibilities of caring often constrain social participation and necessitate withdrawal from the work force. Intensive caring can have adverse effects on the psychological health of carers, with consistent evidence that carers are more at risk of mental health problems, particularly stress and depression, than other adults of the same age (Bauld et al, 2000). One of the aims in providing services to carers is to reduce these negative effects of carer stress by supporting carers.

There is much emphasis in current government policy on providing support for carers through specific carer services, such as breaks from caring or respite care. Social policy literature in this country, however, also emphasises another kind of support for carers, namely care directed at the older person with a carer, such as home care services. Recognition of the importance of core mainstream services provided to older people with carers acknowledges the 'dual focus of caring' (Twigg, 1992), that is, that caring takes place within a relationship involving both the carer and the cared-for older person.

*Informal care is defined as unpaid care to family, partners or friends in need of help because they are ill, frail or have a disability. Use of the term 'informal' care reflects usage in the literature and is not meant to imply that the care provided is of low intensity.*

## About the study

A wide definition of services is adopted to support informal carers. It includes both specific carer services, such as breaks from caring, and services primarily aimed at the older person, such as home care. The focus is on five services: day respite care, residential respite care, in-home respite, social work/counselling and home care.

The review examines which services are effective and/or cost-effective for informal carers of older people. A service or form of support for informal carers of older people is effective if it yields positive outcomes for carers, such as increased carer well-being or reduced carer 'burden'. From the perspective of the older person, a service or form of support is effective if it yields positive outcomes for the older person, such as increased satisfaction with services or reduced rates of admission to residential care. An intervention is defined here as cost-effective if it yields either a better outcome than a comparator at the same cost, or an equivalent outcome at a lower cost.

Evidence is examined from the national and international literature about effective and cost-effective services to support carers. The review draws on other recent systematic literature reviews in the field, in particular Arksey et al (2004). Since the effectiveness and cost-effectiveness of services may be contextual, particular emphasis is given to recent literature relating to England and Wales in the context of current community care policies and practices, and the review draws in particular on the study by Davies and Fernández (2000).

## What works? Effective services for carers of older people

The national and international literature shows that provision of breaks from caring or respite care, such as day care and overnight respite in a residential care home, is often associated with very high levels of satisfaction on behalf of carers, although this is not always associated with changes in their psychological health (Levin et al, 1994; Arksey et al, 2004). In the context of current community care policies and practice in England and Wales, there is evidence that both day care and residential respite care have positive outcomes for carers. In a recent study (Davies and Fernández, 2000), for example, day care reduced stress for about 85 percent of the carers of users of day care, and was particularly effective for carers of severely cognitively impaired older people (receiving up to around two days a week of daycare) and carers in paid employment.

It has for some time been recognized that home care, provided to the cared-for older person, is beneficial to carers' well-being (Twigg, 1992). This finding has recently been confirmed in a study in England and Wales, which shows that levels of stress decline among carers of older people with mild and severe cognitive impairment with increases in home care, and that home care is effective among carers of older people as a whole, when combined with daycare (Davies and Fernández 2000).

It is common, in the international literature on interventions for carers, for counselling to be cited as an effective measure to relieve carer distress (for example, Zarit and Leitsch, 2001). The study by Davies and Fernández (2000) of community care in England and Wales in the 1990s also shows that counselling or therapeutic social work, additional to the tasks performed in care management, is effective in reducing carer burden. The

authors found that relatively small amounts of therapeutic social work produced relatively large reductions in carer stress.

Recent evidence relating to interventions in England and Wales suggests that reduction in carer stress can increase significantly the cared-for older person's ability to stay in the community for extended periods of time (Davies and Fernández, 2000). In terms of delaying admissions to residential care, three support interventions have recently been found to be effective in England and Wales: day care, residential respite care and home care. It should, however, be noted that there is a well-established international finding that residential respite care can increase the probability of permanent admissions to residential care for some groups of older people (Davies and Fernández, 2000; Zarit and Leitsch, 2001).

### What works economically? Cost-effective interventions for carers of older people

The international evidence with regard to the cost-effectiveness of interventions for carers is somewhat mixed. A comprehensive review of respite services for carers by Arksey and colleagues (2004), for example, recently identified four economic evaluations of day care internationally, although none were UK-based. Two of the evaluations suggested that day respite might be cost-saving and two suggested that day respite might provide greater benefits but at a higher cost as compared to standard care.

In the context of current policy and practice in England and Wales, three interventions have been found to be cost-effective in improving outcomes for carers: day care, overnight respite care and social work/counselling (Davies and Fernández, 2000). Of these, the most cost-effective is social work/counselling. It was found that the same reduction in carer stress was achieved by spending only around £3 (in 1996 prices) on therapeutic social work with the carer, compared with around £35 on day care (provided to older people with severe cognitive impairment) or around £70 on respite care (provided to older people with cognitive impairment).

The link between reductions in carer stress and delayed admissions to residential care means that some interventions that are cost-effective in reducing carer stress are also cost-effective in delaying admissions to residential care. There are three interventions that are cost-effective in delaying admissions of the older person to residential care in England and Wales at the present time: day care, residential respite care and home care (Davies and Fernández, 2000).

### What are the effects of interventions for carers on the older people they care for

*The Department of Health, as part of its Service Delivery and Organisation (SDO) Research and Development Programme, is currently undertaking new research into the effectiveness of innovative models of respite care, including home-based day care.*

In terms of the impacts of services on older people themselves, both day care and residential respite care can generate ambivalent feelings for older people (Twigg, 1992). For example, day care received quite frequently (beyond about two days a week) appears to be associated with reductions in user satisfaction with services (Davies and Fernández, 2000). Moreover, many older people do not want residential respite care, because they simply do not wish to be admitted to a care home, even temporarily (Twigg, 1992). Other forms of respite, such as in-home respite, in which a (paid) carer comes into the family home to 'sit' with the care recipient, may be preferable (Arksey et al, 2004), but the effectiveness and cost-effectiveness of this form of respite needs further research.

## How far do carers have access to effective/cost-effective services?

Assessments are a key to services. All carers providing substantial and regular care have the right to an assessment, either jointly with the person they care for, or separately. However, a recent survey found that only about a third of carers had had an assessment (Carers UK, 2003).

*These analyses of receipt of services by disabled older people derive from the PSSRU study of long-term care finance (see Wittenberg et al, 2006).*

Access to breaks from caring is low. The 2001-02 General Household Survey (GHS) shows that less than 10 percent of disabled older people with a carer attend a day centre in Britain. The GHS data on provision of informal care in Britain indicate that, in 1995, the majority caring at least 20 hours a week never had a break of as much as two days (Parker and Clarke, 2002). Department of Health data suggest that the numbers of temporary admissions of older local authority-supported residents to care homes in England declined from around 165,000 in 2000 to around 150,000 in 2003-04.

Access to home care by disabled older people with carers is also low. Most home care is still targeted on older people living alone. In the 2001-02 GHS, approximately 20 percent of disabled older people living alone received home care, but less than 10 percent of those living with others (Wittenberg et al, 2006).

Although therapeutic social work is highly effective in reducing carer stress, carers of less than 20 percent of frail older users of community services actually receive this intervention (Davies and Fernández, 2000).

Overall, access to services by carers providing substantial amounts of care to older people is low. The majority of older people to whom informal care is provided for 20 hours a week or more do not receive any regular visits from health, social or voluntary services.

### Key messages

There is evidence to suggest that both services aimed at the carer, such as day care/residential respite care, and services aimed at the older person, such as home care, can be effective and/or cost-effective in terms of outcomes for carers and/or the older person cared for. Both types of service should therefore be available to older people with carers.

On balance, however, services aimed at the older person may be more acceptable to both the older person and the carer. Older people are often ambivalent about services such as day care and institutional respite care. Other forms of respite, such as in-home respite, may be more acceptable to older people, but the effectiveness and cost-effectiveness of in-home respite has not yet been evaluated. Given our level of knowledge, services provided for the older person seem less likely to raise issues of conflict between older people and their carers than specific carer services.

Therefore this review suggests that there is a particular need to provide more services, such as home care, directed at older people with carers. The home care service is the bedrock of community care in this country and yet it is still primarily directed at older people without carers. In the interests of effectiveness and cost-effectiveness, home care needs to be more available to older people with carers than it has been up to now.

Overall, however, the main conclusion is that it would be cost-effective to make much greater provision of day care, residential respite care, home care and social work/counselling for more carers of older people.

## Effective and cost-effective services – Key findings

- In the context of current community care policies and practice in England and Wales, there is evidence to suggest that day care, home care, residential respite care and social work/counselling can all be effective and/or cost-effective in terms of outcomes for carers and/or the older person cared for.
  
- **Effective services for carers of older people**
  - Day care, home care, residential respite care and social work/counselling can be effective in reducing the negative psychological effects of caring for carers and therefore have some positive outcomes for carers.
  - Day care, home care and residential respite care can be effective in delaying admissions to residential care. It should also be noted, however, that residential respite care can increase the probability of admissions to residential care for some older people.
  
- **Cost-effective services for carers of older people**
  - Day care, residential respite care and social work/counselling can be cost-effective in reducing the negative psychological effects of caring for carers.
  - Day care, home care and residential respite care can be cost-effective in delaying admissions to residential care.
  
- **Impact of carer interventions on older people**
  - Older people may feel ambivalent about using some forms of support and services, in particular day care and residential respite care.
  - In-home respite care may be preferred by older people, but there is insufficient evidence to evaluate the effectiveness and cost-effectiveness of this form of respite care at present.

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