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Briefing *Paper*



A Proper Break: effective respite services for carers of people with dementia

Key action points based on a literature review and consultation which examined ways to improve respite services and short-term breaks for carers of people with dementia:

- Many carers of people with dementia still have only **limited access** to a break from caring.
- Many carers voice a need for a **broader range of services**, including greater access to in-home respite.
- A **single type of respite service**, however good, is unlikely to be effective in meeting carers' ongoing needs.
- **Short breaks** should be easily accessible and those not provided free seen as affordable. Anomalies in charges and benefits systems, which may deter carers from taking breaks, should be addressed.
- To be effective, short breaks should be based on **thorough assessment** and on-going review.
- Breaks should also be able to maintain the **well-being of the care recipient**.
- Services need to be **diverse** enough to meet the needs of people of different ages, cultures and conditions and be appropriate to the stage of illness of the care recipient.
- **Recruitment and retention** of high quality staff, together with ongoing training and development, are important.
- **New and existing policies**, types of grant and other schemes should be used to make respite services more widely available and flexible.
- At the same time, **quality standards** may need strengthening in order to reduce variability in the quality of, and access to, services.
- Measures designed to assess **cost-effectiveness** need to include carers' and, where possible, care recipients' views.
- **Respite care does not exist in isolation.** Other services play a crucial role in helping carers to get the most out of respite services that exist in their area.

A Proper *Break*

access to effective respite care for all who want it



Dementia is a diagnosed condition which is estimated to affect more than 750,000 people in the UK, and the numbers affected are increasing (AS, 2004). The majority of older people with dementia are cared for at home by a relative or friend. Caring for people with dementia is known to be physically and emotionally exhausting. Respite care aims to relieve carers of caring responsibilities in the short term, and offer a positive experience for the person being cared for.

Despite the potential range of service models, carers and cared for often feel they have little choice in what is available. Since the Carers Special Grant was introduced in 1999, as part of the National Strategy for Carers (DH, 1999a), funds have been made available to local authorities to enhance services so that carers can take a break from caring.

What, then, is known about what makes for effective and cost-effective service provision in this area? And how can policy-makers, managers and practitioners use this knowledge to deliver improved respite services for carers of people with dementia? This paper summarises a review of research evidence and consultations on this topic (Arksey *et al.*, 2004).

Martha's friends have gradually lost contact, and she has become very depressed. Although she does have a regular break when her husband attends the day centre, she often just sleeps on the settee until he returns. She admits that she is dreading the day he goes into care: 'You forget how to live with other people, I've just become a vegetable ... the loneliness is terrible, I've no friends any more'.

Practical *Findings*

Review. Evidence from studies included (see 'About the study', page 6) was mixed and at times contradictory. Overall, evidence about the effectiveness and cost-effectiveness of respite care and short-term breaks was limited. **However, this is a very complex area to research; an important message is that it would be wrong to assume that lack of evidence about effectiveness should be interpreted as evidence that respite is ineffective.** For example, there was considerable qualitative evidence from carers (and some from care recipients) of what they regarded as the benefits of respite services. The review identified the following key points in respect of different types of respite care available.

Day care: *encompasses planned services provided outside of the home, not involving overnight stays.*

- Many carers placed a high value on day care services, perceiving benefits for both themselves and the person with dementia. However, some carers experienced problems relating to day care attendance.
- Few studies attempted to collect the views of people with dementia themselves, but there was some evidence to suggest patients enjoy the company, the sense of belonging and activities provided.
- Evidence about the impact on carers of using day care was unclear. Some studies showed demonstrable improvements in physical health, stress and psychological well-being, while others showed no change.
- Evidence about the impact on people with dementia of day care attendance was unclear. Some studies showed improvements or stabilisation, while others showed no positive effects.
- Time freed up by day care did not necessarily reduce the total amount spent on caregiving.
- There was some evidence to suggest that day care attendance might have a preventative effect on entry to long-term care.

Two of the economic evaluations suggested that day care might save costs while two suggested that day care might provide greater benefits but at a higher cost, compared to standard care. All four studies suggested that the benefits of day care might be similar to, or greater than, those achieved by standard care.

In-home respite: *involves a (paid) care worker coming into the family home to 'sit' with the care recipient.*

- Carers said they were highly satisfied with this; satisfaction seemed to be closely linked to what they saw as benefits the service brought their relative, and the quality of care provided.
- Carers would have liked more frequent and prolonged respite of this kind; relatively short respite periods placed limits on the type of activities they could do.
- No study demonstrated statistically significant positive effects of in-home respite on a range of measures.
- Evidence suggested that in-home respite could help to maintain family routines and roles as well as the care recipient's sense of self.
- No evidence was found in relation to cost-effectiveness of in-home respite.

Host family respite: *an opportunity for the carer and person with dementia to take a break together, staying with a 'host family'.*

- The little evidence available suggests that this was effective in addressing the needs of carers and care recipients.
- Carers reported positive 'outcomes', e.g. feeling comfortable, relaxed and happy during the respite period.
- Care recipients preferred a break in a homely environment to a stay in a residential home.
- Very little is known about the longer term impacts of host family respite.

Overnight respite away from home (including care home and hospital): *allows breaks away from the family home for the care recipient for one or more nights.*

- Physical and emotional benefits were seen as worthwhile when set against the difficulties of organising this type of service.
- Services were seen to help in some way, but other short-term breaks were seen as more beneficial to the care recipient.
- Some evidence showed that care recipients returned home in a worse state, but also that medical conditions could be diagnosed during breaks.
- Some carers felt guilty about using services; others said services helped them to continue in their caring role.
- Carers were able to sleep much better.
- There was little evidence that services reduced the demand for long-term placements.

Respite programmes: *offer carers, and care recipients, the choice of combining together different forms of respite care and short-breaks.*

- These might reduce carer burden, depression and carers' reported health problems.
- They might be more or less beneficial to carers and care recipients, depending on the characteristics of the person with dementia.
- Time freed up was likely to be spent catching up on chores rather than leisure activities.
- Care recipients were as likely to maintain or improve in physical and mental functioning as to decline.

Multi-dimensional carer support packages: *provide a range of services to carers and care recipients, including a respite or short-break option.*

- There were no demonstrable lasting improvements to carers' health and well-being.
- While some carers believed they had benefited, they were less positive about gains for care recipients.
- Results suggested no gains in terms of care recipients' psychological health, but positive effects regarding behavioural problems.
- There was a strong trend towards delayed entry to long-term care away from home, i.e. care recipients receiving these packages stayed at home for longer.

The *consultation* found a consensus of views among representatives from national bodies and between these and carers themselves. **Many carers still have only limited access to a break from caring**, although the picture varies significantly across the country. A need was voiced for a broader range of services, including greater access to in-home respite. There was a strong view that **the quality and appropriateness of respite services were very variable**, with services for carers of younger people with dementia or those with multiple problems or challenging behaviour being the least well served.

Developing new practice. The Health Act 'flexibilities', and the emergence of **Care Trusts** and **Partnership Trusts**, were seen as leading to some interesting new forms of practice, as was the requirement in the National Service Framework (NSF) for Mental Health (DH, 1999b) to recognise and address the needs of younger people with dementia by 2004. In general, contributors felt that the **Carers Special Grant** had allowed providers and commissioners to think more broadly, and the combination of ring-fenced monies to pump-prime projects, together with good practice guidelines in the Carers and Disabled Children's Act 2000, encouraged providers to offer a wider range of services. There were, however, concerns about how the Carers Special Grant had been used in some areas. The introduction **of direct payments and voucher schemes** was welcomed as a way to increase the flexibility of respite provision.

Difficulties with service provision. These included major difficulties in **recruiting and retaining staff** with the right skills, knowledge and attitudes. Many services were working within significant cost constraints and this was felt to affect their ability to respond to carers' needs in a flexible, individualised manner. There was concern that the **Best Value tendering process** could stifle newer forms of care and practice by insisting that services fit into social services' categories. Contributors called for better coordination between commissioners and providers.

How to measure effectiveness and cost-effectiveness.

There was agreement that respite is complex and that a range of measures are needed, encompassing:

- Qualitative measures based on carers' (and, where possible, care recipients') own perceptions of the impact of respite care on quality of life
- Qualitative and quantitative measures based on the impact of respite care on the health and well-being of the carer and care recipient
- Quantitative measures based on long-term cost-effectiveness analysis of the impact of respite care on service usage by both carer and care recipient.

Developing effective services. Respite services do not exist in isolation from other services to support carers, and these services and systems play a crucial role in facilitating access to, and take-up of, respite, and generally enabling carers to get the most out of the respite services that exist in their area. The consultation revealed the importance of certain underpinning factors or characteristics likely to lead to effective respite services:

- Knowledgeable and supportive doctors
- Appropriate management of the condition
- Responsive social services
- Fair and understandable benefits/charging system
- Supportive carers' networks
- Helpful family, friends and neighbours
- Well-coordinated services.

The consultation also suggested that, to be effective, short breaks should be:

- Based on thorough assessment and on-going review
- Appropriate to the needs and circumstances of the carer
- Appropriate for the age, culture, condition and stage of illness of the care recipient
- Able to maintain or improve the well-being of the care recipient
- Delivered by appropriately trained and caring staff
- Affordable to the carer.

Further *Research* agendas for action



Research/action for policy makers

- Planning, delivery and evaluation of respite services and short-term breaks must be set in the context of other support services.
- Services need to be sufficiently diverse to meet the needs of carers and care recipients in different situations and from varied backgrounds, e.g. younger people with dementia and from black and ethnic minority populations.
- Delivering flexible and person-centred services implies the need for spare capacity to be built in to service provision.
- Quality standards may need strengthening in order to reduce variability in the quality of, and access to, services.
- Anomalies in charging and benefits systems, which may deter carers from taking breaks, should be addressed.
- The recruitment and retention of high quality staff, together with ongoing training and development, is important.

Penny's husband Tom now needs full-time care and toileting throughout the night. Penny also has her own health problems. While Tom receives a substantial pension from his previous job, Penny is worried about long-term finances. Help in the home, she feels, is a luxury they cannot afford. She could go out in the evening but a sitter would cost £8–9 an hour, which she also considers beyond her means. She is receiving treatment for depression and feels that 'life is nothing any more'.

- Local authority social services departments need to be responsive and accessible. In particular, regular assessments and reviews should be conducted to help identify carers (and care recipients) who would benefit from a short-term break.
- When the new Carers (Equal Opportunities) Bill becomes law, this will have implications for the development and promotion of respite services for carers for people with dementia.
- Ways to enhance the opportunities for carers (and people with dementia) to have a voice in the development of respite services and short-term breaks should be promoted.

Research/action for further research

- ***New respite services and short-term breaks.*** Research into new services set up in the wake of the Carers Special Grant, which should have been developed following consultation with local carers.
- ***Alternative forms of respite services and short-term breaks.*** Research into different forms of respite care, including carers' preferences and decision-making about use of services at different points in the disease progression.
- ***Respite care and other community care services.*** Research to investigate the effectiveness of different community care packages, and/or the interface between short-term breaks and entry into long-term care.
- ***Amount of respite care.*** Research to examine the magnitude or amounts of respite care used, in particular to examine the idea that there may be a threshold below which breaks may not have significant effects.
- ***Respite services for specific groups of carers.*** Research to investigate regional availability, quality, and appropriateness, of short-term breaks for: carers for younger people with dementia; black and ethnic minority carers; carers of people with Down's syndrome and dementia.
- ***Organisational context.*** Research into the organisational context and service configurations of respite care provision.

About the Study

The aims of the study were to summarise available research evidence in the area of respite services and short-term breaks for carers of people with dementia, to identify key gaps in existing knowledge and to identify priorities for further research. The study consisted of a *literature review* and *consultation*.

The *literature review* examined and summarised evidence from published and unpublished literature (both UK and international) since 1985 about effective and cost-effective services to support carers in this area. Searches were made of key electronic databases and the Internet. Other search strategies included hand searching, searching websites of key organisations and contacting key researchers in the field. Bibliographies of studies were checked to ensure relevant referenced studies were included. The initial number of references generated in the searches was 2,287; of these, 52 articles reporting on a total of 45 studies met the inclusion criteria. Forty-seven of the 52 articles reported on general issues related to the effectiveness of services; the remaining five articles comprised economic evaluations. Relevant data were extracted from each article using an Access database. The review findings were reported according to type of respite service: day care; in-home respite; host family respite; institutional/overnight respite; respite programmes; multi-dimensional carer support packages; and video respite, showing customised videotape programme to patients (currently rare in the UK so findings not included in this briefing).

The *consultation* sought to find out more about:

- gaps in the research, and areas where future research might be targeted
- how research findings relate to current policy and practice in the NHS
- what carers and carer representatives value in terms of support services
- examples of good and/or new types of practice.

Key individuals from national statutory and voluntary organisations (n=20) were interviewed by telephone. In addition, telephone interviews and/or group discussions were conducted with carers (n=20) and local managers (n=5) in four different localities in England.

The research team also benefited from the advice of members of an Expert Reference Group, comprising professionals and 'key informant' carers.

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¹ Social Policy Research Unit, University of York, ² Centre for Housing Policy, University of York, ³ Centre for Health Economics, University of York, ⁴ Centre for Reviews and Dissemination, University of York, ⁵ Acton, Shapiro, ⁶ The late Sally Baldwin was a professor in the Department of Social Policy and Social Work at the University of York

Further Information

The full report, this briefing paper and details of current SDO research in the field can be downloaded at: www.sdo.lshtm.ac.uk/carers.htm

About the SDO Programme

The SDO R&D Programme is a national research programme managed by the National Co-ordinating Centre for NHS Service Delivery and Organisation Research and Development (NCCSDO) under contract from the Department of Health's R&D Division.

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NCCSDO
London School of Hygiene & Tropical Medicine
99 Gower Street
London WC1E 6AZ
Tel: +44 (0)20 7612 7980
Fax: +44 (0)20 7612 7979
Email: sdo@lshtm.ac.uk



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